RESILIENCE IN FAMILIES WITH AN AUTISTIC CHILD

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STATEMENT

I, the undersigned, hereby declare that the work contained in this thesis consists of my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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Signature   Date

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SUMMARY
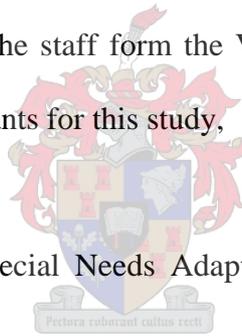
The primary aim of this study was to identify the characteristics and resources that families possess that enable them to adapt successfully, and as such, be resilient despite the presence of an autistic child in the family. The study was rooted within the contextual framework of the Resilience Model of Adjustment and Adaptation of McCubbin, Thompson and McCubbin (1996). Self-report questionnaires were completed by the parents of 34 families whose children attend either the Alpha School for Autistic Learners, the Vera School for Autistic Learners, or the Special Needs Adapted Programme. The self-report questionnaires were based on the Resilience Model of Adjustment and Adaptation. In addition, families were required to complete a biographical questionnaire and an open-ended question relating to their experience of factors relating to adaptation. The results pointed towards the importance of resilience factors in adaptation. The most significant resilience factors identified in this study include higher socioeconomic status; social support; open and predictable patterns of communication; supportive family environment, including commitment and flexibility; family hardiness; internal and external coping strategies; a positive outlook; and family belief systems. The clinical utility of the study in facilitating adaptation lies in its ability to provide parents with confirmation of the value of their efforts to improve the quality of life of their autistic child, as well as the family, and in providing all those involved in helping the autistic child, albeit parents or professionals, with insight into ways of creating a family environment, which will enhance the well-being of the autistic child, without detriment to the total family system. Family resilience theory provides a relevant framework within which the process of adapting to an autistic child can be considered. By applying these theories to their specific crisis situation, families of autistic children can work towards identifying, as well as implementing those factors which will lead to better adaptation, and thus increased resilience.

OPSOMMING

Die hoofdoelstelling van hierdie ondersoek was om die eienskappe en hulpbronne van gesinne te identifiseer wat dit moontlik maak vir hulle om suksesvol aan te pas, en dus veerkragtigheid te vertoon, ten spyte van die teenwoordigheid van 'n outistiese kind in die huishouding. Die ondersoek is gebaseer op die kontekstuele raamwerk van McCubbin, Thompson en McCubbin (1996) se Veerkragtigheidsmodel. Selfrapporteringsvraelyste is voltooi deur ouers van 34 gesinne met kinders wat die Alpha Skool vir Outistiese Leerders, die Vera Skool vir Outistiese Leerders, of die "Special Needs Adapted Programme" bywoon. Die selfrapporteringsvraelyste is gebaseer op die Veerkragtigheidsmodel. Daar was ook van die gesinne verwag om 'n biografiese vraelys sowel as 'n vraag te beantwoord oor hul ondervinding van hul aanpassing. Die resultate beklemtoon die belangrikheid van veerkragtigheidsfaktore in gesinsaanpassing. Die belangrikste veerkragtigheidsfaktore wat in hierdie studie geïdentifiseer is, sluit in hoër sosio-ekonomiese status; sosiale ondersteuning; oop en voorspelbare kommunikasiepatrone; ondersteunende gesinsomgewing, insluitend toewyding en buigsaamheid; gesinsweerbaarheid, interne en eksterne hanteringsmeganismes; 'n positiewe uitkyk en gesinsoortuigings. Die kliniese bruikbaarheid van hierdie studie is gekoppel aan die vermoë om die waarde van wat hulle doen om die lewenskwaliteit van hul outistiese kind, sowel as die van die gesin te verbeter, vir ouers te beklemtoon. Dit verskaf diegene wat betrokke is by die outistiese kind, insluitend ouers en professionele persone, insig in maniere om 'n gesinsomgewing te skep wat die welstand van die kind sal bevorder, sonder om die gesin as geheel te benadeel. Die veerkragtigheidsteorie verskaf 'n relevante raamwerk waarin die aanpassingsproses by 'n outistiese kind geëvalueer kan word. Deur hierdie teoriëe by hul spesifieke krisissituasie toe te pas kan gesinne van outistiese kinders daarna strewe om die faktore wat kan lei tot beter aanpassing en dus hoër veerkragtigheid, te identifiseer en te implimenteer.

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CHAPTER 1

INTRODUCTION, AIMS AND MOTIVATION FOR THE STUDY

1.1. Introduction

Autism is a severely debilitating developmental disorder with potentially harmful effects on the entire family. It is a chronic disability, which is more common than childhood cancer, cystic fibrosis and multiple sclerosis combined and appears in all racial, ethnic, cultural and social backgrounds around the world (Autism Society of America, 2003). Because of the severity of the disorder many families struggle to come to terms with their child's diagnosis and to adjust to having a child with special needs in their home. McAdoo and DeMyer (cited in Cantwell & Baker, 1984) believe that the most productive approach to studying family factors in autism is to focus on the autistic individual as a source of chronic stress on the family.

This chapter focuses on the various ways in which autism affects family functioning, as well as on the increasing prevalence rates of the disorder, which form the basis of the motivation for the current study. The chapter will conclude with a description of what the study aims to achieve.

1.2. Motivation for the Study

The motivation for the present study rests on two main factors, namely the increase in prevalence rates of the disorder and the potentially adverse effects the disorder may have on family functioning.

The belief currently exists that the prevalence of autism is on the increase. Although it is not clear as to whether there is an actual increase in the number of children affected with the disorder or whether the increase merely reflects changes in the diagnostic practices related to autism, the elevated figures create cause for concern. A study conducted in the United States of America found that autism is now ten times more prevalent than it was in the 1980's (Blakeslee, 2003). The study found that numbers had elevated from four to five in every 10 000 children between the ages of three and ten being affected with autism in the 1980's, to 3.4 in 1000 children in 1996 (Blakeslee, 2003). According to the Autism Society of America (2003), one in every 250 babies born will develop autism, while more recent estimates indicate that one in 158 children under the age of six years will be affected (G. Pieterse, Autism Western Cape, personal communication, March 16, 2004). Based on this statistic, potentially 270 000 South African children under the age of six years are affected by autism (Autism South Africa, 2005). Furthermore, the number of children affected is rising by 10 to seventeen percent per year (Autism Society of America, 2003).

The presence of an autistic child in the family may have adverse effects on various domains of family life, including the marital relationship, sibling relationships and adjustment, family socialisation practices, as well as normal family routine.

Marital conflict may occur as one or both parents struggle to come to terms with their child's disability (Bristol, Gallagher & Schopler, 1988; Rodrigue, Morgan & Geffken, 1990; Sanders & Morgan, 1997). Because of the demands associated with caring for an autistic child parents do not have much personal time (Court Appointed Special Advocate (CASA) Programme, 2003). The result may be a weakened affectional bond between parents (Cantwell & Baker, 1984), depression, the withdrawal of one parent from caregiving responsibilities or even divorce. When people are under constant stress, small problems may remain unresolved or be exaggerated, thus weakening the marriage and adding more stress

(CASA, 2003). It has also been noted that mothers of autistic children experience increased marital turmoil and decreased marital satisfaction as a result of the daily pressures associated with raising their disabled child. The salience of this observation relates to the fact that marital satisfaction has been found to be a strong predictor of a mother's ability to manage her child's disability (Rodrigue et al., 1990).

Rivers and Stoneman (2003) noted that parental conflict and marital stress leads to behaviour problems, poorer adjustment, lower self-esteem and higher rates of depression in siblings of children with autism. Siblings often feel resentment towards the child with the disability as they feel deprived of parental attention due to the demanding nature of the autistic child's needs (CASA, 2003; Dyson, Edgar & Crnic, 1989; Rodrigue, Geffken & Morgan, 1993; Howlin & Rutter, 1987; Wing, 1971). In order to vie for their parents' attention siblings may become overachievers to compensate for their autistic sibling's limitations (CASA, 2003; Howlin & Rutter, 1987) or they may develop behavioural problems to achieve the same goal (CASA, 2003). Other stressors for siblings include increased care-taking responsibilities, stigmatisation, the loss of normal sibling interaction (Dyson, Edgar & Crnic, 1989), as well as feelings of guilt and shame, and changes in family roles, structure and activities (Rodrigue et al., 1993). According to Rodrigue et al. (1993) the two most significant family and child characteristics leading to poorer sibling adjustment are decreased marital satisfaction and older sibling age.

The family's routine is often dictated by the autistic child and must often be changed at the last minute to accommodate the child's needs (Wing, 1971). Because family life often revolves around the child (Morgan, 1988) and due to the somewhat unusual behaviour exhibited by autistic children (Sanders & Morgan, 1997), the family may come to isolate itself from family, friends, activities and the community. In this way the family jeopardises their opportunities to obtain much needed social support (Wing, 1971). Other factors causing

families to isolate themselves may include difficulty in finding a reliable person to look after the autistic child (Wing, 1971), and fatigue or loss of energy due to the constant burden of caregiving (Sanders & Morgan, 1997).

Parents go through a wide range of emotions relating to their autistic child. Parents often experience feelings of guilt (Howlin & Rutter, 1987) and tend to blame themselves for their child's condition (Rodrigue et al., 1990). Many mothers feel incompetent and experience loneliness and isolation (Rodrigue et al., 1990). Having a child that shows no emotion toward them can lead parents to feel rejected (Howlin & Rutter, 1987), useless and unwanted (Wing, 1971). Other emotions associated with raising an autistic child include frustration, anxiety, tenseness (Rodrigue et al., 1990), shock, helplessness, anger, grief and resentment (Powers, 2000).

Financial strain, caretaker burden, disruptions in planned activities, restrictions on travelling, last minute changes to plans, and a focus on short-term rather than long-term goals are additional chronic stressors with which the family must often deal (Rodrigue, Morgan & Geffken, 1990; Sanders & Morgan, 1997; Wing, 1971).

Despite the challenges faced by the families of autistic children, some families are able to cope remarkably well, while others have considerable difficulty in dealing with these challenges.

The factors discussed above, in conjunction with the fact that South African research in this area is very limited, form the basis of the motivation for the current study.

1.3. Aims of the Study

The purpose of this study is to identify those characteristics of families that enable them to adapt successfully to the presence of an autistic child in the family. The study therefore focuses on family strengths and competencies as opposed to family deficits.

The study further aims to provide both professionals and parents with insight into how to create a family environment, which will benefit the autistic child, without detriment to the total family system.

1.4. Presentation of the Research

Chapter two looks at the theory relating to autism and family resilience respectively. This is followed by a review of the literature on autism and adaptation in chapter three. Chapter four focuses on the methodology of the study. It looks at the research design, the research question and the questionnaires being used. In chapter five the results of the statistical analysis of the data are reported. Finally, chapter six contains a discussion of these results, as well as conclusions drawn from these results. Furthermore, this chapter discusses the limitations of the study and recommendations for further research.

CHAPTER 2

THEORETICAL BACKGROUND

2.1. Introduction

This chapter provides an overview of the two main constructs in this research study, namely autism and family resilience. The constructs will be defined and various theories underlying these constructs will be examined. The chapter aims to provide an indication of the stressors associated with an autistic disorder and to highlight the importance of a strengths-based approach in adapting to such stress.

2.2. Autism

2.2.1. Definition
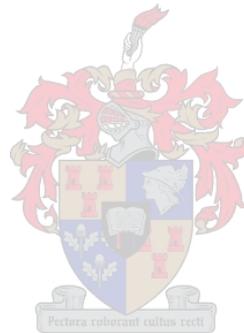
Autism is a chronic and often severely debilitating disorder that is typically diagnosed within the first three years of a child's life (Autism Society of America, 2003). It is a broad-spectrum neurological disorder (Debbaudt & Rothman, 2001), which means that its symptoms, range of abilities, and characteristics are expressed in different combinations (Mash & Wolfe, 2002), and in different degrees of severity (Fleming, 1999). Autism does not consist of one primary deficit, but rather several deficits that affect the child's social-emotional, language, and cognitive development (Mash & Wolfe, 2002). Autism is a physical disorder of the brain that results in a lifelong developmental disability (Powers, 2000). Autism is four to five times more likely to occur in males than in females (Mesibov, Adams & Klinger, 1997; Sadock &

Sadock, 2003), although it is often more severe in females (Lord & Schopler, cited in Mesibov et al., 1997).

Autism is described as a Pervasive Developmental Disorder (PDD), which is defined as a condition that affects development extensively and in all aspects of the child's life (Powers, 2000). It involves a delay and deviance in the development of social skills, language and communication, and behavioural repertoire (Sadock & Sadock, 2003). These areas of impairment have been coined the triad of impairments (Wing & Gould, cited in Mesibov et al., 1997). Autism involves many parts of the brain and undermines many of the traits that characterise human beings, such as social responsiveness, the ability to communicate and feelings for other people (Mash & Wolfe, 2002).

Apart from autism, which is also referred to as autistic disorder, four other developmental disorders fall under the diagnostic umbrella of PDD. These are Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder: Not Otherwise Specified (PDD: NOS). Children with PDD often have a narrow range of interests, are resistant to change and are unresponsive to their social environment. Pervasive developmental disorders affect most areas of development, are manifested early in life and result in persistent dysfunction (Sadock & Sadock, 2003).

Although most symptoms are present in all children with autism, it is important to remember that these symptoms will manifest themselves differently in each child. In addition, it is important to note that all children with autism vary in their abilities, behaviour (Powers, 2000) and intelligence (KidSource, 1997). Thus children with autism can be very different from one another. Three factors contribute to these differences. Firstly, children with autism may possess any level of intellectual ability, ranging from profound mental retardation to above-average intelligence. Secondly, children with autism vary in the severity of their language problems. They may fall anywhere between the two extremes of talking a lot to

being completely mute. Lastly, the behaviour of children with autism changes with their age. Some children may make little or no progress, while others may develop speech or become more outgoing (Mash & Wolfe, 2002). Despite each child's individual range of symptoms and behaviours, broad areas of similarity have been identified (Powers, 2000).

2.2.2. Physical characteristics

Children with autism are often described as being very attractive. They do however have high rates of minor physical anomalies, such as ear malformations. These physical anomalies may reflect the stage in foetal development in which the abnormalities arose (Sadock & Sadock, 2003).

2.2.3. Symptoms

According to Powers (2000) the six major symptoms of autism include failure to develop normal socialisation; disturbances in speech, language and communication; abnormal relationships to objects and events; abnormal responses to sensory stimulation; developmental delays and differences; and onset during infancy or childhood.

2.2.3.1. Problems related to socialisation

The most noticeable symptom in children with autism is their inability to develop normal social skills. Some children interact with others in ways that differ from most other children, while others don't interact at all. It appears that they live a life of isolation, as they prefer to be on their own (Powers, 2000). The DSM-IV (1994) identifies four areas of social interaction

which are qualitatively impaired or absent in children with autism. The first of these areas involves impairment in the use of nonverbal behaviours, including eye contact, facial expressions, body postures and gestures.

A child with autism may avoid eye contact completely or stare at a person so intently that it makes them uncomfortable (Mesibov et al., 1997; Sadock & Sadock, 2003). Some children even use eye contact meaningfully, albeit on a very basic level. The impairment therefore lies in the absence of interactive eye contact, which is essentially the quality of the eye contact (Aarons & Gittens, 1999). In terms of facial expression, an autistic child's affect may be flat and blunted or inappropriate in amount or intensity. Body gestures such as nodding or pointing are often absent (Mesibov et al., 1997). Despite their attractive appearance, this lack of nonverbal communication, which often reflects everyday life experiences, may result in diminished attractiveness (Aarons & Gittens, 1999).

The second area involves the failure to develop peer relationships that are appropriate to developmental level. Many children with autism have no interest in making friends while others want friends but don't understand how to establish friendships (Mesibov et al., 1997). Children with autism often lose any chance of making friends due to their tactless remarks, which may offend other children. These problems can be understood in terms of an impaired theory of mind and weak central coherence. A child with autism is unable to put him/herself into another person's shoes, thus making it difficult to extract meaning from a situation (Aarons & Gittens, 1999; Sadock & Sadock, 2003).

The third area of impairment, according to the DSM-IV (1994), is a lack of spontaneously seeking to share enjoyment, interests or achievements with others (Mesibov et al., 1997). Children with autism experience difficulties in joint social attention, which is the ability to direct the focus of attention on another person and an object of mutual interest at the same time (Mash & Wolfe, 2002). The inability to share a focus of attention with others

through gestures is one of the earliest symptoms of autism (Mesibov et al., 1997). Although a child with autism may bring an object to a person, or gesture towards an object when they want something, they show little desire to share interest or attention with another person for the pleasure associated with it (Mash & Wolfe, 2002).

The final area involves a lack of social and emotional reciprocity (Mesibov et al., 1997). Children with autism experience great difficulty in understanding and expressing emotion. They do not look for or attend to the emotional cues provided by others, and may exhibit bizarre or mechanical facial expressions when attempting to express emotion (Mash & Wolfe, 2002). In addition, children with autism may demonstrate few or unusual signs of attachment (Powers, 2000). Such children often show no particular preference for their parents (Sadock & Sadock, 2003), or they display an obsessive attachment to one or other parent. Some are indifferent to human contact and instead develop attachments to particular objects (Mash & Wolfe, 2002). The removal of these objects usually leads to severe distress (Aarons & Gittens, 1999). In the eyes of an autistic child, other people are often seen as instruments that can be used to obtain what they want and need (Aarons & Gittens, 1999; Powers, 2000).

2.2.3.2. Problems related to language and communication

In terms of language and communication problems, approximately forty percent of children with autism do not speak at all (Powers, 2000). Often these children develop speech towards the end of their first year, but lose it again and are unable to generate speech or language of their own (Aarons & Gittens, 1999). One of the first signs of language difficulties in children with autism is the inconsistency with which they use preverbal communications, such as facial expressions, vocalisations, and gestures to communicate their needs, interests and

feelings. Children with autism may fail to develop protodeclarative gestures, which are gestures or vocalisations aimed at joint social attention, but are likely to develop protoimperative gestures, which are gestures or vocalisations to express needs. In addition children with autism will use instrumental gestures to get someone to do something for them, but do not make use of expressive gestures to convey feelings. It is believed that the common element underlying the communication deficits in autism is the failure to understand that language can be used to inform and influence others (Mash & Wolfe, 2002).

The DSM-IV (1994) lists four criteria under the category of impaired communication. The first criterion entails a delay or a total lack of development of spoken language. This impairment is not compensated for by the use of gestures or other forms of communication. If language is not absent it is almost always deviant. Deviant language may include pronoun reversals ("you" instead of "I") or echolalia (Mesibov et al., 1997). This is when the child simply repeats what has been said in a parrot-like fashion, either immediately or after a period of time (Aarons & Gittens, 1999; Powers, 2000).

The second criterion involves individuals with adequate speech. The DSM-IV (1994) states that in autistic individuals that are able to speak, their ability to initiate or sustain a conversation with others is impaired (Mesibov et al., 1997). Although these children may develop complex language, the communication is often not functional or may be used out of context (Powers, 2000). Efforts at social contact are unnatural and repetitive, with the child speaking in a one-sided and stereotyped manner. Parents of verbal autistic children describe their communication as silly, incoherent, nonsensical and irrelevant (Mash & Wolfe, 2002). Often children with autism develop normal language at the normal time, and it is only when other problems develop that parents realise that the child is not using their language skills communicatively (Aarons & Gittens, 1999). The primary impairment in children with autism that develop language, relates to pragmatics, or the appropriate use of language in social and

communicative contexts. As a result, children with autism find it difficult to understand nonliteral statements or to adjust their language to fit the situation (Mash & Wolfe, 2002).

The third criterion involves stereotyped and repetitive use of language or idiosyncratic language. This criterion includes unusual aspects of language such as echolalia (immediate and delayed), pronoun reversal, and metaphoric speech (Mesibov et al., 1997). Abstract concepts are difficult to understand and pragmatics may be impaired. Children with autism often misinterpret social cues and fail to develop the ability to play, albeit imaginary play or social play (Powers, 2000). This ties in with the fourth criterion of the DSM-IV (1994), which is the "lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level" (p. 75). Some children may never engage in make-believe play, while other will insist on playing the same social game according to the same theme, with the same words, and the same people every time. Children with autism often find it difficult to imitate motor movements of others. Their verbal imitative skills, on the other hand, are often very good (Mesibov et al., 1997).
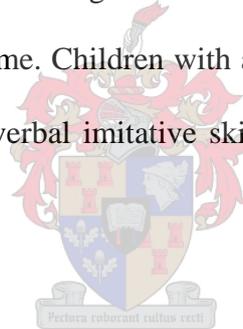
2.2.3.3. Unusual patterns of behaviour

Children with autism often engage in restricted, repetitive and stereotyped patterns of behaviour, activities and interests (DSM-IV, 1994). This impairment involves deviant rather than absent behaviour (Mesibov et al., 1997). The first criterion, according to the DSM-IV (1994), involves "encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus" (p. 75). Children with autism may learn a great deal of information about a very restricted topic, memorising facts and conversing only about their chosen topic. Children may also focus on only one particular toy while playing or play with unusual objects, such as straws or strings (Mesibov et al., 1997;

Sadock & Sadock, 2003). Children with autism are often unable to see the big picture and tend to focus on a miniscule object or event (Mash & Wolfe, 2002).

The second criterion involves inflexible adherence to specific, non-functional routines or rituals. Children become upset if there is the slightest change to their normal routines (Aarons & Gittens, 1999) or to commonly performed rituals, such as bedtime (Mesibov et al., 1997). This may lead to panic, fear or temper tantrums (Sadock & Sadock, 2003). This adherence to routines and rituals often disrupts family life as the child may refuse to carry out an activity unless the appropriate rituals have been carried out. They often insist that the same route be followed and will experience great distress if another direction is taken. They may lash out and scream if an object is moved from its usual location (Mash & Wolfe, 2002). Interestingly, more extreme changes and new experiences may go unnoticed by the child and these children may show no signs of disturbance to outings or holidays (Aarons & Gittens, 1999).

Stereotyped body movements such as rocking, spinning, hand-flapping or head-banging are common in children with autism (Mesibov et al., 1997). This is the third DSM-IV criterion in this area of impairment (DSM-IV, 1994). The final criterion is the unrelenting preoccupation with parts of objects. Children with autism may smell their toys, consistently spin the wheels on their toy truck, or focus on parts of objects such as door hinges (Mesibov et al., 1997). Stereotyped behaviour may also occur in unfamiliar situations suggesting that these behaviours provide the child with a sense of control over the environment and a way of coping with changes, which they do not understand (Mash & Wolfe, 2002).

Self-stimulatory behaviour (repetitive body movements or movements of objects) may involve one or more of the senses and is common in children with autism. It is however not known why these children engage in these behaviours. One theory states that these children crave stimulation and self-stimulation excites the nervous system. Another theory postulates

that there is too much stimulation in the environment and self-stimulation serves as a way to block out and control unwanted stimuli. Other theories maintain that self-stimulation is carried out for the reinforcement it provides (Mash & Wolfe, 2002).

2.2.3.4. Sensory problems

Children with autism find it difficult to filter out unimportant or unnecessary stimuli in the environment. They tend to over-attend to certain stimuli and to under-attend to others (Powers, 2000; Sadock & Sadock, 2003). Some children have strange or extreme responses to sensory stimuli such as a high pain threshold, fascination with certain visual or auditory stimuli, and hypersensitivity to light, sound or touch (Mesibov et al., 1997). Children may be fascinated with bright lights or certain colours, textures, or foods (Powers, 2000) and may go to great lengths to experience the sensations associated with them or otherwise to avoid them (Autism Society of America, 2003).

Sensory function refers to the use of vision, hearing, touch and smell (Aarons & Gittens, 1999). Typically, children with autism show a great deal of ability in terms of visual perception and it is believed that such children learn best through the use of visual strategies. On the auditory side, children with autism are often considered to be deaf, as they do not respond to human voices or even to loud noises (Sadock & Sadock, 2003). Children with autism may demonstrate distress in the face of auditory stimuli in general, or to specific sounds, which they do not understand. Proximal senses relate to touching, smelling and feeling. Children with autism, particularly those that are lower functioning, often lick, sniff or scratch surfaces, themselves or even other people. In addition they may lack awareness of pain, heat and cold, often struggling to locate and express the source of their discomfort (Aarons & Gittens, 1999).

2.2.3.5. Developmental irregularities

Children without disabilities develop at a relatively even pace across all areas of development. Children with autism, on the other hand, develop differently in the areas of communication, social and cognitive skills, while motor development tends to be relatively normal or only slightly delayed. The sequence of development in any area of development may be unusual. Children will sometimes develop skills at the expected time after which these skills disappear (Powers, 2000).

2.2.3.6. Additional symptoms

Other symptoms may include inappropriate social responses, inability to form relationships, lack of emotional reciprocity and restricted, repetitive and stereotyped patterns of behaviour, interests and activities (DSM-IV, 1994). In severe cases of autism the child may engage in behaviours that are self-injurious, highly unusual or aggressive (Autism Society of America, 2003). Another typical feature of autism is what has been termed the preservation of sameness, that is, an aversion to change, albeit in the environment or in normal routine (Mash & Wolfe, 2002; Nevid, Rathus & Greene, 2000). Children with autism also find it difficult to generalise. They struggle to adapt what they have learnt in one situation to suit a new situation. This inability to generalise extends to all areas of daily life (Aarons & Gittens, 1999). Attention control may also be a problem in children with autism. They may be easily distracted unless they are focusing on an activity which is of interest to them, or which is meaningful (Aarons & Gittens, 1999; Sadock & Sadock, 2003).

2.2.4. Comorbid disorders

The symptoms of autism may occur by themselves or in combination with other conditions such as epilepsy, deafness and blindness (Powers, 2000). People with autism often show irregular cognitive patterns, in that they tend to perform better on nonverbal, visual-spatial tasks than on verbal tasks (Mesibov et al., 1997; Sadock & Sadock, 2003). They may also have comorbid obsessive-compulsive disorders, language disorders, attention-deficit disorders (Frith, cited in Olney, 2000) or mental retardation (Debbaudt & Rothman, 2001). Gillberg (cited in Mesibov et al., 1997) reported that 23% of people with autism have an IQ of above 70, while the remaining 77% have mental retardation in addition to autism.

Associated behavioural symptoms may include hyperactivity, impulsive behaviour, aggressive behaviours, temper tantrums and self-injury, such as head banging, biting, scratching and hair pulling (Mesibov et al., 1997; Sadock & Sadock, 2003). This behaviour is often brought about by change or demands (Sadock & Sadock, 2003). Self-injury may occur for purposes of self-stimulation, to gain attention or to eradicate unwanted demands (Mash & Wolfe, 2002). In addition, children with autism may engage in abnormal eating behaviour, experience disturbed sleep cycles or suffer from enuresis (Sadock & Sadock, 2003).

Fearfulness, or a lack of appropriate fear may also be present (Mesibov et al., 1997). Even though children may be taught to avoid a particular danger in one setting, they may be unaware of an identical hazard in a different situation (Aarons & Gittens, 1999). Higher-functioning individuals with autism may develop depression as they approach adolescence and adulthood (Mesibov et al., 1997). Young children with autism often have higher than normal incidence of upper respiratory infection and other minor infections, as well as gastrointestinal symptoms such as burping, constipation and loose bowels (Sadock & Sadock, 2003).

2.2.5. Causes of autism

Although the cause of autism has not yet been pinpointed, several models have attempted to explain the disorder (Mash & Wolfe, 2002; Olney 2000; Sadock & Sadock, 2003). According to Mash and Wolfe (2002), it is generally accepted that autism is a "biologically based neurodevelopmental disorder with multiple causes" (p. 274).

2.2.5.1. Historical and theoretical models

In the early 1940's Leo Kanner and Hans Asperger, the founders of the disorder, believed autism to be an inborn biological disorder. Due to the early onset of autism, Kanner believed the disorder to be the result of an inborn inability to form loving relationships with others (Mash & Wolfe, 2002). Kanner, along with Bruno Bettleheim, further believed the disorder to be the result of parents who were obsessive, cold, mechanical and detached in their relationships to their children (Mash & Wolfe, 2002). This view therefore focused on pathological family relationships (Nevid et al., 2000). Bettleheim (cited in Nevid et al., 2000) believed that the extreme self-absorption was the child's defence against parental rejection. Due to the emotionally and socially barren atmosphere in which these children were reared, their attempts to develop language and social skills declined. The child then gave up all efforts to develop mastery over their external world and withdrew into a world of fantasy. Their pathological insistence on the preservation of sameness was a means of imposing order and predictability in their world (Nevid et al., 2000). Although this belief was held for many years, it has now been completely disputed (Olney, 2000).

2.2.5.2. Biological factors

According to the more recent neurobiological model the symptoms of autism are the result of impaired structure and function of the brain (Olney, 2000). The various impairments that are associated with autism, such as mental retardation, language difficulties, peculiar motor behaviour, and even seizures, suggest the presence of some form of brain damage (Mash & Wolfe, 2002; Nevid et al., 2000; Sadock & Sadock, 2003). Several brain abnormalities have been identified that appear to be consistent with disturbance in neural development that occurs at least 30 weeks before birth (Mash & Wolfe, 2002). Neuropsychological impairments in autistic disorder occur in many areas, such as orienting and selective attention, verbal intelligence, memory, pragmatic language, and executive functions. Due to the widespread nature of these deficits, it is clear that autism involves multiple regions of the brain at both the cortical and subcortical levels (Happe & Frith, cited in Mash & Wolfe, 2002).

Brain imaging studies have consistently found abnormalities on the frontal lobe cortex of people with autism (Mash & Wolfe, 2002). Magnetic resonance imaging (MRI) scans comparing autistic children to normal controls indicate that the total brain volume of autistic children is larger than that of the controls, although children with autism who have severe mental retardation tend to have smaller heads (Sadock & Sadock, 2003). The largest average percentage increase in size was in the occipital lobe, parietal lobe and temporal lobe (Sadock & Sadock, 2003). The increased volume can be accounted for by three possible mechanisms: increased neurogenesis, decreased neuronal death, and increased production of nonneuronal brain tissue such as glial cells or blood vessels (Sadock & Sadock, 2003). MRI scans of the brains of boys and men with autism do show structural differences, including enlarged ventricles, indicating a loss of brain cells (Nevid et al., 2000). Brain enlargement has been proposed as a possible biological marker for autism (Sadock & Sadock, 2003).

Studies have also identified structural abnormalities in the cerebellum, and in the medial temporal lobe and its related limbic system structures, such as the amygdala and hippocampus (Mash & Wolfe, 2002).

The temporal lobe is believed to be a crucial site of brain abnormality in autism. This is based on the fact that people with temporal lobe damage often exhibit autistic-like symptoms (Sadock & Sadock, 2003). The medial temporal lobe and its related limbic system structures are associated with functions that are often disturbed in children with autism. These functions include emotion regulation, learning and memory. The amygdala plays a salient role in recognising the emotional significance of stimuli and the relation between social behaviour and rewards. It also plays an essential role in orienting towards social stimuli, the perception of eye gaze direction, and, along with the hippocampus, long-term memory (Mash & Wolfe, 2002).

The cerebellum, which is most often associated with motor movement, is also partially involved in language, learning, emotion, thought and attention. Specific regions of the cerebellum have been found to be notably smaller in people with autistic disorder. It has been suggested that abnormalities in the cerebellum may account for the difficulty children with autism have in quickly shifting their attention from one stimulus to another (Mash & Wolfe, 2002).

Neuroimaging studies of brain metabolism in children with autism indicate a decreased blood flow in the frontal and temporal lobes. Neurotransmitter abnormalities have also been found in children with autism. Approximately one-third of people with autism show elevated levels of whole blood serotonin (Mash & Wolfe, 2002).

Some brains of people with autism show a decrease in cerebellar Purkinje's cells, which may account for abnormalities in attention, arousal and sensory processes (Sadock & Sadock, 2003). It is however believed that autism originates from multiple causes, in which

more than one type of brain abnormality is involved (Ritvo & Ritvo, cited in Nevid et al., 2000).

2.2.5.3. Genetic factors

Reports on specific chromosomal anomalies and genetic disorders, and results of family and twin studies point towards a significant role for genetics in the origins of autistic disorder (Mash & Wolfe, 2002; Nevid et al., 2000). The strong genetic component is supported by concordance rates of 60% for monozygotic twins and approximately 10% for dizygotic twins (Nevid et al., 2000). Further, between 2 and 4 percent of siblings of children with autism also had autistic disorder (Sadock & Sadock, 2003). This rate is 50 times higher than that in the general population (Mash & Wolfe, 2002).

Reports suggest that the nonautistic members of families with autistic members have higher rates of less severe language or other cognitive deficits (Sadock & Sadock, 2003), social deficits and personality traits similar to those found in people with autism (Mash & Wolfe, 2002). These deficits, referred to as the broader autism phenotype, include social oddities such as aloofness, rigidity, and lack of tact; pragmatic language difficulties such as over- or undercommunicativeness; and poor verbal comprehension. Families with this broader phenotype do not however exhibit the unusual language (e.g. echolalia), extreme stereotyped repetitive behaviour, or mental retardation that is associated with a formal diagnosis of autism (Rutter, cited in Mash & Wolfe, 2002).

Fragile X syndrome appears to be associated with autism (Mash & Wolfe, 2002). This is a genetic disorder in which a portion of the X chromosome fractures (Sadock & Sadock, 2003). Generally, people with autism have an increased risk of approximately 5% for chromosomal anomalies. These anomalies do not however indicate specific gene sites

underlying autistic disorder, due to the fact that autism has been associated with anomalies on almost all chromosomes (Mash & Wolfe, 2002). Tuberous sclerosis, a rare single-gene disorder characterised by multiple benign tumours, with autosomal dominant transmission is more common in children with autism (Sadock & Sadock, 2003) and may result in neural deficits, seizures, and learning difficulties (Mash & Wolfe, 2002).

Researchers examined the DNA of about 150 pairs of siblings with autism and found very strong evidence that two regions on chromosomes 2 and 7 contain genes involved in the development of autism (Mash & Wolfe, 2002; Sadock & Sadock, 2003). Locations for genes related to autism were also found on chromosomes 16 and 17 (Sadock & Sadock, 2003). Multiple genes are believed to be involved in giving rise to autism (Mash & Wolfe, 2002). These genes possibly interact with other factors, such as environmental or biological factors in the development of the disorder (Nevid et al., 2000).

2.2.5.4. Problems in early development
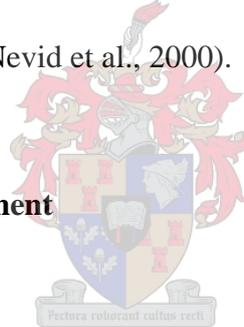
Higher than normal rates of perinatal complications (Sadock & Sadock, 2003), birth complications and neonatal problems (Mash & Wolfe, 2002) occur in infants who are later diagnosed with autistic disorder. Maternal bleeding after the first trimester and meconium in the amniotic fluid are two factors that have been reported more often in the histories of children with autism than in the general population (Sadock & Sadock, 2003). Premature birth, toxaemia (blood poisoning), viral infection or exposure, and a lack of energy following birth have been identified in about a quarter of children with autism (Mash & Wolfe, 2002).

The neonatal period of children with autism is often characterised by high rates of respiratory distress and neonatal anaemia (Sadock & Sadock, 2003). It has also been suggested that immunological incompatibility (maternal antibodies directed at the foetus) may

contribute to the development of autism (Sadock & Sadock, 2003). Although problems during pregnancy and at birth are not seen to be the primary causes of autism, they suggest that foetal and neonatal development may be compromised in some way (Mash & Wolfe, 2002). A recent theory that has proven to be very controversial concerns the role of vaccinations in the development of autism. Combination vaccinations for measles, mumps and rubella (MMR) have received the most attention in this regard (Mash & Wolfe, 2002). This concern was first aired by Andrew Wakefield in 1998 although his research was criticised and disputed on many grounds. In 2005 Robert F. Kennedy proposed that it was not the MMR vaccine in itself that was responsible for the development of autism, but rather the mercury-based preservative, thimerosal, that is used in the preparation of several vaccines (Autism Society of America, 2003). According to the Autism Society of America (2003) the Institute of Medicine in the United States of America rejects the theory (Montgomery & Wakefield, 1999) of a causal relationship between MMR vaccines and autism but they maintain that the possibility of a link could not be ruled out.
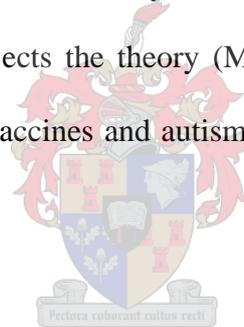
2.2.5.5. Psychosocial and family factors

In contrast to the beliefs held by Kanner and Bettleheim, more recent theories show no significant differences in child-rearing skills between the parents of autistic children and the parents of normal children (Sadock & Sadock, 2003).

Children with autism may respond to psychosocial stressors, such as family discord, the birth of a new child, or a family move, with exacerbated symptoms. Some children may be extremely sensitive to even the slightest changes in their families or immediate environment (Sadock & Sadock, 2003). Proponents of the social model prefer to view autism as a difference in the way people interact rather than a dysfunction (Olney, 2000).

2.2.5.6. Clinical-behavioural model

This model does not reject the neurobiological theories, but interprets autism differently. Researchers in this model view autism as a thematisation disorder; they speculate that individuals with autism create meaning in different ways to others; and proponents of theory of mind believe that children with autism are unable to comprehend thoughts and experiences that occur outside of themselves (Olney, 2000).

Although no single model can describe the experience of autism, they all contribute to our understanding of the disorder (Olney, 2000).

The discussion will now turn to various theories surrounding family resilience.

2.3. Family Resiliency Theory

A large body of literature exists describing the problems families experience as a result of various stressors. This literature thus focuses on family deficits and pathology. Over the last few years, however, there has been a shift from this deficit model towards a resilience model, which focuses on resilience and adaptation (Hawley & DeHaan, 1996). In addition, resilience theory initially focused primarily on the individual (Walsh, 2003). Resilience was seen as an innate characteristic of individuals, and families were viewed as contributing to risk but not to resilience. However, in the past two decades, the concept of resilience has been extended to include family resilience (Walsh, 2003).

2.3.1. Definition

According to Hawley and DeHaan (1996):

> Family resilience describes the path a family follows as it adapts and
> prospers in the face of stress, both in the present and over time. Resilient
> families respond positively to these conditions in unique ways, depending
> on the context, developmental level, the interactive combination of risk and
> protective factors, and the family's shared outlook. (p. 293)

This definition implies that family resilience describes the path a family follows as it adapts to a stressor and recovers from the stress-producing situation in ways that allow them to grow as a family unit. Resilience should therefore be viewed as a developmental process, rather than a set of predetermined strengths. Family resilience is influenced by the context of the family, including developmental factors, as well as risk and protective factors. It includes short- and long-term coping techniques and focuses on the family's continued ability to adapt and be flexible (Hawley & DeHaan, 1996).

Several other definitions of family resilience have been put forward (McCubbin et al., 1996; Walsh, 2003). According to McCubbin et al. (1996):

> Family resilience can be defined 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 unit

as a whole. (p. 5)

These definitions encompass a number of common ideas. Firstly, resilience appears to surface in the face of family difficulties or hardships (McCubbin et al., 1996; Walsh, 2003). It includes characteristics of families that enable them to maintain stability despite the stressors they encounter. The term coping entails families with greater resilience adapting to the hardships they come upon in ways that are productive for the well-being of the family unit (Hawley & DeHaan, 1996; McCubbin et al., 1996). Secondly, inherent in resilience is the property of buoyancy. That is, the ability to bounce back to a prior level of functioning after experiencing family adversity (Hawley & DeHaan, 1996). Finally, resilience is seen in terms of competence as opposed to pathology. It aims at identifying those factors that contribute to healthy family functioning, rather than family deficits (Hawley & DeHaan, 1996; McCubbin et al., 1996).

In line with the above discussion, the concept of resilience is housed within the salutogenic perspective, which was introduced by Antonovsky (1979). This perspective contrasts the traditional pathogenic approach and looks at what keeps people healthy. It encompasses ideas such as vitality, the prevention of disease and the promotion of health, and is therefore a strengths-based approach (Antonovsky, 1979).

2.3.2. Development of models of family resilience

Several models of family resilience have been put forward over the past few years. The first of these is the ABCX model of Hill (cited in McCubbin, Thompson & McCubbin, 1996), which looked at the stressor (A), resources (B), and the definition of the stressor (C), that

reconcile and protect the family from experiencing a decline in family functioning during a crisis situation (X). Building on this model, the double ABCX model of McCubbin and Patterson (cited in McCubbin et al., 1996) was introduced. This model attempted to describe the adaptation of the family to stressors or crises in terms of several factors, such as coping and social support, that play a role in family adaptation. The model was further extended to produce the Family Adjustment and Adaptation Response (FAAR) Model of McCubbin and Patterson (cited in McCubbin et al., 1996), which included pre- and post-crisis factors in family adaptation, and described the processes involved in the family's attempts to balance stressors and resources.

Following this model, McCubbin and McCubbin (cited in McCubbin et al., 1996) introduced the Typology Model of Family Adjustment and Adaptation. This model focused on the significance of established patterns of family functioning and the family's assessment of the situation, as defence against family breakdown, as well as factors advancing adaptation. This model was extended, resulting in the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin et al., 1996). The Resiliency Model draws attention to the four major areas of family functioning involved in recovery; establishes important family processes and goals of harmony and balance during times of adversity; highlights the significance of five levels of family appraisal involved in family transformation and recovery; and emphasises the importance of family relational processes, namely adjustment and adaptation.

2.3.3. Resiliency Model of Family Stress, Adjustment and Adaptation

The Resilience Model of Adjustment and Adaptation focuses on "what family types, patterns, processes, system properties, appraisal strategies, meanings, coping, supports, problem solving abilities and transactions with the community play a role in family recovery"

(McCubbin & McCubbin, 1996, p. 3). The Resiliency Model looks at why some families are able to rise above their circumstances and are seen as resilient and why other families are unable to recover from or even decline under the same kinds of circumstances. This model may be viewed as a contextual framework, in that the family is seen as a fundamental and interacting part of its larger social ecology such as nature, community, society, nation and world. Due to the fact that the family is a system, all of these domains affect each other, and the family thus aims for balance and harmony in all these domains (McCubbin et al., 1996). The model distinguishes between two interrelated phases, namely the adjustment phase and the adaptation phase (McCubbin et al., 1996).

2.3.3.1. Adjustment vs. adaptation

The adjustment phase of the Resiliency Model encompasses a sequence of components that interact to shape family processes and outcomes (McCubbin et al., 1996). Outcomes can be represented on a continuum and vary from bonadjustment (established patterns of functioning are maintained) to maladjustment (in which the family must change their established patterns of functioning in order to achieve harmony and balance in the face of stressful situations). According to McCubbin et al. (1996) the process of adapting also involves the process of transforming the environment, the community, as well as the family's relationships to the community in order to re-establish harmony, balance and family well-being. The distinction between adaptation and adjustment therefore emphasises the focus on what changes must take place. Adjustment involves changes in patterns of family functioning, while adaptation focuses on changes in external systems, as well as relationships to these systems. In the face of family stressors, the family first moves through the adjustment phase, which is followed by the adaptation phase of the Resiliency Model (McCubbin et al., 1996).

2.3.3.2. Adjustment phase

Looking at the adjustment phase, successful or unsuccessful adjustment depends on numerous essential interacting elements, namely the stressor and its severity; family vulnerability; established patterns of family functioning or family typology; resistance resources; appraisal of the stressor; and family problem solving and coping strategies. These components interact with one another to determine the family's level of adjustment, i.e. the continuum from bonadjustment to maladjustment (McCubbin et al., 1996). Each of these components and their relationship to the family's level of adjustment will be described briefly.

A stressor can be described as any demand placed on the family that may produce changes in the family system. Such changes may influence all areas of family life, including the marital relationship, family goals, parent-child relationships and the family's level of balance and harmony. The severity of the stressor may be determined by the extent to which it threatens family stability, disturbs family functioning, or puts considerable demands on or depletes family resources and capacities (McCubbin et al., 1996).

Family vulnerability relates to pile-up and family life cycle changes. It is the interpersonal and organisational situation of the family unit and ranges from high to low. It is determined by the pile-up of demands on or within the family system, such as poor health, financial burdens, or changes in the family environment; and the normative problems associated with the family's current life cycle stage (McCubbin et al., 1996).

Family typology is defined by a set of traits that describe how the family typically operates. It represents a predictable pattern of family functioning. During normative transitions, families described as resilient were more competent in terms of managing family difficulties and promoting family strengths. Family typologies play a significant role in

assisting the development, restoration and preservation of harmony and balance in the family unit (McCubbin et al., 1996).

Family resistance resources refer to the family's capabilities and strengths that can be utilised to deal with a stressor and the demands associated with it. These resources are also called upon in an attempt to avoid crises by promoting balance and harmony, as well as to address changes or deterioration in established patterns of family functioning (McCubbin et al., 1996). Family resistance resources help the family to resist a crisis and promote resiliency and ultimately, adjustment. Significant family resources include social support, economic stability, cohesiveness, hardiness, flexibility, shared spiritual beliefs, patterns of open communication, traditions, celebrations, routines, and organisation (McCubbin et al., 1996).

A family's appraisal of the stressor is its definition of the severity of the stressor, as well as the difficulties relating to the stressor. This may range from viewing the situation as uncontrollable and potentially leading to family disintegration, to viewing it as a challenge, which may result in growth of the family unit (McCubbin et al., 1996).

Family problem solving and coping provides an indication of a family's ability to manage stress and distress by utilising its skills and abilities to deal with or eliminate a stressor and its associated difficulties. Problem solving involves the ability of the family to organise stressors into manageable components, to identify possible solutions to manage each component, and to engage in constructive patterns of problem solving communication in order to re-establish balance and harmony in the family unit. Coping, on the other hand, refers to the family's active or passive strategies, patterns, and behaviours that promote the maintenance or strengthening of the family unit, as well as the emotional stability and well-being of its members. It includes the mobilisation and utilisation of family and community resources, and attempts to resolve family difficulties resulting from the stressor (McCubbin et al., 1996).

It is important to look at the family's response to a stressor as part of the process of adjustment. Stressors result in tension. If this tension is not eliminated or made manageable, distress occurs. This distress may be influenced by the established patterns of family functioning, the resistance resources, the family's appraisal processes and the problem solving and coping responses. In addition, family stress may vary according to the severity, intensity and anticipation of the stressor; the family's resources and competency to manage the stressor; and the well-being, both physical and psychological, of family members at the onset of the stressor (McCubbin et al., 1996).

In most cases, stressors do not create major family hardships, especially when the stressor is mediated by the established patterns of family functioning, the resistance resources, the family's appraisal processes and the problem solving and coping responses. In such cases, the outcome is bonadjustment. Here the family moves through the stressful circumstances relatively easily, with only minor changes in the family system and its ways of functioning. However, in other stressful situations the stressor may result in substantial family difficulties, and thus greater changes must be made in order to restore or maintain harmony and balance. In some cases families may choose to remain in imbalance in order to force changes in family functioning to occur. Therefore, new patterns of family functioning must be established for balance and harmony to be restored. In such situations families are likely to experience maladjustment, which later results in family crisis (McCubbin et al., 1996).

Family crisis can be defined as a "continuous condition of disruptiveness, disorganisation, or incapacitation in the family social system" (Burr, cited in McCubbin et al., 1996, p. 22) to re-establish balance and harmony, which in turn demands greater changes in patterns of family functioning (McCubbin et al., 1996). Family stress is a state of imbalance between the demands placed on the family and its capabilities to manage those demands, whereas family crisis represents family imbalance, disharmony and disorganisation. Within

the Resiliency Model a family in crisis is not viewed as dysfunctional, having failed, or being

in need of professional help. In contrast, as has been mentioned, many families purposefully

create crises in order to bring about changes in patterns of family functioning. Such crises are

seen as normative and growth-producing and should therefore be viewed as natural elements

in the process of family development and adjustment. Family crisis represents disharmony

and imbalance in the family system and therefore demands changes in patterns of family

functioning in order to re-establish order, stability, balance and harmony. The process of

initiating changes in patterns of family functioning marks the beginning of the adaptation

phase of the Resiliency Model of Family Adjustment and Adaptation (McCubbin et al., 1996).

2.3.3.3. Adaptation phase

The Resiliency Model includes a series of adaptation-oriented components and resiliency

processes in an attempt to describe the behaviour of a family in the relational process of

adaptation (McCubbin et al., 1996). These incorporate 1) vulnerabilities, which may include

additional life stressors and changes that undermine or restrict the family's capacity to achieve

a satisfactory level of adaptation when faced with family crisis; 2) resources, which consist of

the psychological, family, and social resources that families utilise and are shaped by in the

process of adaptation; 3) appraisal, which comprises the factors that give meaning to the

changes in the family, and play a role in establishing new patterns, eliminating old patterns,

affirming old patterns, creating and utilising resources, as well as problem solving, coping and

adaptation; 4) support, including intrafamily and family-community support processes that

facilitate adaptation; 5) patterns of functioning, which involves the elimination, modification,

and establishment of patterns of family functioning to bring about balance and harmony, as

well as adaptation; 6) coping and problem solving, which involves expanding the range and

effectiveness of coping behaviours and strategies that facilitate adaptation; and 7) processes, which includes the explanation of the relational processes involved in adaptation, and that shape the processes and outcomes of adaptation (McCubbin et al., 1996).

The level of family adaptation when faced with a crisis is determined by numerous interacting elements (McCubbin et al., 1996). These elements are schematically represented in Figure 2.1.
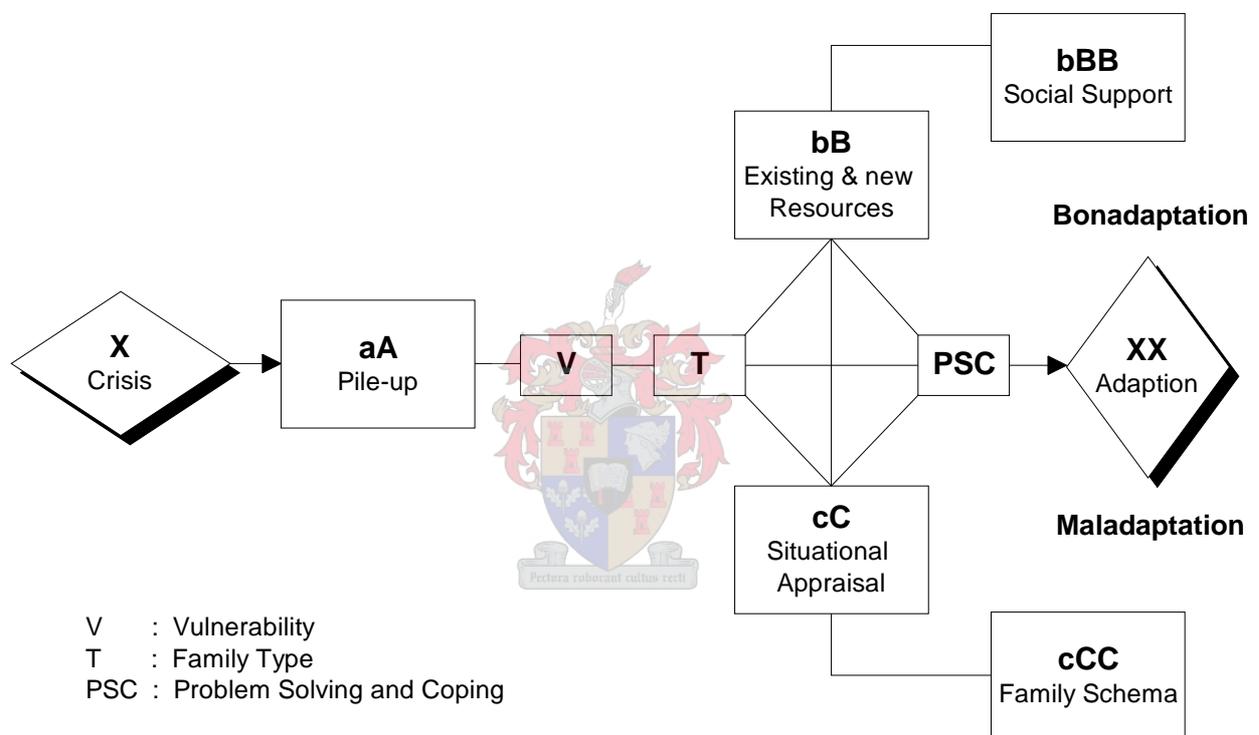
Figure 2.1. The "Resiliency Model of Family Stress, Adjustment and Adaptation" (McCubbin, Thompson & McCubbin, 1996).

When at-risk families (those who experience imbalance and disharmony as a result of a stressful situation) are unable to restore harmony and balance, they enter into a crisis situation (X). In such situations the family is vulnerable but still in the position to make constructive changes in family functioning. Some families may view the crisis situation as a challenge and

an opportunity to work towards restoring balance and harmony, and therefore a level of adaptation (XX). Families must aim towards achieving balance and harmony in their interpersonal family relationships, the family's function and structure, the development and well-being of the family and its members, and the family's relationship to the community and their natural environment. A level of successful adaptation is known as Bonadaptation, and is determined by a number of interacting factors. There are several interacting components that form part of the adaptation phase and which influence the family's level of adaptation (McCubbin et al., 1996). These will be discussed below.

Pile-up (aA) of Demands: The crisis situation may be exacerbated by a coinciding pile-up (aA) of demands such as other life changes or difficulties. It is important to remember that family crises evolve over time and are dealt with over time. As such, families are most often dealing with more than one stressor at a time. Both normative and non-normative demands occur regularly and often predictably. A pile-up of demands is therefore common and is especially significant in families dealing with chronic stressors, such as caring for a disabled child (McCubbin et al., 1996).

Family adaptation takes place within a social context and consequently, there are nine broad categories of stressors and strains that contribute to pile-up and vulnerability. These in turn influence the crisis situation and establish the family's ability to achieve balance and harmony (McCubbin et al., 1996).

The first of these categories refers to the initial stressor and its associated difficulties. Such difficulties may include problems in the marital or sibling relationships, parent-child conflict, community conflict, and decreased resources, albeit emotional or financial (McCubbin et al., 1996).

Normative changes in the family unit and individual family members represent the second category. Such changes take place as a result of normal growth and development (e.g.

increased need for nurturance and supervision); development of adult members (e.g. commitment to work, career development); changes in extended family (e.g. death or illness in the extended family); and predictable life cycle changes (e.g. children starting school, adolescence). These changes may take place concurrent with a crisis situation, making the crisis more difficult to resolve (McCubbin et al., 1996).

The third category involves prior family strains that have built up over time. Such strains may be residual strains resulting from earlier stressors or they may be inherent in certain family roles, such as parenthood. These strains may be aggravated by new stressors and thus contribute to the family's pile-up of demands (McCubbin et al., 1996).

The fourth category focuses on unexpected situational demands and contextual complexities. These are demands created by society that adversely affect family functioning and the family's ability to cope with the crisis situation. Such demands may include the threat of job loss or the inability to finance child care programmes (McCubbin et al., 1996).

The fifth category relates to the consequences of the family's efforts to cope. Because coping is a process involving trial-and-error, families may adopt coping strategies that appear to be effective in the short-term but in fact produce greater difficulties in the long-term. Such coping strategies include taking on an extra job in order to alleviate financial problems, or alcohol consumption to alleviate the psychological tension arising from the stressor McCubbin et al., 1996).

The sixth category includes intrafamily and social ambiguity resulting from inadequate societal guidelines on how to cope effectively. Crisis situations are generally coloured by ambiguity and uncertainty. Family's may rely on guidelines from the community on how to act appropriately in their given crisis situation. In some cases these guidelines may be inadequate or absent, leading families to experience a greater degree of tension relating to their situation (McCubbin et al., 1996).

Newly instituted patterns of family functioning (T), demanding additional changes in family functioning, represent the seventh category. Although these newly instituted patterns of family functioning are most likely to bring about balance and harmony in the long-term, they may lead to added strain in the short-term as families struggle to make sense of their new roles, rules, values and relationships. This may prolong the crisis situation by bringing about greater disharmony (McCubbin et al., 1996).

The eighth category refers to newly established patterns of family functioning, which are incongruent with the Family's Schema (values and beliefs) or the Family's Paradigms (e.g. rules and expectations). Existing patterns of family functioning are often difficult to replace by the much-needed new patterns, as family members resist changes to their known routines. This ties in with the final category (9) which includes the old established patterns of functioning which are incongruent or incompatible with newly adopted patterns of family functioning (McCubbin et al., 1996).

Family Resources (bB) – Strengths and Capabilities: Family capabilities refer to the potential the family can draw upon or create to meet the demands of the crisis. Three potential sources of resources can be identified, namely individual family members, the family unit and the community. McCubbin et al. (1996) define a resiliency resource as a "characteristic, trait, or competency of one of these systems (individual, family, community) that facilitates adaptation (p. 33). Resources may be either tangible (e.g. money) or intangible (e.g. integrity, cultural heritage, self-esteem). Resources that have been identified as being important to family adaptation include personal resources and family system resources. Personal resources include the innate intelligence of family members; knowledge and skills; personality traits; physical, emotional and spiritual health of family members; a sense of mastery; self-esteem; sense of coherence; and the ethnic identity, cultural heritage, and world view adopted by the family (McCubbin et al., 1996). Family system resources refer to

cohesion and adaptability. Family organisation, including agreement, clarity, and consistency in family roles and family rules; shared parental leadership; and clear generational boundaries are also important family system resources. Communication skills, family problem solving, family hardiness, family time together, and family routines have also been identified as family system resources that play a significant role in family adaptation to the crisis situation (McCubbin et al., 1996).

Social Support (bBB): Social support includes all people or institutions that the family unit or individual family members may turn to for assistance in the face of a crisis situation. These community resources and support include both informal resources such as extended family and family, and formal resources such as schools, churches, medical or social services, and national government policies (McCubbin et al., 1996).

Family Appraisal Processes: Family appraisal processes in the face of family crisis entail five basic levels, namely Schema (cCC), Coherence, Paradigms, Situational Appraisal (cC), and Stressor Appraisal. Stressor Appraisal takes place during the adjustment phase of the Resiliency Model, while the remaining four levels take place during the adaptation phase. In managing family crisis the family's culture plays an important role in three levels of appraisal, namely Family Schema, Coherence and Paradigms (McCubbin et al., 1996). These processes assist families in giving meaning to stressful situations and play a critical role in shaping strategies directed towards adaptation.

Level five of the appraisal process refers to Family Schema (cCC). This develops as a significant part of the family's attempts to changes its patterns of functioning. Over time families adapt their own set of values and beliefs, which become a fundamental part of their identity (McCubbin et al., 1996). A family schema is described as "a structure of fundamental convictions, values, beliefs and expectations" (p. 39). It is determined by and adopted by the family over time and is highly resistant to change. A family schema represents the family's

unique character and serves as a shared informational network through which experiences and stimuli are evaluated. Family schema gives rise to order, stability, balance and harmony, and influences the shaping and justification of old, established, newly instituted and maintained patterns of family functioning, as well as problem solving and coping strategies (McCubbin et al., 1996). One of the crucial functions of family schema relates to the development of meanings. This comprises the creation of joint family understandings to assist the family in adapting to the crisis situation (McCubbin et al., 1996). Family schema promotes the development of meaning through numerous processes: 1) affirmation – understanding the situation by looking for the positive aspects; 2) spiritualization – understanding the situation in the context of the family's spiritual beliefs; 3) temporalisation – understanding the situation in terms of both long-term and present benefits; and 4) naturalisation – understanding the situation in terms of natures and its order of things, and the community and personal relationships and the interpersonal order of things (McCubbin et al., 1996).

Level four of the appraisal process looks at Family Coherence, which explains the motivation and appraisal for changing the family's potential resources into actual resources, thereby facilitating transitions in the family system, coping and promoting the health and well-being of the family unit and its individual members (McCubbin et al., 1996). This is the family's view of the world as being comprehensible, manageable, and meaningful (Antonovsky, 1979).

The third level of the appraisal process looks at Family Paradigms. These are the shared rules and expectations of the family that guide the development of particular patterns of functioning around specific domains of family life, such as child rearing or communication. Once a paradigm has been adopted and used to guide family behaviours, family functioning cannot occur in the absence of a paradigm (McCubbin et al., 1996).

Level two of the appraisal process represents situational appraisal. The family's ability to deal with changes is determined by its ability to evaluate the relationship between the family's capabilities and the demands of the stressor, as well as the demands faced by the family to change some established patterns of functioning (McCubbin et al., 1996).

Finally, level one of the appraisal process looks at stressor appraisal, which refers to the family's definition of the stressor and its severity (McCubbin et al., 1996).

A brief description of the appraisal process as it occurs within the context of a family crisis situation, such as the birth of a child with a disability, will now follow. When a family is faced with the crisis, it has been found that their established patterns of functioning may be inadequate to deal with the situation. Therefore, changes in all levels of family appraisal, namely Family Schema, Coherence, Paradigms, and Situational appraisal must take place. These levels of appraisal steer the family's response to the stressor and its accompanying demands. In the face of long-term stressors, such as having a child with a disability, and the associated challenges to family beliefs, expectations and goals, the family may come to realise that the demands of having a disabled family member exceed their capabilities. Therefore new capabilities and resources are required; family routines must be changed; family roles must be re-established; family paradigms may be challenged; and newly established patterns of family functioning, along with new roles and expectations will materialise (McCubbin et al., 1996). All of the above then lead to a shift in the family's established patterns of functioning. This shift leads to new family paradigms, which include new or adapted rules and expectations that in turn reinforce or justify the newly established patterns of functioning. Due to the family's patterns of functioning being challenged, the family's schema is also called into play. When families derive new meaning from the stressor, they may come to view the crisis situation as less threatening than they had previously anticipated. In combination with the other three

levels of appraisal, the family's schema serves to develop the family's unique identity, as well as its sense of coherence (McCubbin et al., 1996).

The adaptation phase of the Resilience Model also involves achieving congruency. Newly established patterns of family functioning must be congruent with the family's schema and paradigms. Family Bonadaptation, which is the desired outcome of the appraisal process, is characterised by family harmony, balance, and congruency between family schema, coherence, paradigms and patterns of functioning (McCubbin et al., 1996).

All the above-mentioned factors are influenced by the **Family Problem Solving and Coping (PSC)** strategies. These strategies represent the process of obtaining, assigning, and utilising resources in order to meet the demands associated with the crisis situation. Because resources are limited, they must be assigned in such as way as to meet multiple goals and demands.

Within the Resiliency Model coping is defined as the particular effort (overt or covert), by which individual family members or the family unit attempts to reduce or manage demands on the family and create resources to deal with the situation. Specific coping behaviour may be grouped into patterns, such as strategies aimed at maintaining family integration and cooperation (which has been found to be important in families with a chronically ill child), while coping patterns are more generalised means of managing the stressful situation that may also be applicable to many kinds of stressful situations (McCubbin et al., 1996).

In addition, McCubbin et al. (1996) have conceptualised family level coping as coordinated problem solving behaviour by the family as a unit, which may also include complementary efforts by individual family members. This assists in bringing about a balance between demands and resources, as well as eliminating family difficulties and stressors (McCubbin et al., 1996). Coping facilitates adaptation to a crisis situation, in the following

ways. Coping and problem solving are directed towards reducing or eliminating stressors, and acquiring additional resources to manage the stressor. Coping involves ongoing management of tension within the family system that results from ongoing strains associated with chronic stressors. Finally, coping involves shaping the family's appraisal at both the situational and the schema level (McCubbin et al., 1996).

The term family adaptation refers to an outcome of the family's efforts to restore balance and harmony, and to bring about a new level of functioning. Bonadaptation involves the family unit, as well as the family's relationships to the community. Changes in the family unit involve changes in rules, boundaries and patterns of functioning, as well as the family's efforts at the appraisal level. Efforts at the appraisal level attempt to bring about acceptance of changes over time and therefore play a crucial role in family Bonadaptation (McCubbin et al., 1996). The process of change involves changes in transactions between the family and the community. Therefore, it can be said that the family works towards achieving a fit at both the individual-family and the family-community levels of functioning. Changes in one area of functioning affect other levels of functioning and therefore the process of adaptation involves reflection regarding both levels.

The family engages in a continuing cycle of attempting to restore balance and harmony in their interfamily relationships, as well as their relationships to the community and the environment. In some cases the family's efforts to restore balance and harmony may prove unsuccessful, at which point the family will experience Maladaptation and return to a crisis situation. The cycle discussed above repeats itself, starting with changes in patterns of functioning and once again moves through the process of adaptation until new, acceptable patterns of functioning are established (McCubbin et al., 1996).

2.3.4. Family resilience framework

Walsh also contributed towards resiliency theory by outlining the key processes in family resilience (Walsh, 2003). The family resilience framework aims to identify family processes that may reduce stress and vulnerability during crisis situations and foster healing, growth and family empowerment. These processes occur within three domains of family functioning (Walsh, 2003), which will be discussed below.

The first domain centres on family belief systems. These systems have a strong influence on how families view a crisis situation and the options they have in dealing with hardships (Wright, Watson & Bell, cited in Walsh, 2003). In addition, family belief systems organise family processes, as well as the family's approach to dealing with crises. Such systems help families to make meaning out of adversity, to maintain a positive outlook and provide transcendent and/or spiritual attachments (Walsh, 2003).

An essential component of family resilience involves approaching hardships as a "shared challenge" (Walsh, 2003, p. 407) and the idea that by coming together individuals can bolster their potential to overcome adverse situations. The inclination towards pathologising crisis situations can be reduced if families view their reactions to the hardship as normal and expectable among families facing similar situations (Walsh, 2003).

Several studies have documented the strength of maintaining a positive outlook in adapting to stress (Seligman & Csikszentmihalyi, cited in Walsh, 2003). Preserving a shared confidence through an adverse situation contributes towards family resilience. This involves family members becoming active participants in the search for solutions to their problems. By doing this they show support for one another's efforts and build competencies. Furthermore, families that show resilience look beyond the difficulties surrounding their situation and focus on making the best of the options available to them (Walsh, 2003). Most families are able to

find comfort, strength and guidance through connections to cultural and religious traditions (Walsh, cited in Walsh, 2003). Spiritual resources and religious affiliation have been shown to contribute to family resilience (Walsh, 2003).

Family organisational patterns, which comprise flexibility, connectedness, as well as social and economic resources, represent the second domain of family processes that contribute to family resilience (Walsh, 2003). Flexibility is viewed as a fundamental process in resilience. It involves the family's ability to "bounce forward" (Walsh, cited in Walsh, 2003, p. 411) from a crisis situation. This is achieved by adapting to the stressor and reorganising patterns of family interaction in such a way as to fit the new demands placed on the family (Walsh, 2003).

Connectedness or family cohesion is another essential component of family resilience, and contributes towards effective family functioning (Walsh, 2003). Mutual support, collaboration and commitment to optimal family functioning, all lend towards increased resilience.

Social and economic resources are also important contributors to family resilience (Walsh, 2003). Such resources include kin and social networks, friends, community groups and religious congregations. Financial security is also an important resource in family resilience, particularly where the stressor is ongoing (Walsh, 2003).

Communication processes play a significant role in family resilience. Such processes entail clarity, open emotional expression and collaborative problem-solving (Walsh, 2003). It is important that family members clarify and share important information regarding crisis situations with one another. This enables family members to make meaning of the situation, to relate to one another truthfully, and to make informed decisions. Parents should avoid trying to protect their children from the reality of crisis situations, and instead try to find age-appropriate ways of sharing such information with their children (Walsh, 2003).

Family members should attempt to foster an environment of open communication, in which mutual trust, empathy and tolerance for individual differences prevails. This facilitates the sharing of feelings aroused by a crisis situation or chronic stressor, which in turn lends towards increased family resilience. Collaborative problem-solving and effective conflict management are vital for family resilience. These processes open new possibilities for overcoming hardships, and foster growth and healing (Walsh, 2003).

2.4. Conclusion

Autism and its accompanying symptoms represent a tremendous stressor for the families of these children. It requires that parents and siblings make changes and sacrifices in order for the family to function at an optimal level. Resiliency theory provides insight into an alternative way of looking at the difficulties faced by these families. By focusing on family strengths, resiliency theory can contribute towards providing families with a different perspective on their crisis situation and offer them a means to work towards optimal family functioning by focusing on the positive aspects that the family already possesses.

The chapter that follows will review the literature on coping with an autistic child in the family. It will focus on several aspects inherent in the family as well as the family environment, family composition, parents, siblings, treatment programmes, social support and religion.

CHAPTER 3

LITERATURE REVIEW

3.1. Introduction

Much of the literature on coping with an autistic child focuses on practical strategies for facilitating the process of adjustment. Little has been written on the qualities that families possess that makes them resilient in the face of this chronic stressor. Further, the literature on resilience in the South African context is limited with no worthwhile studies focusing on this concept in the context of families with an autistic child. The review that follows has taken from various international studies and highlights those qualities that might be found in resilient families.

3.2. Factors contributing to resilience

The family's level of functioning prior to the birth of the autistic child appears to be a significant factor in the family's ultimate level of adjustment (McHale, Simeonsson & Sloan, 1984). This means that its is not necessarily the arrival of the autistic child that causes family stress, but rather one additional stressor that is added to an already stressful situation that leads to family instability. Several factors contribute to resilience are highlighted in the literature on autism. These include family demographic variables, parents' attitudes towards the autistic child, parental well-being, locus of control, sibling adjustment, involvement in child's educational programmes, social support, family environment and religion. These factors will be discussed below.

3.2.1. Family demographic variables

Several sibling and family variables appear to have a buffering effect against the impact of the autistic child on the family (Hastings, 2003). Such variables include sibling sex, birth order of the siblings and the autistic child, the age of the sibling (Dyson, Edgar & Crnic, 1989; Hastings, 2003), match between the sex of the two children and whether the autistic child lives in the home or in institutional care (Hastings, 2003). Siblings who are younger than the autistic child appear to be less accepting of their autistic brother or sister (Kaminsky & Dewey, 2001). This may be due to the fact that older siblings form an attachment with their parents before the birth of the autistic child, which may act as a protective factor for future adjustment (Hastings, 2003). Furthermore, younger siblings possess a less positive role of the child in the family and more concerns about the future when their autistic sibling is male. The age of the child with autism also plays a role in the extent to which families are able to adapt to the presence of a developmentally disabled child (Powers, 2000). The initial feelings of helplessness, anger and shock when families learn that their child is autistic, as well as the initial difficulties associated with adjusting to this stressor, often decline slightly as the child reaches school-going age. At this time parents have more time for themselves while the child is at school, giving them much needed space and time to manage other household and child-care responsibilities, or to take time out for relaxation. Although each stage of development brings about its own crises or difficulties, families gradually learn to adapt to having a child with special needs in the home (Powers, 2000). Larger family size appears to mediate feelings of embarrassment associated with the autistic child, as well as feelings of burden (Kaminsky & Dewey, 2001). Families with a single parent have reported feeling overwhelmed by their responsibilities regarding the child with autism, experiencing greater feelings of burden, as well as greater difficulties in coping (Powers, 2000).

3.2.2. Parents' attitudes towards autistic child

Parents of autistic children must undergo a change in attitude when they learn of their child's diagnosis (Wing, 1971). Because parents set the tone for the way the rest of the family will react to the autistic child it is important that they demonstrate love and acceptance from the start (Powers, 2000). Essential to enabling the whole family to adapt to the autistic child is to look past the child's label and to love the child underneath. By accepting the child's disorder, parents can help to teach the child to fit into the family (Powers, 2000). Parents often have to change their hopes for the future and might experience failure, guilt and shame (Wing, 1971). It is therefore important for parents to realise that they should not set long-term goals for their child as this may prevent them from achieving their full potential (Powers, 2000). Rather, they should be optimistic that their child will be able to learn new skills (Powers, 2000). In order for parents to set realistic expectations for their child they will require information and exposure to the disorder (Powers, 2000). Parents often feel that they have to be with their child at all times and that they have to do everything for them. Although this is normal parents should encourage their child to develop the skills that will enable them to function as independently as possible, otherwise the child will come to dominate every aspect of family life (Powers, 2000). Important skills to focus on are self-help skills such as dressing and feeding, and skills that will enable parents to take the child out in public (Powers, 2000).

Some parents are never able to develop a realistic or accepting view of their child's disability (McHale et al., 1984). It is, however, important that parents resolve their feelings about the autistic child, as this is likely to affect the degree to which the nonhandicapped siblings accept the autistic child (McHale et al., 1984). Tommasone and Tommasone (2000) also report the importance of acknowledging and working through the feelings that are evoked by the news of their child's diagnosis. Parents have the right to express whatever emotions

they are feeling in order to come to terms with their child's autism. They add that parents should not feel ashamed or guilty about these feelings, as they are a normal reaction to often devastating news and are essential in putting the process of acceptance into motion. It was found that mothers who accept their child's diagnosis of autism and do not blame themselves or other family members for the child's disability showed higher marital satisfaction and better family adaptation to the child's disability (Bristol, 1987). The degree to which parents accept the autistic child and make sacrifices for him/her influences the way in which siblings respond to the presence of their disabled sibling (Cantwell & Baker, 1984; McHale et al., 1984).

Social adjustment by siblings of handicapped children was also found to be related to parental attitudes (Caldwell & Guze, in Dyson et al., 1989). Parental acceptance was important in predicting acceptance of handicapped siblings in teenagers and college students (Dyson et al., 1989). Children were more optimistic about their relationship with their autistic sibling when they accepted their sibling as a member of the family and experienced minimal parental favouritism. Positive responses from parents and others towards the autistic child and understanding their sibling's disability, pave the way for more positive sibling relationships (Kaminsky & Dewey, 2001). Henderson and Vandenberg (1992) also pointed towards the importance of parental perceptions in adjustment.

Tommasone and Tommasone (2000) emphasise the importance of parents taking their time in working through their feelings relating to their child's diagnosis. The healing process should not be rushed as in time the family will come to accept the child along with all the difficulties and sacrifices associated with the disorder. Once parents have reached this point of acceptance they are ready to start obtaining as much information about the disorder as possible (Tommasone & Tommasone, 2000), which in turn will assist them in taking positive steps towards helping their autistic child. High information seeking is a coping strategy that is

often employed by mothers of autistic children. This strategy must be seen as adaptive as it enables parents to learn how to successfully help their child and prevents the use of maladaptive coping strategies (Rodrigue, Morgan & Geffken, 1990). The more information parents have about the disorder, the more confidence they have in their ability to make a difference in their child's life (Powers, 2000).

3.2.3. Parental well-being

Parents have emphasised a combination of consistency, routine and firmness, together with love and caring, as leading to more successful family functioning (Howlin & Rutter, 1987; Paluszny, 1979). Organizing a routine enables parents to make time for their autistic children and their nonhandicapped children, as well as time together for themselves to relax. Making time for themselves is extremely important for parents of autistic children as it allows them to invest in their relationship (Bristol, 1984; Powers, 2000) and to develop some of their own resources (Paluszny, 1979). This is likely to be beneficial, not only for the couple, but also for the long-term benefit of the child (Bristol, 1984). Time away from the autistic child also leads to higher marital satisfaction (Paluszny, 1979). Higher marital satisfaction among parents of autistic children was related to higher self-esteem in siblings. This indicates that both parents and siblings benefit from positive marital relations, leading to better adjustment in families with an autistic child (Rodrigue, Geffken & Morgan, 1993). According to Bristol (1984) family stability and integration are enhanced through coping strategies involving the spouse and doing things with the children.

The autistic child's mother is most often the primary caregiver in the family and as such plays an important role in family adaptation. An aspect that seems to be central to coping with the chronic stress of raising an autistic child is the importance of the mother developing

herself as a person so as to ensure that she has interests, activities and reinforcements that are not dependent on the child (Bristol, 1984). Maternal psychological well-being may be a factor in predicting the extent to which siblings adjust to the presence of an autistic child. The reason for this is that when parents are under stress they may have less time and energy to spend with the nondisabled child, or these interactions may be adversely affected (Hastings, 2003).

Tunali and Power (2002) found that mothers coped with the stressors of raising an autistic child through a process of active redefinition of what's important to them, by redefining what the fulfilment of various human needs comprises and/or finding alternative means to fulfil them. For example, they found that an autistic child altered a mother's conception and the functions of her marriage, in that they placed greater emphasis on parental roles and spousal support in their discussions of marriage. These are two aspects of marriage that are extremely important in dealing with the demands of a developmentally disabled child. These mothers were less concerned with the opinions of others with regard to their child and were more inclined to be tolerant of ambiguity in general. This helped them to cope with the ambiguity and atypical characteristics of their child's behaviour. In addition, mothers of autistic children placed more emphasis on their parental role than on their careers and spent more of their leisure time with extended family members (Tunali & Power, 2002).

3.2.4. Locus of control

Some authors have pointed to locus of control as a factor facilitating successful adaptation of families with an autistic child (Bristol, 1987; Henderson & Vandenberg, 1992). According to Henderson and Vandenberg (1992) families experience better adaptation when family members possessed a greater internal locus of control. This internal attribute influences social support links, as well as the use of specific coping strategies, which in turn serve as a buffer

against depression (Bristol, 1987). Furthermore, it is presumed that those people who have an internal locus of control are more likely to employ behaviours that are aimed at overcoming the deleterious effects of the chronic, external stress of raising an autistic child. Those with an internal locus of control are also likely to be less overwhelmed and experience fewer feelings of helplessness in response to the burden of having an autistic child in the home than those with an external locus of control (Henderson & Vandenberg, 1992).

3.2.5. Sibling adjustment

It is important that parents are open and honest with all their children about the autistic child's condition (Wing, 1971). When telling siblings about the autistic sibling parents should try to do so in a way that corresponds to the child's developmental level. Parents should also realise that their children are likely to experience the same feelings they did once they realised that their child has autism. This means that parents must give other children the space to express these feelings and assist them in coping with them. Siblings need to be helped to understand that their feelings are normal and acceptable. A useful way of doing this is to introduce siblings to other children with an autistic brother or sister (Tommasone & Tommasone, 2000). Siblings are often concerned about developing symptoms like their autistic brother or sister and it may be difficult for them to understand why the autistic child is different. It is important that parents create an environment in which these concerns can be expressed and heard so as to assist their children in coming to accept their autistic sibling (Wing, 1971).

Adjustment by siblings is facilitated when parents are able to arrange their time in such a way as to provide all their children with enough attention. They can do this by organising their time so that their children do not feel that they are being deprived of attention. Parents should also ensure that they do not give their non-disabled children too

much responsibility as this may lead to resentment towards the autistic child (Powers, 2000). Rather they should involve the non-disabled children in the child's educational and therapeutic programmes. This can be followed by praising them for their compassion and their coping abilities, and letting them know that their contributions to the family in general and more specifically to the autistic child, are appreciated (Powers, 2000).

Certain family psychological factors such as parental stress and resources, perceived family social support, family relationships, family's emphasis on personal growth, and maintenance of the family system are related to the adjustment of siblings of developmentally disabled children (Dyson, Edgar & Crnic, 1989). Together, these psychological factors contribute to aspects of adjustment such as self-concept, behaviour problems and social competence.

The siblings' self-concept is greatly influenced by parental stress and resources, with siblings of parents who experience a great deal of stress having lower self-concepts than those of less stressed parents. Siblings' self-concept is mainly influenced by problems related to the care and the condition of the disabled child (Dyson et al., 1989). The family's emphasis on personal growth, particularly with regard to independence, moral-religious emphasis and cultural-recreational activities, accounted for much of the siblings' social competence and behaviour adjustment. Other significant resources for facilitating sibling adjustment include an accepting attitude towards parenting a disabled child, as well as a nurturing and cohesive family relationship. Strengthening these and the above-mentioned family psychological domains would be beneficial to siblings of autistic children, as they appear to facilitate adjustment (Dyson et al., 1989).

3.2.6. Involvement in child's educational programmes

The concept of using parents as co-therapists or teachers of their own children is important in determining the success of programmes (Paluszny, 1979), and thus the degree to which the autistic child gains in terms of behavioural outcomes. Resultantly, family stress and concerns are substantially relieved (Cantwell & Baker, 1984). Along with the amount of schooling the child receives, this appears to be critical in maintaining positive outcomes outside the treatment setting (Paluszny, 1979). Providing parents with effective coping strategies forms an integral part of the treatment programme as they assist parents in reducing the worries and anxieties associated with raising an autistic child (Howlin & Rutter, 1987). It is important that parents be given a realistic notion of what their child is likely to achieve, as well as knowledge about normal developmental processes. This enables them to gain a better perspective on the autistic child's functioning (Howlin & Rutter, 1987). The success of programmes that employ parents as co-therapists depends as much on the support of the parent who is less actively involved in the child's schooling, as on the one that is (Paluszny, 1979). It is also evident that families experience less stress the longer their child has been on a programme, but more stress if treatment began later in early childhood (Hastings & Johnson, 2001).

The use of siblings as co-therapists has also proved successful, not only in terms of the autistic child, but also with regard to the siblings themselves. Involvement of the whole family in the treatment programme results in improved rates of learning, as well as the maintenance and generalisation of new skills by autistic children (Howlin & Rutter, 1987). In addition, siblings reported greater self-esteem as well as feelings of achievement (Howlin & Rutter, 1987). The approach of using siblings as co-therapists also focuses on family strengths as opposed to the family's weaknesses (Cantwell & Baker, 1984).

3.2.7. Social support

Resources, which facilitate family adaptation, include, not only the immediate family, but also other informal networks, such as extended family, friends, neighbours and other parents who have autistic children (Bristol, 1984). Family adjustment increases with greater social support, which mediates the difficulties associated with raising an autistic child (Henderson & Vandenberg, 1992).

Of most value to mothers, is the perceived support she receives from her husband, both in terms of expressive and instrumental support (Bristol, 1984; Bristol, Gallagher & Schopler, 1988). When this source of support was strong, mothers reported less depressive symptoms, happier marriages, and were more accepting of their autistic child (Bristol, 1984). The degree to which fathers are able to adapt to the autistic child is dependent on perceived support received from their wives (Bristol et al., 1988). Belsky (cited in Bristol et al., 1988) proposed that the relationship between the parents is psychologically transmitted to the parents' well-being, as well as to the care of the child.

Having support from both the wife and husband's relatives, which fulfils some of the family's social/affiliative needs (Tunali & Power, 2002), related positively to acceptance of the child, as well as the quality of parenting and marital adjustment (Bristol, 1984). Siblings of autistic children found the support of their grandparents and other relatives to be of value in reducing their anxiety related to the autistic child (Dyson et al., 1989).

Mothers who have an extensive network of friends appear to cope more successfully and to be more effective in parenting (Wahler, cited in Harris & Powers, 1984). This source of support is particularly important in single-parent families with an autistic child (Harris & Powers, 1984).

Other parents who also have autistic children provide an additional source of support for parents as they can facilitate acceptance of the autistic child and provide valuable support and information (Paluszny, 1979; Tommasone & Tommasone, 2000).

Access to social support has been associated with positive family and child outcomes in families with an autistic child (Rivers & Stoneman, 2003).

Successful family adaptation is dependent on adequate and appropriate vocational, educational, and medical services. Parents who felt that such services were available to them reported less stress than those who did not have access to such services (Bristol, 1984). Support groups consisting of other parents who have an autistic child were also evaluated positively, as they provide parents with emotional support and practical advice (Tommasone & Tommasone, 2000), as well as a means of contributing towards improving the future of services for people with autism (Bristol, 1984).

In caring for an autistic child, a holistic professional approach is essential (Akerley, 1984), including doctors and teachers (Wing, 1971). Not only do the autistic children require adequate interventions, but parents, too, need support and advice in dealing with the daily stressors associated with caring for a developmentally disabled child (Akerley, 1984; Sanders & Morgan, 1997). Respite care has consistently been specified as an important support network in helping parents to cope (Factor, Perry & Freeman, 1990; Paluszny, 1979; Powers, 2000). Respite services are judged to be beneficial to the family, with parents reporting that it has improved their quality of life (Factor et al., 1990).

Furthermore, parents need access to competent sitters so that they can go out together and have some relief from constant childcare (Akerley, 1984). This gives them the opportunity to rest, revitalise their strengths, give attention to each other and their other children (Paluszny, 1979) or to pursue their intellectual, cultural and recreational interests

(Sanders & Morgan, 1997). For those who are able to afford it, a home help such as an au-pair, may assist the family in organising their time (Wing, 1971).

3.2.8. Family environment

Certain family environments are more effective in helping families cope with having an autistic child (Morgan, 1988). According to Bristol (1984) certain family psychological characteristics are of importance. These include integration, cohesion, organization and adaptability. She adds that families were rated as having greater acceptance of and greater competence in coping with the autistic child when they demonstrated a higher degree of commitment, help and support for one another.

Families with a supportive home environment, a high degree of cohesion and expressiveness, as well as an active recreational orientation are more likely to adapt successfully. Such families also tend to foster more accepting and competent relationships with both the child and the spouse (Bristol, 1984). In addition, Dyson et al. (1989) reported that such families are characterised by fewer behaviour problems and greater social competence.

Bristol (1984) notes other important coping strategies as focusing on maintaining self-esteem and family integration, maintaining an optimistic definition of the child and the situation and reaching out to both formal and informal social support networks.

The results of Bristol's study point towards a family focus for intervention. She contends that intervention should not encourage an autistic child-centred home but rather a family-oriented home. Families must not only adapt to the child, but must help the child to adapt to the family (Bristol, 1984). This means that parents do not have to choose between the

autistic child and their family, but rather the child is incorporated into the existing family structure (Powers, 2000).

Sanders and Morgan (1997) compared the families of autistic children, Down syndrome children and a control group of healthy children. They found no difference between the three groups in family environment in terms of cohesion, expressiveness, independence, conflict, control, achievement orientation, moral-religious emphasis or organisation. This can be accounted for by the fact that families with a developmentally disabled child generally possess a degree of resilience and adaptability (Sanders & Morgan, 1997).

Open and honest communication between family members is essential. Family members should talk about what works and what doesn't, and also about their feelings regarding the autistic child (Powers, 2000). Family members will often share the same emotions. Creating an accepting atmosphere in which these feelings can be shared will enable the family to work through them together (Powers, 2000). This sharing of feelings will produce a supportive and nurturing environment in which growth can take place (Powers, 2000). Tommasone and Tommasone (2000) also highlight the importance of the family maintaining a sense of humour in order to mediate the stress associated with the autistic child and to maintain a sense of perspective with regard to the disorder.

3.2.9. Religion

Families of autistic children appear to have a markedly higher moral-religious emphasis (Bristol, 1984). Furthermore, there is evidence that belief in God and/or adherence to clear moral standards serves to mediate the difficulties experienced by these families by giving meaning and purpose to the sacrifices the family makes in caring for the autistic child (Bristol, 1984). The conviction that the autistic child is "part of God's plan" and that "God

will give me the strength to deal with my child" also appear to facilitate coping. This underpins the importance of personal religious beliefs in coping with the stressors associated with raising an autistic child (Bristol, 1984).

Parents often find it easier to cope when they look forward to their child's improvement and when they find purpose and meaning in having a child with autism (Bristol, 1984). Because it is impossible to predict what the autistic child will achieve at an early age, it is important to focus on taking small steps at a time and striving towards achieving short-term goals, which will eventually lead to longer-term goals (Tommasone & Tommasone, 2000).

3.3. Conclusion

The above discussion highlights several factors that lead families to adapt more easily to the presence of an autistic child. Some of these are characteristics inherent in the family, while others incorporate resources outside the family. All of them however require certain behaviours or family patterns. For this reason resilience is a concept which is of great importance in trying to improve the lives of families who have an autistic child.

The following chapter will focus on the methodology employed throughout the study. Aspects that will be discussed include the participants in the study, the measuring instruments used, the procedure followed, and the statistical techniques employed by the researcher.

CHAPTER 4

METHODOLOGY

4.1. Introduction

This chapter focuses on the methods employed during the course of this study. The discussion will begin with a formulation of the problem that was explored and the research design employed. This will be followed by a description of the participants who took part in the study, the measuring instruments used, the procedures followed, as well as the statistical analyses utilised.

4.2. Problem Formulation

Autism represents a profound stressor for the families of the children living with the disorder (Autism Society of America, 2003). It can place a great deal of strain on all areas of family life. In addition, the number of children being diagnosed with autism is on the increase (Aarons & Gittens, 1999; Mesibov et al., 1997). This along with the difficulties experienced by the families of these children, and the sacrifices they are often forced to make (Bristol, 1984), creates cause for concern and the need to assist these families in the adaptation process. Although the autistic child places a lot of strain on the family, some families are able to adapt to the presence of the child, while others experience great difficulty in coping with this chronic stressor.

The purpose of this study is to identify the characteristics and resources that families possess that enable them to be resilient despite the presence of an autistic child in the family.

The main research question is therefore as follows: What are the family characteristics and resources that contribute to resilience in families with an autistic child?

4.3. Research Design

This study makes use of a cross-sectional survey research design. It is therefore a once off study in which information is obtained from the participants in their natural environment (Graziano & Raulin, 2000). For the purpose of this study, both qualitative and quantitative methods were used to collect data from the participating families. One parent from each family was required to complete the questionnaires. Qualitative data were obtained by asking the participants to answer an open-ended question, while quantitative data were collected through the use of various existing measuring instruments. These quantitative measures used in this study are based on the Resiliency Model of Adjustment and Adaptation (McCubbin et al., 1996) described in Section 2.3. These measuring instruments will be comprehensively described in section 4.5 below.
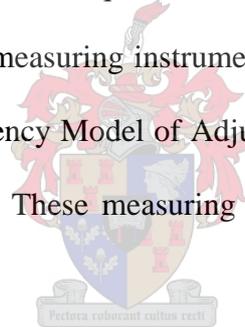
4.4. Participants

The first step in conducting this research involved obtaining permission to conduct the study from the Western Cape Education Department, the respective governing bodies of the Alpha School for Autistic Learners and the Vera School for Autistic learners, and the Special Needs Adapted Programme. These facilities were included due to their geographic location and their focus on educational programmes specific to children with autism. Once this permission had been granted the researcher met with the relevant persons at the respective schools to discuss

the research proposal and the practical issues surrounding the process of obtaining the data from the families of the autistic learners.

A letter was then sent via the Alpha School and the Vera School to the families that qualified for the study based on the following selection criteria: (1) the family structure (two-parent families where both parents are present in the child's life), (2) the age of the autistic child (the child should not be older than 10 years old) and, (3) the families should have had knowledge of their child's diagnosis for a minimum period of eighteen months.

The above-mentioned letter provided parents with information regarding the purpose of the study, the procedures associated with the study, the time required to complete the questionnaires, as well as adherence to ethical principles such as anonymity and confidentiality. Based on this information families were requested to indicate whether they would be willing to participate in the study. This ensured agreement with the ethical principle of informed consent. At this time families were given the opportunity to ask questions or voice any concerns they might have. Due to the low response rate to the letters, those families who had not responded were contacted telephonically in order to provide additional information and to request their participation. This technique proved more successful as the majority of families agreed to participate.

Once the researcher had knowledge of those who were willing to participate, the questionnaires were sent to the families via the school. Twenty-five questionnaires were sent out to each of the schools. Questionnaires were required to be completed by one of the child's parents, who served as a representative of the family. Parents were given a period of two weeks in which to complete the questionnaires and return them to the school. Due to the ethical consideration of confidentiality, families could not be contacted again and thus only those questionnaires returned to the school could be used for the purpose of the study. In addition, participation took place only on a voluntary basis.

The Special Needs Adapted Programme (SNAP) is a private organisation that primarily caters for the needs of children with developmental disabilities. In order to recruit participants for the study, the researcher met with a group of parents at an informal gathering held at the organisation's offices in Durbanville, Cape Town. The researcher explained the purpose of the study, what it would entail on their behalf, and requested their participation in the study. Ten questionnaires were handed out to those who were willing to participate and they were asked to return them to the SNAP offices at a later date. Only those files returned could thus be used for the purpose of the study.

Due to the small number of completed questionnaires received by the researcher (n=34), the decision was made to allow for the inclusion of single-parent families. An analysis of variance (ANOVA) revealed no statistically significant difference in scores between two-parent and single-parent families on the dependent variable (F (1, 30)=2.5480, p=0.12).

In total, 34 families from the Alpha School (n=16), the Vera School (n=15) and SNAP (n=3) participated in the study. The majority of the parents who completed the questionnaires were female (n=24) while a substantially smaller number were male (n=4). The remaining six parents did not complete this question. Most of the participating parents (n=28) were aged between 34 and 43 with a mean age of 36.21 (*SD*=6.36). The mean age of the other parent (n=25) in the family was 38.92 (*SD*=5.31) with most being between the ages of 33 and 45. Most of the families were two-parent families (n=27), while four parents were unmarried, one was divorced, one was separated and one was widowed. The length of the parental relationship in most families (n=23) was between seven and thirteen years, with a mean length (n=34) of 9.53 years (*SD*=5.00). Most of the autistic children in the families were male (n=31) while the remainder were female (n=3). The mean age of the autistic children (N=34) was 6.48 years (*SD*=2.16). Fifteen of the families had one other child apart from the autistic child, while twelve had no other children, five had two other children, and two families did not

indicate whether there were other children present in the home. Most of the children had been diagnosed with autism between one and four years ago (n=25) with the mean number of years since diagnosis (n=33) being 3.24 years (*SD*=1.90). Eighteen of the families were English-speaking, eleven were Afrikaans-speaking and five speak languages other than English or Afrikaans at home. Four families were of a lower socioeconomic status, eight were of middle socioeconomic status and twenty-one were of a higher socioeconomic status. The parent of one family did not complete the questions relating to socioeconomic status.

4.5. Measuring Instruments

The quantitative measures discussed below were used to measure the independent variables that are of importance in resilience and that are relevant to this study. All questionnaires were available in both English and Afrikaans.

4.5.1. Family Hardiness Index

The Family Hardiness Index (FHI) that was developed by McCubbin, McCubbin and Thompson (McCubbin et al., 1996) was used to measure the characteristic of hardiness, which specifically refers to the internal strengths, and the durability of the family unit. Family hardiness is further characterised by a sense of control over the outcome of various events and difficulties. Family hardiness also entails an outlook on change as being beneficial and producing growth, as well as an active orientation towards managing and adjusting to stress.

Hardiness may be seen as a family resource that buffers the effects of stressors and facilitates adaptation over time. The FHI is a five-point Likert type scale (False=0, Mostly False=1, Mostly True=2, True=3, Not Applicable=0) consisting of 20 items, in which

respondents are required to consider the extent to which each statement describes their family. The FHI is divided into three subscales, namely commitment, challenge and control. The commitment subscale measures the family's sense of dependability, internal strengths and their ability to work together. The challenge subscale assesses the family's attempts to experience new things and to learn, to be innovative and active. Finally, the control subscale measures the family's view of being in control of their family life as opposed to being shaped by outside events and circumstances.

The overall internal reliability of the scale is .82 (Cronbach's alpha) while the internal reliabilities for the three subscales (Commitment, Challenge and Control) are .81, .80, and .65 (Cronbach's alpha) respectively. The alpha values obtained in this study are .67 for the total scale, and .62, .34 and .82 for the challenge, control and commitment subscales respectively. The validity coefficients range from .20 to .23 with regard to the variables of family satisfaction, time and routines, and flexibility (McCubbin et al., 1996).
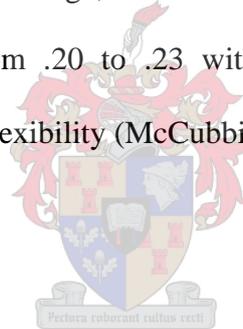
4.5.2. Social Support Index

The Social Support Index (SSI) was developed by McCubbin, Patterson and Glynn to determine the extent to which families find support in the communities in which they live. Community-based social support is an important factor and dimension in family resiliency. The SSI is a 17-item scale, which makes use of a five-point Likert scale (Strongly Disagree=0, Disagree=1, Not Sure=2, Agree=3, Strongly Agree=4). It was included to measure community integration, community support, and the family's view that the community can provide resources necessary for emotional support, esteem support and network support. This instrument has an internal reliability of .82, a test-retest reliability of

.83, and a validity coefficient of .40 with the criterion of family well-being (McCubbin et al., 1996). A reliability analysis of the data in this study yielded a Cronbach alpha value of .91.

4.5.3. Relative and Friend Support Index

The Relative and Friend Support Index (RFS) was developed by McCubbin, Larsen and Olson. It consists of eight items, which assess the degree to which families make use of friend and relative support as a strategy to manage stressors and strains. The internal reliability (Cronbach's alpha) of the RFSI is .82, with a validity coefficient (correlating with the original F-COPES) of .99 (McCubbin et al., 1996). The Cronbach alpha obtained from the data in this study is .82.

4.5.4. Family Crisis Oriented Personal Evaluation Scales

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) was developed by McCubbin, Olson and Larsen to distinguish problem solving and behavioural strategies used by families during times of hardship. F-COPES draws upon the coping dimensions outlined in the Resiliency Model of Family Adjustment and Adaptation, which integrates the factors of pile-up, family resources and meaning/perception. It comprises 30 items centred around coping behaviour and that focus on two systemic levels of interaction. These levels include a) the individual and the family system, or ways in which the family handles difficulties among its members internally, and b) the family and the social environment, which includes the ways in which the family manages crises that affect the family unit and its members, but emerge outside its boundaries. It is assumed that when families possess coping behaviours that focus on both levels of interaction, they will adapt more successfully to stressful situations.

The F-COPES is a five-point Likert scale (Never=1, Seldom=2, Sometimes=3, Frequently=4, Always=5) consisting of five subscales, grouped into two dimensions, namely internal and external family coping strategies. Internal coping strategies refer to the way in which individual family members use resources within the family to manage difficulties. Such strategies consist of (a) redefining or reformulating the problem in terms of the meaning it has for the family in order to make it more manageable (Cronbach's alpha = .64) and (b) passive evaluation, which involves passively accepting the problem and doing nothing about it (Cronbach's alpha = .66). External coping strategies are the behaviours the family engages in to obtain resources outside the family system. These strategies include (a) spiritual support, including the family's ideology in dealing with hardships, its involvement in religious activities, as well as its ability to acquire such support (Cronbach's alpha = .87); (b) the family's ability to acquire social support in terms of friends (Cronbach's alpha = .74), extended family (Cronbach's alpha = .86) and neighbours (Cronbach's alpha = .79) and (c) mobilising the family to acquire community resources and accept help from others (Cronbach's alpha = .70).
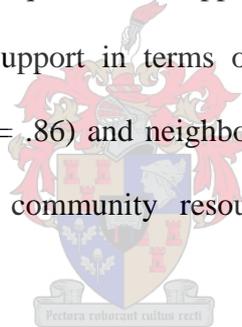
The F-COPES total scale has an internal reliability coefficient (Cronbach's alpha) of .77 and test-retest reliability (Cronbach's alpha) of .71 (McCubbin et al., 1996). The internal reliability coefficients derived from the data in this study are .50 (passive evaluation); .72 (redefining the problem); .66 (spiritual support); .70 (social support); and .53 (mobilising community resources).

4.5.5. Family Time and Routine Index

The Family Time and Routine Index (FTRI) was developed by McCubbin, McCubbin and Thompson, and was used to a) explore the routines and activities used by families, and b) to

evaluate the value families place on these practices. The time families spend together and the routines they adopt are relatively reliable indication of family stability and family integration, which incorporate valuable ways of dealing with common problems and to manage major crises.

The FTRI is a 30-item scale, which assesses eight subscales. These subscales include Parent-Child Togetherness (family's emphasis on creating predictable communications between parents and children), Couple Togetherness (family's emphasis on creating predictable routines to encourage communication between spouses), Child Routines (family's emphasis on creating predictable routines to promote children's sense of independence and order), Meals Together (family's attempts to create predictable routines to encourage togetherness through mealtimes), Family Time Together (family's emphasis on family togetherness including special events, quiet time and family time), Family Chores Routines (family's emphasis on establishing predictable routines to encourage children's responsibilities in the home), Relatives Connection Routines (family's attempts to create predictable routines to encourage a meaningful connection with relatives) and Family Management Routines (family's attempts to create predictable routines to promote an atmosphere of family organisation and accountability necessary to uphold family order in the home).

The FTRI is a Likert-type scale that assesses a) the degree to which each statement describes the family (False=0, Mostly False=1, Mostly True=2, True=3) and b) the degree to which the family views the routines listed as important (Not Important=0, Somewhat Important=1, Very Important=2, Not Applicable=0).

The overall internal reliability (Cronbach's alpha) of the FTRI is .88, while the validity coefficient range from .24 to .34 with regard to family bonding, family satisfaction, marital satisfaction, family celebrations and family coherence (McCubbin et al., 1996). The

reliability coefficients obtained from the data in this study are .77 for the total scale; .48 for the Parent-Child Togetherness Subscale; .61 for the Couple-Togetherness Subscale; .33 for the Child Routines Subscale; .78 for the Meals Together Subscale; .70 for the Family Time Together Subscale; .83 for the Family Chores Routines Subscale; .60 for the Relatives Connection Routines Subscale; and .44 for the Family Management Routines Subscale.

4.5.6. Family Problem Solving and Communication Scale

The Family Problem Solving and Communication Scale (FPSC), developed by McCubbin, McCubbin and Thompson was employed to evaluate the two predominant family communication patterns that play an important role in a family's coping. Due to the fact that all families have both positive and negative communication patterns, it is essential to measure both patterns as important factors in family problem solving and resiliency.

It is assumed that the quality of the communication within the family provides a good indication of the degree to which families manage tension and strain and obtain a satisfactory level of family functioning, adaptation and adjustment.

The FPSC is a ten-item scale, which has a Likert-type format (False=0, Mostly False=1, Mostly True=2, True=3). It consists of two subscales, namely incendiary communication and affirming communication. Incendiary communication refers to a pattern of family communication that is provocative and tends to intensify a stressful situation. Affirming communication, on the other hand, refers to a pattern of family communication that expresses support and caring and has a calming influence on a stressful situation.

The total alpha reliability of the scale is .89 with alpha reliabilities of .78 and .86 for incendiary communication and affirming communication respectively. The obtained reliability coefficients for this study are .83 for incendiary communication, .87 for affirming

communication, and .90 for the total scale. The test-retest reliability for the subscales, as well as the overall FPSC is .86 (McCubbin et al., 1996).

The dependent variable in this study is the family's level of adaptation following the stressful situation. This was measured using the total score of the following measure:

4.5.7. Family Attachment and Changeability Index 8

The Family Attachment and Changeability Index 8 (FACI8) was adapted by McCubbin, Thompson and Elver from the Family Adaptability and Cohesion Evaluation Scales (FACES). FACES self-report instruments are based on the Circumplex Model of Marital and Family Systems. The Circumplex Model is grounded in systems theory and illustrates the changes that families go through developmentally and in reaction to stressors. The Circumplex Model focuses on three dimensions of family theory in order to describe marital and family dynamics, namely family cohesion, flexibility and communication. The model is designed specifically for family research, clinical assessment, treatment planning and outcome effectiveness of marital and family therapy. The Circumplex Model can be described as dynamic as it assumes that families will change their levels of cohesion and flexibility, and that change is beneficial to the maintenance and improvement of family functioning.

Critique that the FACES self-report instruments did not adequately record the extremes of cohesion or flexibility, eventually led to the development of FACI8. This instrument is an ethnically sensitive measure of family adaptation and functioning. This scale was used to measure the degree to which the family has adapted to the stressful situation. As mentioned above, it represents the dependent measure against which all other independent measures will be correlated in order to determine whether they can be identified as resilience factors.

The FACI8 is a 16-item Likert scale (Never=1, Sometimes=2, Half the time=3, More than half the time=4, Always=5) consisting of two subscales, namely attachment and changeability. The attachment subscale measures the strength of the family members' attachment to one another, while the changeability subscale determines the degree to which family members are flexible in their relationships with each other.

The internal reliability of the scale as well as the two subscales (Cronbach's alpha) varies between .73 and .80 (McCubbin et al., 1996), while the obtained alpha values for the total scale, attachment subscale and changeability subscale are .75, .79 and .85 respectively.

4.5.8. Additional questionnaires

A biographical questionnaire was designed to collect information on family composition, marital status, and duration of the parental relationship, age and gender of family members, level of education, employment, income and home language.

The family's socioeconomic status (SES) was calculated using an adapted version of the composite index derived by Riordan (cited in Tennant, 1996). Because no information was obtained regarding the families' ethnic group, all families were treated in an equal way in terms of ethnic groups. Their SES was derived by using information about the type of work they perform (rated on a 9-point scale) and the level of education attained (rated on a 7-point scale). The scores on these two scaled were added together to obtain an indication of SES. Due to the fact that all families were treated as equal in terms of ethnic group, the middle group (Coloured) was chosen as the reference group (Tenant, 1996). According to this, scores between two and six indicated a low SES, scores between seven and ten indicated middle-class SES, while scores between eleven and sixteen indicated a high SES.

The qualitative measure comprised an open-ended question regarding the family's perspective with regard to the factors that have helped them to adapt to the presence of the autistic child. The question read: In your own words, what are the most important factors, or strengths, which have helped your family to adapt to living with your autistic child? Parents were thus required to respond in writing by giving their own personal account of factors that have facilitated their adaptation.

4.6. Procedure

4.6.1. Practical data gathering

Once informed consent had been obtained from the families, the data-gathering process commenced. Ideally the researcher would have liked to meet with the parents of the autistic child at his/her school or an alternative venue and for the questionnaires to be completed in the presence of the researcher. This was however not possible as most of the autistic children were sent to school with the school bus. Consequently, the questionnaires were sent to the families via the schools, along with a letter explaining the procedure to be followed in answering the open-ended question and completing the questionnaires. Where required, instructions for completion of the questionnaires were given telephonically. Parents were requested to complete the questionnaires and to return them to the respective schools by the specified dates in order for the researcher could collect them.

The first step in gathering the data involved completion of the biographical questionnaire described above. Secondly the qualitative aspect of the study, consisting of an open-ended question, was undertaken. Finally, respondents were requested to complete a series of questionnaires in order to complete the quantitative phase of the study. Throughout the study privacy and confidentiality were maintained.

4.6.2. Scoring of questionnaires

Once the data had been collected from the various schools and institutions, the process of scoring the questionnaires began. Firstly, all the questionnaires, along with the biographical data were checked for completeness. Following this, all the data was entered into a Microsoft Excel spreadsheet.

In the scoring of the biographical data, it was decided to convert the answers provided by the participants to numbers. This was done in order to make the process of entering the data into the Microsoft Excel spreadsheet easier and to facilitate the statistical analysis of the data.

The remaining questionnaires were entered into the Excel spreadsheet according to already established formulae. The responses on the Family Time and Routine Index, the Family Hardiness Index and the Family Problem Solving and Communication Scale were entered into the data file by allocating a number between one and three to each response. The Social Support Index required a number between one and four to be allocated to each response, while the Relative and Friend Support Index, the Family Crisis Oriented Personal Evaluation Scales and the Family Attachment and Changeability Index 8 all required the allocation of a score between one and five. In some cases scores had to be reversed, but this was done automatically by the Excel spreadsheet.

Once the data had been recorded in the data files, the statistical analyses could be undertaken.

4.7. Data Analyses

In order to generate findings from qualitative data it essential that specific analytic procedures are followed (Thorne, 2000). In analysing the qualitative data, a process of inductive reasoning was followed, that is, ideas were generated from the data that was obtained from the respondents (Thorne, 2000).

The first step in the qualitative analysis was to become familiar with the data. This involved reading the data several times in order to start identifying potential categories (Lacey & Luff, 2001). Once the researcher was familiar with the data the process of coding the data began. Initially preliminary codes were assigned to the data, after which the codes were refined in order to better depict the data (Lacey & Luff, 2001). These codes eventually become categories that were derived from the data in order to identify various themes (Pope, 2000). All data were checked in order to identify in which category it belonged. The end result was that data were now grouped together in themes, which could then be used to report the results of the qualitative aspect of the study (Pope, 2000).

With regard to the quantitative data, the Excel files on which all the individual responses of the participants had been entered, were used in conjunction with Statistica (StatSoft, 2003), which is a statistical package, to analyse the data.

An analysis of variance (ANOVA) was carried out in order to test for mean differences among groups (Graziano & Raulin, 2000) that were identified according to various biographical variables. These variables include the parents' marital status, the number of siblings in the home, the gender of the parents, the family's socioeconomic status, and the family's home language.

In order to identify possible independent variables that may be associated with the dependent variable (family adaptation), Pearson product-moment correlation coefficients were

calculated. This correlation coefficient is a measure of the relationship that exists between variables (Howell, 1999). In order to visually depict the relationships that were identified between variables, scatterplots were drawn up. A scatterplot is a figure in which individual data points are plotted against one another (Howell, 1999). Scatterplots facilitate the observation of the direction of the relationship between variables by allowing the researcher to draw a regression line across all the data points. A line that slopes upwards from left to right represents a positive correlation, while a line that slopes downwards represents a negative correlation. A line with no slope usually indicates no relationship at all between the variables (Graziano & Raulin, 2000).

Finally, multiple regression analysis was carried out in order to identify which combinations of independent variables (or predictor variables) can best predict the dependent variable (or outcome or criterion variable) (Graziano & Raulin, 2000). In the context of this study, the multiple regression analysis aimed to identify possible combinations of resilience characteristics of the participating families, which were best able to predict adaptation. The outcome variable, namely family adaptation was determined using the FACI8, while the remainder of the instruments described above represent the predictor variables.

In the following chapter the results of the various statistical analyses will be reported.

CHAPTER 5

RESULTS

5.1. Introduction

This chapter reports the results of the statistical analyses of the data relating to the factors contributing to resilience in families with an autistic child. Firstly the analysis of variance in terms of various biographical variables will be discussed. This will be followed by a discussion of relationships that were found by calculating Pearson product-moment correlation coefficients. Finally, in terms of the quantitative data, the results of the multiple regression analysis, which attempts to identify the combination of independent variables that will best predict the dependent variable (family adaptation) will be discussed. Only those results that were found to be statistically significant on a 5% level were viewed as significant findings. The chapter will conclude with the results obtained from the qualitative data.
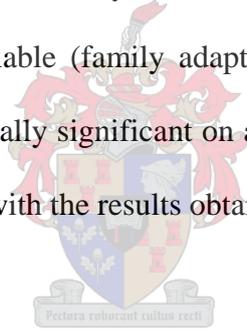
5.2. Analysis of Variance (ANOVA)

The following ANOVAS indicate possible existing differences between the families' mean adaptation scores, based on certain biographical data. Figure 5.1 highlights possible existing differences between family adaptation (FACI8 scores) of single-parent families and two-parent families.

F(1, 30)=2.5480, p=0.12
Vertical bars denote 0.95 confidence intervals
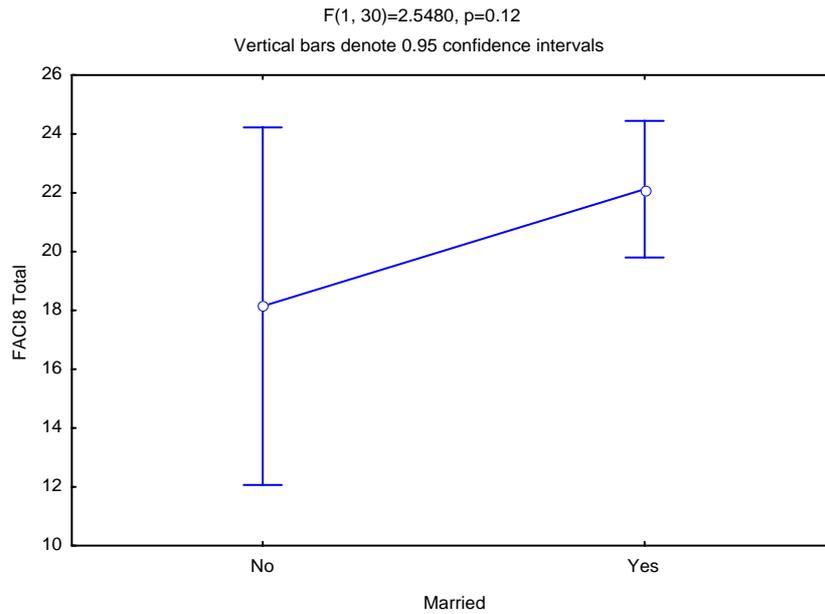
Figure 5.1. A comparison of FACI8 (Family Attachment and Changeability Index 8) scores of single-parent families and two-parent families.

It can be seen from Figure 5.1 that families in which both parents were present in the home appeared to adapt more successfully to the presence of an autistic child. This difference in adaptation approached significance ($p = .12$). There is, however, a great deal of overlap between the 95% confidence intervals of the two groups, which suggests that they are not entirely different.

Figure 5.2 highlights possible existing differences between the adaptation of families in which the autistic child has either zero, one or two siblings.

F(2, 28)=1.6559, p=0.21

Vertical bars denote 0.95 confidence intervals
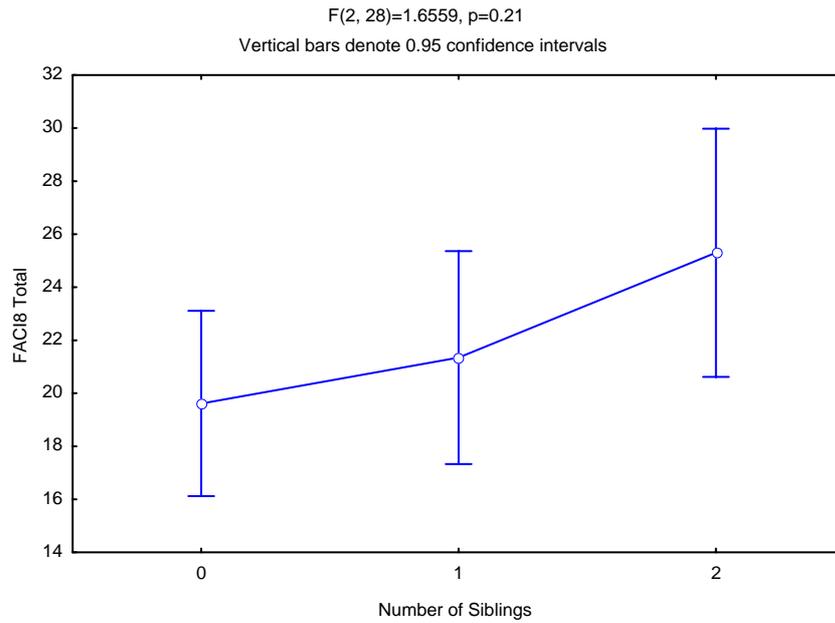
Figure 5.2. A comparison of FACI8 scores of families in which the autistic child has zero, one or two siblings.

As can be seen from Figure 5.2 families in which the autistic child has one sibling appear to exhibit better adaptation than those in which the autistic child has no siblings. Furthermore, there appears to be a higher level of adaptation in families in which the autistic child has two siblings, compared to families in which there is one sibling or no other children. This difference is however, not statistically significant (p = .21), which can also be observed by the overlap of the 95% confidence intervals. Nonetheless, there was evidence of a trend of better adaptation as the number of siblings increases.

In Figure 5.3 the adaptation of families from lower, middle and upper socioeconomic status was compared.

F(2, 28)=9.0142, p=<0.01
Vertical bars denote 0.95 confidence intervals
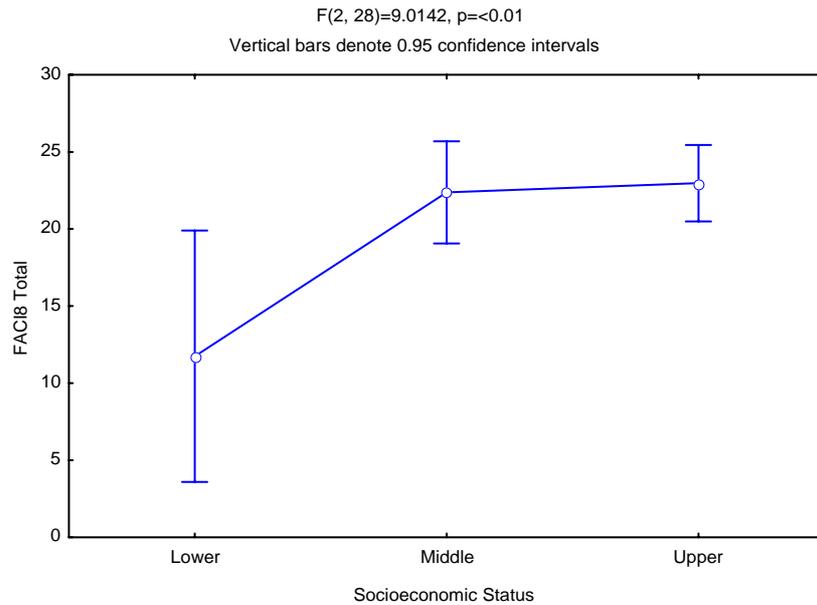
Figure 5.3. A comparison of FACI8 scores of families from lower, middle and upper socioeconomic status.

Figure 5.3 points towards a difference in adaptation between families of middle and upper socioeconomic status and those of lower socioeconomic status, with those of middle and upper socioeconomic status adapting more successfully. This difference is statistically significant (p < .01).

5.3. Scatterplots

In order to determine which independent variables were correlated with adaptation scores on the FACI8, Pearson product-moment correlation coefficients were calculated. The scatterplots that follow are graphic representations of these correlations.

Figure 5.4 shows the correlation between family adaptation and the current age of the autistic child.

Age of autistic child:FACI8 Total: r = 0.4353, p = 0.0232
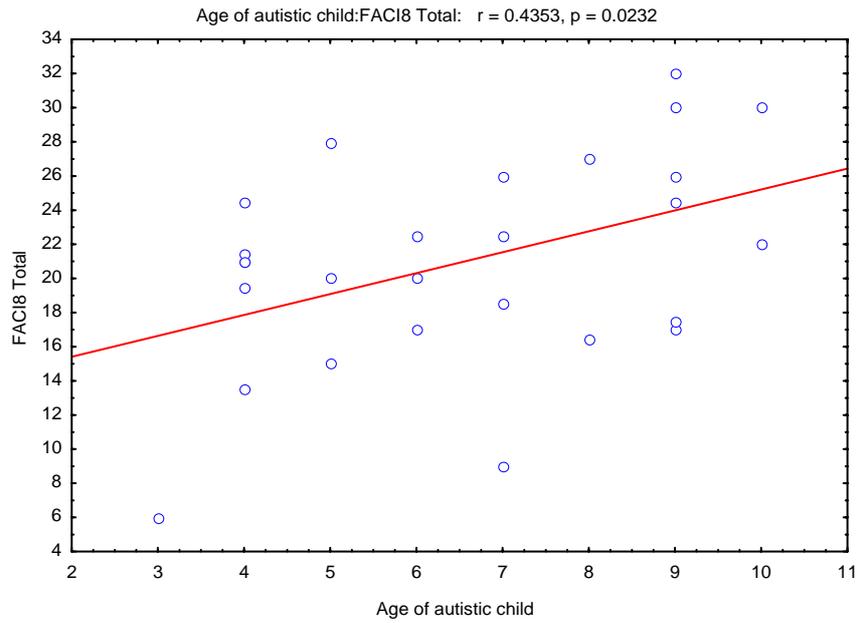
Figure 5.4. The correlation between family adaptation (FACI8 scores) and the current age of the autistic child. The line is a regression line fitted through the data.

It is evident from Figure 5.4 that a positive correlation exists between family adaptation and the age of the autistic child. Furthermore, this correlation is statistically significant (r = .44, p = .02).

In Figure 5.5 the correlation between family adaptation and the occupation of the family's primary breadwinner is shown.

Occupation classification of primary breadwinner:FACI8 Total: r = 0.5590, p = 0.0011
Spearman r = 0.33 p=0.07
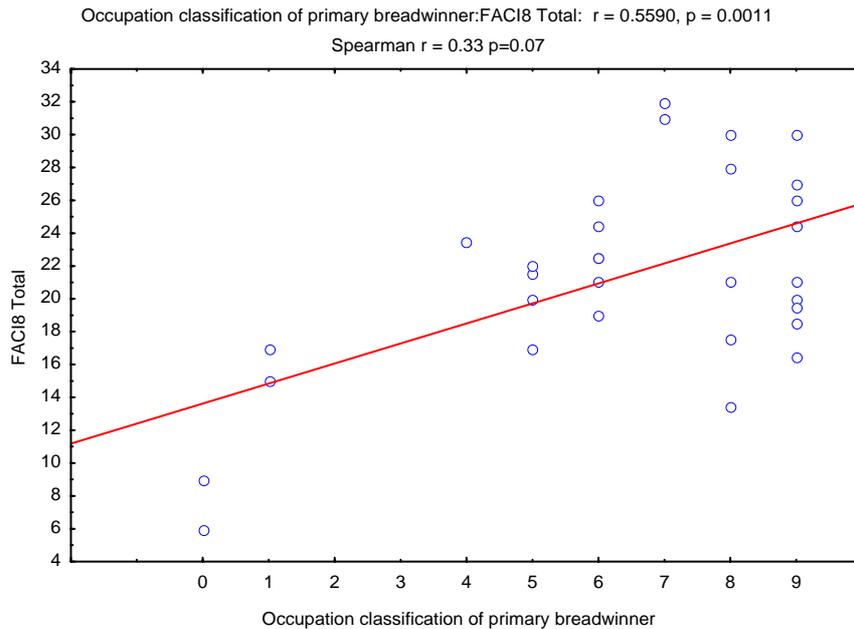
Figure 5.5. Correlation between family adaptation and the occupation of the family's primary breadwinner (See Addendum 3 for a definition of these categories).

From Figure 5.5 it can be seen that there is a strong positive correlation between family adaptation and the occupation of the family's primary breadwinner. In this case, the Spearman correlation coefficient was used, as this coefficient tends to yield more reliable results when various categories are being compared (M. Kidd, Stellenbosch University, personal communication, 17 October 2004). This correlation is only significant on the 10%-level (r = .33, p = .07).

Figure 5.6 represents the correlation between family adaptation and the family's socioeconomic status.

Socioeconomic Status:FACI8 total: r = 0.5261, p = 0.0024

Spearman r = 0.38 p=0.03
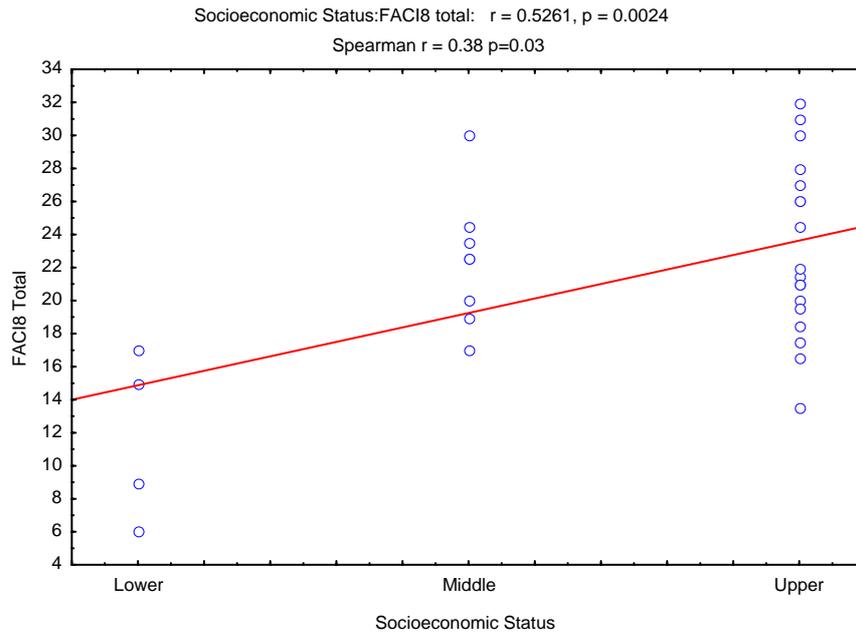
Figure 5.6. Correlation between family adaptation and the family's socioeconomic status.

As can be seen above, Figure 5.6 shows a strong positive correlation between family adaptation and socioeconomic status. Once again the Spearman correlation coefficient was used due to the comparison of various categories. This correlation is further statistically significant   (r = .38, p = .03). Furthermore the correlation is concurrent with the above-mentioned ANOVA (Figure 5.3) in which it was shown that higher socioeconomic status is related to better family adaptation   (F (2, 28)=9.0142, p= <0.01).

Figure 5.7 is a representation of the correlation between family adaptation and social support, as obtained from scores on the Social Support Index (SSI).

SSI Total:FACI8 Total: r = 0.4454, p = 0.0106
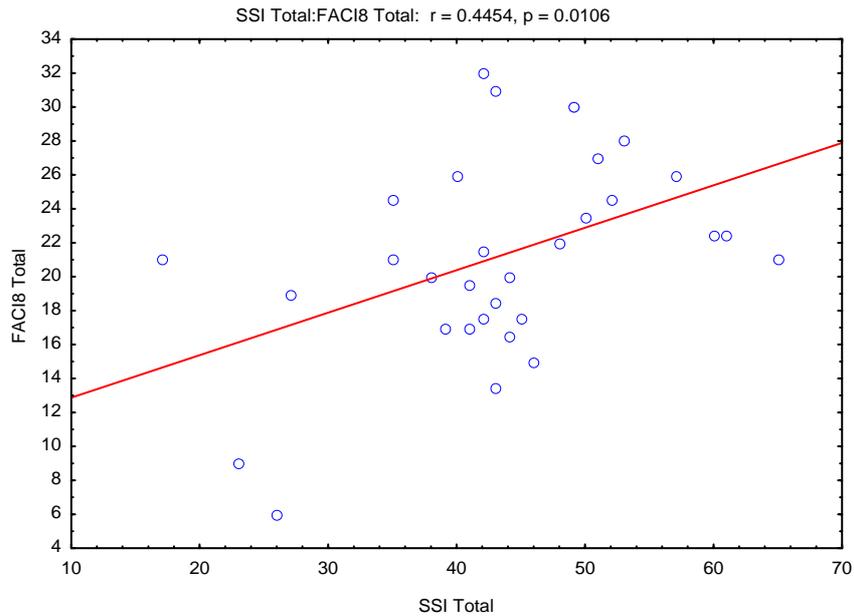
Figure 5.7. Correlation between family adaptation scores and scores on the Social Support Index (SSI).

It can be seen from the above graph (Figure 5.7) that there is a significant positive relationship (r = .44, p = .01) between the family's level of adaptation and the degree to which families find support in their communities.

The graphs that follow, namely Figure 5.8a, Figure 5.8b and Figure 5.8c, illustrate the correlation between family adaptation and various patterns of family communication. Figure 5.8a and 5.8b represent affirming and incendiary communication patterns respectively, while Figure 5.8c depicts a combination of the two patterns.
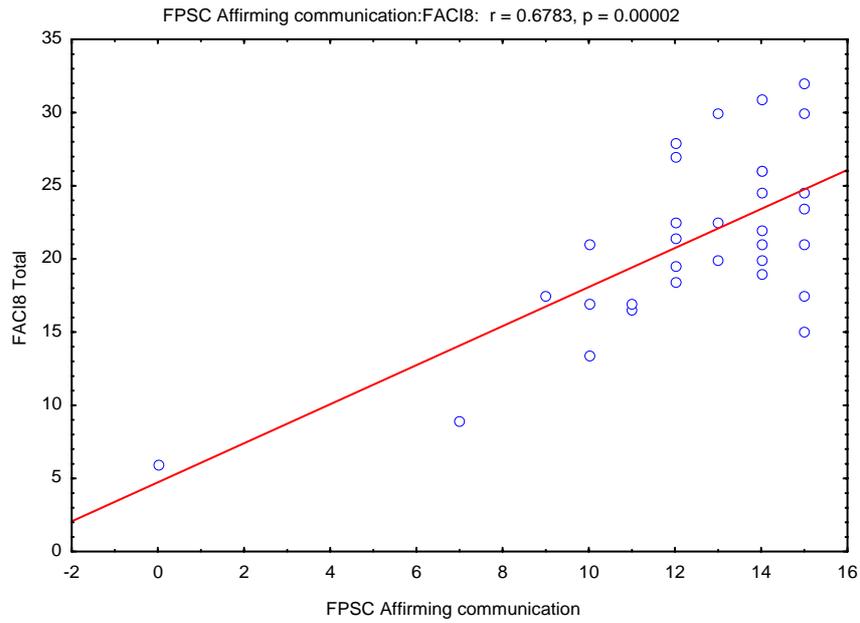
Figure 5.8a. Correlation between family adaptation and affirming communication scores on the Family Problem Solving and Communication Scale (FPSC).

From Figure 5.8a it is evident that there is a strong positive correlation between the level of family adaptation and affirming communication patterns. In addition, this correlation was found to be statistically significant (r = .68, p < .01).

FPSC Incendiary communication:FACI8 Total: r = -0.5677, p = 0.0007
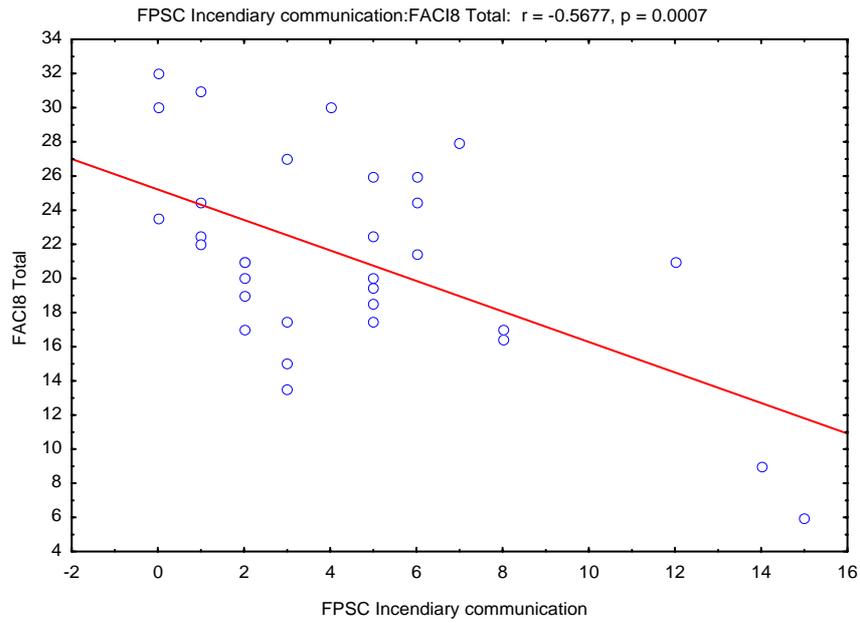
Figure 5.8b. Correlation between family adaptation and incendiary communication scores on the Family Problem Solving and Communication Scale (FPSC).

As can be seen from Figure 5.8b above, a strong negative correlation exists between family adaptation and incendiary communication patterns. This, too, is a statistically significant correlation (r = -.57, p < .01).

FPSC Total:FACI8 Total: r = 0.6514, p = 0.00005
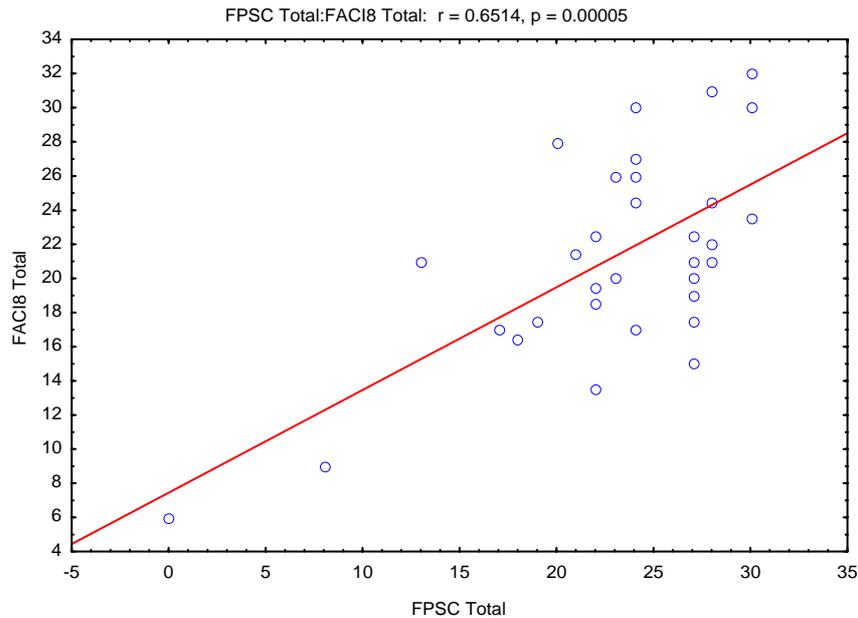
Figure 5.8c. Correlation between family adaptation and total scores on the Family Problem Solving and Communication Scale (FPSC).

In Figure 5.8c a strong positive correlation is seen between family adaptation and the combination of the above-mentioned communication patterns (affirming and incendiary communication). This statistically significant correlation ($r = .65$, $p < .01$) highlights the importance of the quality of communication in adapting to the presence of a chronic stressor (McCubbin et al., 1996).

Figures 5.9a, 5.9b, 5.9c and 5.9d represent the correlations between family adaptation and various dimensions of family hardiness.

Figure 5.9a illustrates the correlation between family adaptation and scores on the commitment subscale of the Family Hardiness Index (FHI).

FHI Commitment:FACI8 Total: r = 0.5874, p = 0.0004
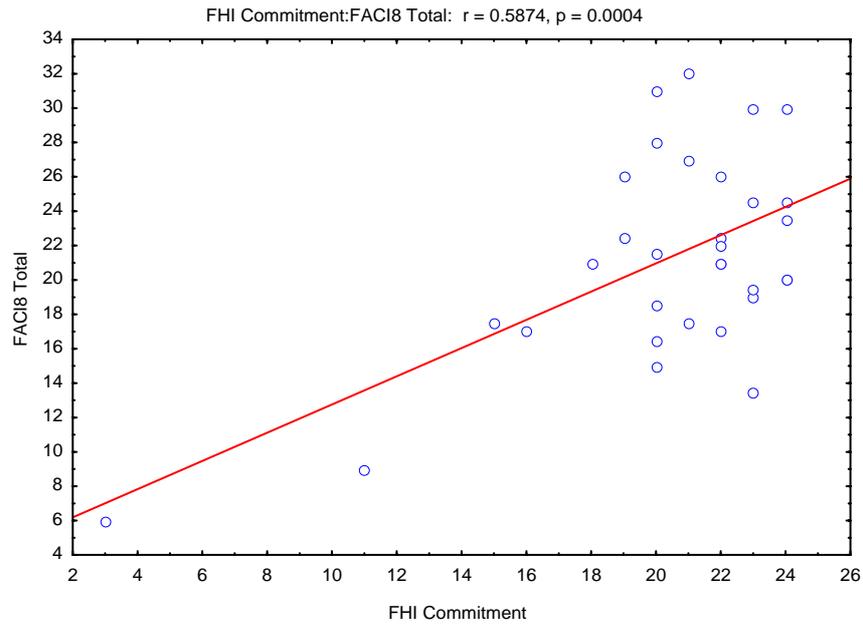
Figure 5.9a. Correlation between family adaptation and commitment scores on the Family Hardiness Index (FHI).

The correlation observed in Figure 5.9a is a strong positive one, which was statistically significant (r = .59, p < .01). Therefore, families who depend upon one another and are able to work together during times of crisis (McCubbin et al., 1996) are likely to show higher levels of adaptation.

Figure 5.9b depicts the correlation between family adaptation and scores on the challenge subscale of the FHI.

85
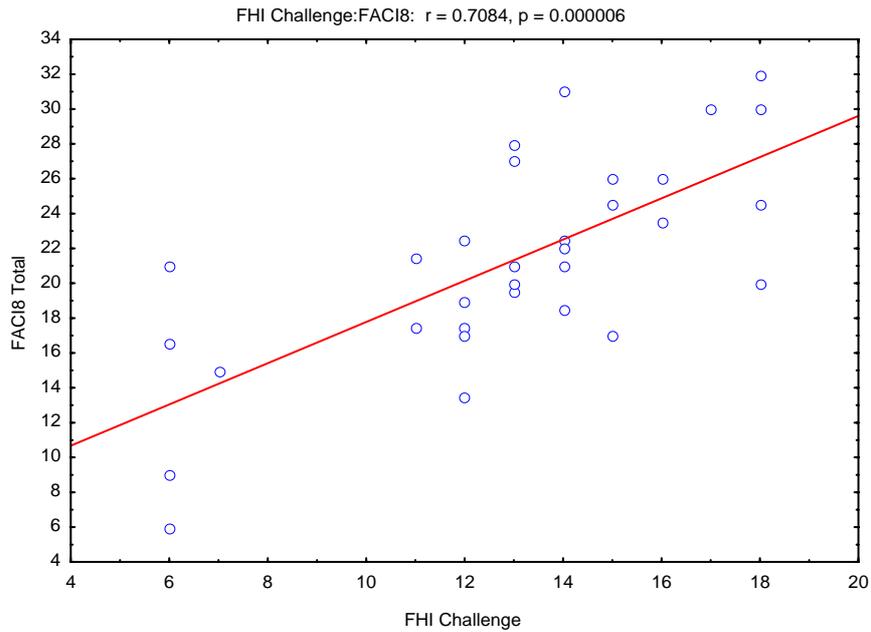
Figure 5.9b. Correlation between family adaptation and challenge scores on the Family Hardiness Index (FHI).

From Figure 5.9b it is evident that there is a very strong positive correlation between a family's level of adaptation after a crisis situation and their ability to experience new things and to learn, and to be innovative and active (McCubbin et al., 1996). In addition this is a statistically significant correlation (r = .71, p < .01).

Figure 5.9c below is an illustration of the correlation between family adaptation and scores on the control subscale of the FHI.

FHI Control:FACI8 Total: r = 0.4653, p = 0.0073
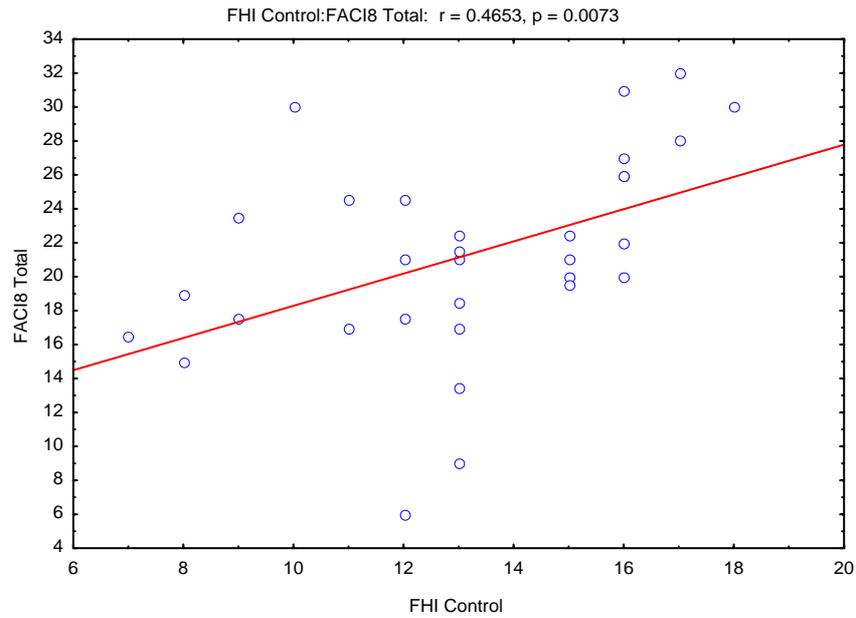
Figure 5.9c. Correlation between family adaptation and control scores on the Family Hardiness Index (FHI).

Figure 5.9c shows a positive correlation between family adaptation scores and a family's perception of being in control of their family life as opposed to being shaped by outside influences (McCubbin et al., 1996). This statistically significant correlation ($r = .47$, $p < .01$) is therefore related to a family's sense of having an internal locus of control.

Figure 5.9d depicts the correlation between family adaptation and total scores on the Family Hardiness Index (FHI).

FHI Total:FACI8 Total: r = 0.7558, p = 0.0000006
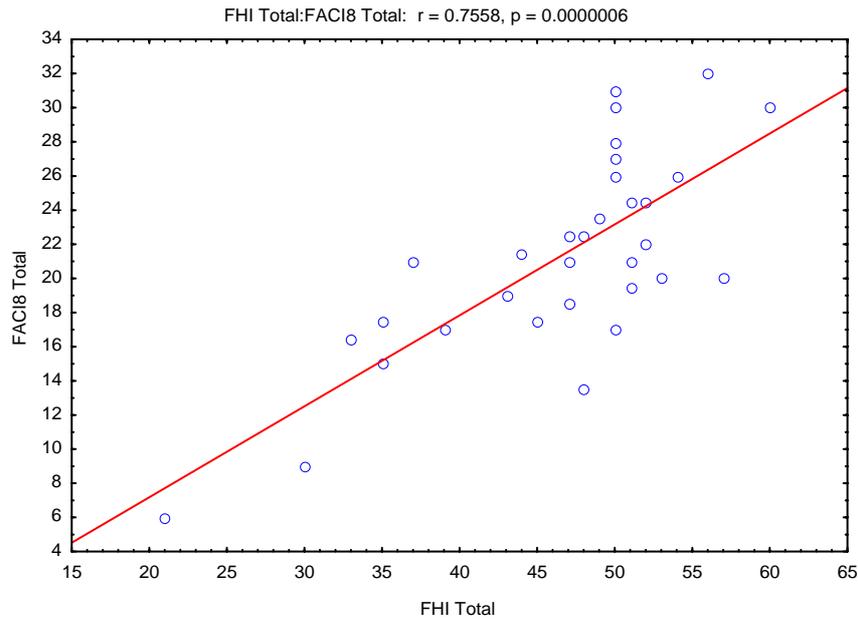
Figure 5.9d. Correlation between family adaptation and total scores on the Family Hardiness Index (FHI).

As can be seen from Figure 5.9d, a very strong positive correlation exists between the family's level of adaptation and the construct of family hardiness. This is a statistically significant correlation ($r = .76$, $p < .01$). Family hardiness is a family resource that buffers the effects of stressors and facilitates adaptation over time and refers to a family's internal strengths and durability (McCubbin et al., 1996).

Figure 5.10a illustrates the correlation between family adaptation and scores on the Passive Evaluation subscale of the Family Crisis Oriented Personal Evaluation Scales (F-COPES).

F-COPES Passive Evaluation:FACI8: r = 0.5889, p = 0.0004
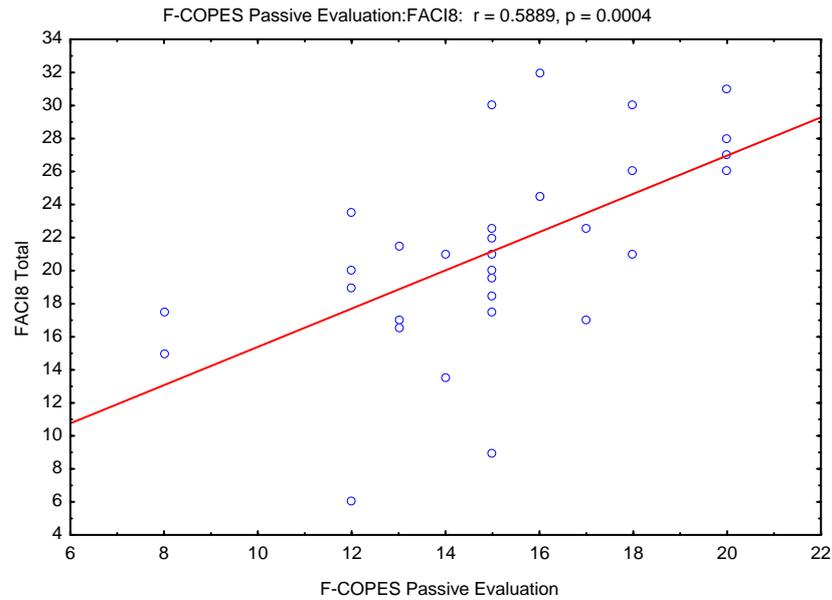
Figure 5.10a. Correlation between family adaptation and scores on the Passive Evaluation subscale of the Family Crisis Oriented Personal Evaluation Scales (F-COPES).

From Figure 5.10a it is apparent that a strong positive correlation exists between family adaptation and passive evaluation. Furthermore, this is a statistically significant correlation (r = .59, p < .01).

Figure 5.10b illustrates the correlation between family adaptation and scores on the Mobilisation subscale of the Family Crisis Oriented Personal Evaluation Scales (F-COPES).
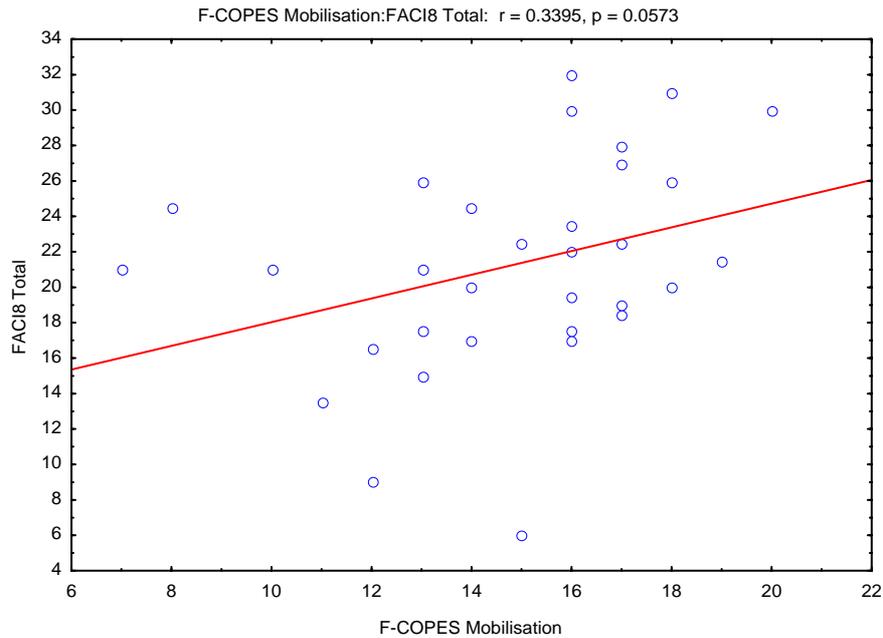
Figure 5.10b. Correlation between family adaptation and scores on the Mobilisation subscale of the Family Crisis Oriented Personal Evaluation Scales (F-COPES).

From the above graph, Figure 5.10b, it can be observed that a positive correlation exists between a family's level of adaptation and their ability to acquire community resources and accept help from others (McCubbin et al., 1996). This Pearson product-moment correlation coefficient is however not statistically significant (r = .34, p = .06), although it certainly represents a definite trend.

Figure 5.11a represents the correlation between family adaptation and scores on the Child Routines subscale of the Family Time and Routine Index (FTRI).
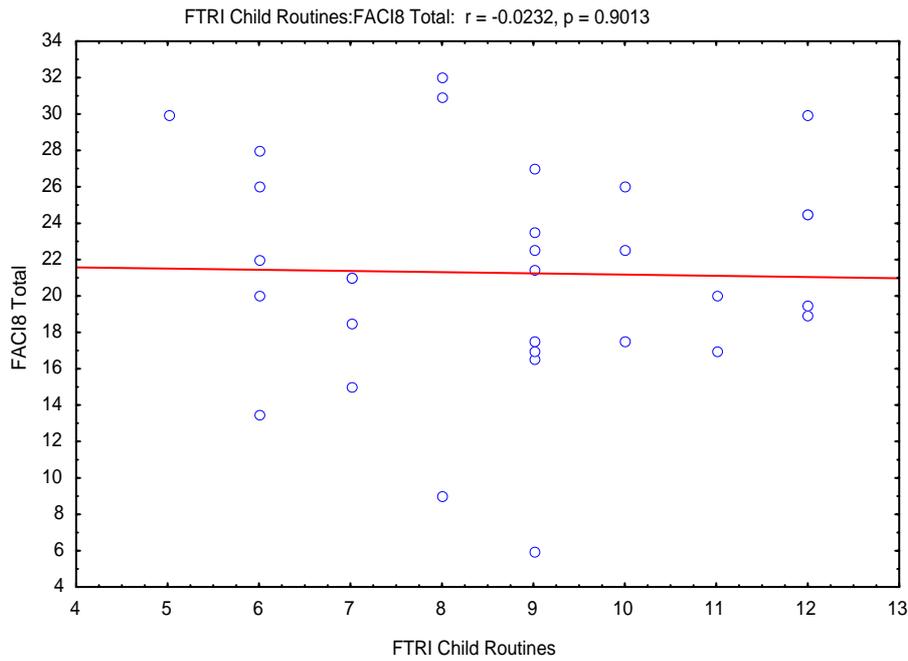
Figure 5.11a. Correlation between family adaptation and scores on the Child Routines subscale of the Family Time and Routine Index (FTRI).

From Figure 5.11a it is evident that no correlation (r = -.02, p = .90) exists between family adaptation and the family's emphasis on creating predictable routines to promote children's sense of independence and order (McCubbin et al., 1996). This is further, not a statistically significant correlation. This correlation has, however, been included due to the fact that child routines are felt to be very important in the adjustment of autistic children (Nevid, Rathus & Greene, 2000) and the results are therefore of interest to the study.

Figure 5.11b depicts the correlation between a family's level of adaptation and scores on the Parent-Child Togetherness subscale of the FTRI.

FTRI Parent-Child Togetherness:FACI8 Total: r = 0.5386, p = 0.0018
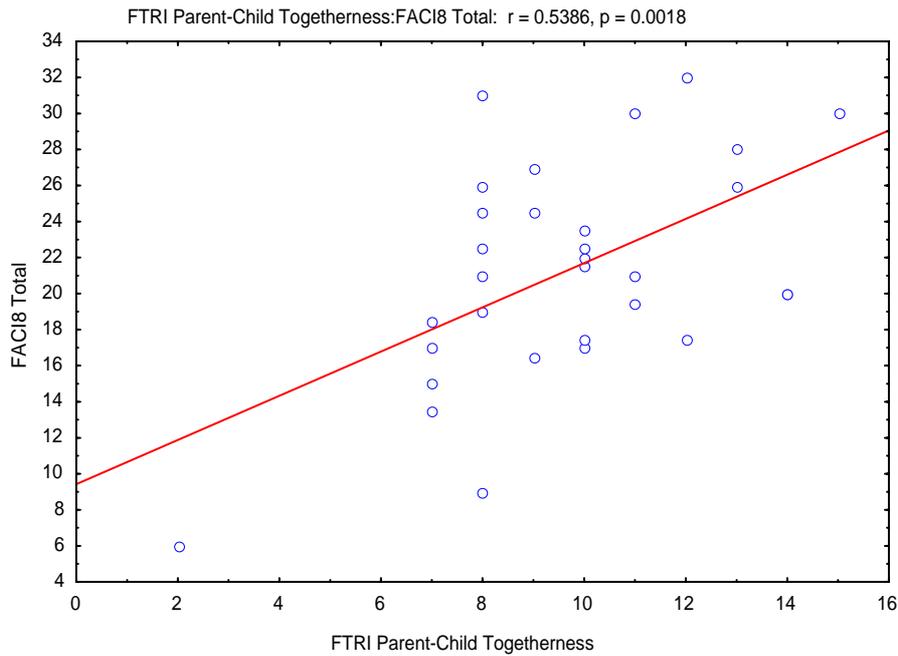
Figure 5.11b. Correlation between a family's level of adaptation and scores on the Parent-Child Togetherness subscale of the FTRI.

As can be seen from Figure 5.11b above, a strong positive correlation (r = .54, p < .01) exists between family adaptation and parent-child togetherness. The Parent-Child Togetherness subscale measures the family's emphasis on creating predictable communications between parents and children (McCubbin et al., 1996).

Figure 5.11c below illustrates the correlation between family adaptation and scores on the Family Time Together subscale of the FTRI.

FTRI Family Time Together:FACI8 Total: r = 0.5171, p = 0.0029
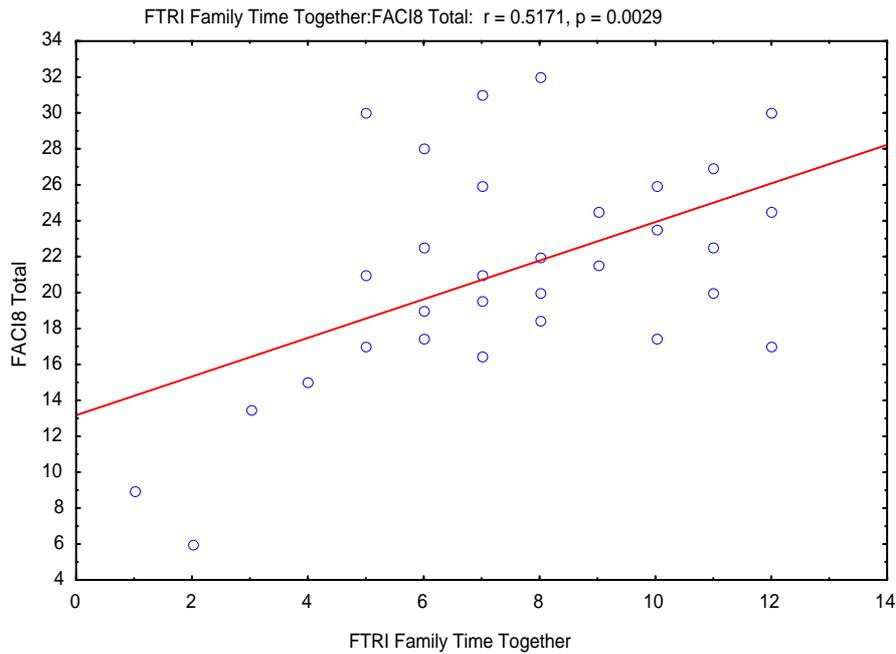
Figure 5.11c. Correlation between family adaptation and scores on the Family Time Together subscale of the FTRI.
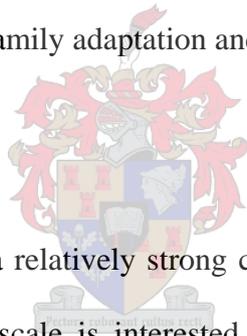
Figure 5.11c above points towards a relatively strong correlation between family adaptation and family time together. This subscale is interested in the family's emphasis on family togetherness including special events, quiet time and family time (McCubbin et al., 1996). This, too, is a statistically significant correlation (r = .52, p < .01).

The final graph in this section, Figure 5.11d, represents the correlation between family adaptation and the total scores of the FTRI.

FTRI Total:FACI8 Total: r = 0.4378, p = 0.0138
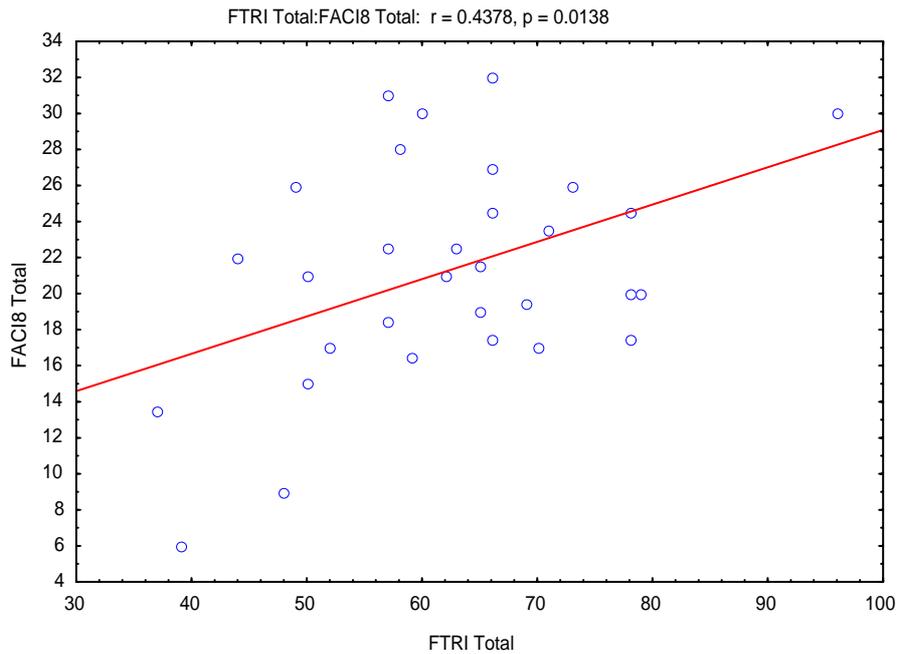
Figure 5.11d. Correlation between family adaptation and the total scores of the Family Time and Routine Index.
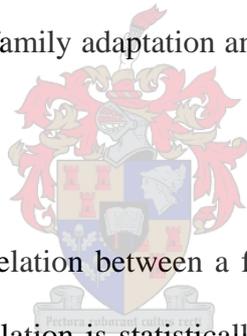
Figure 5.11d depicts a positive correlation between a family's level of adaptation and their total scores on the FTRI. This correlation is statistically significant (r = .44, p = .01). The FTRI explores the routines and activities used by families, as well as the value families place on these practices (McCubbin et al., 1996).

Table 5.1 provides a summary of the correlations found between the dependent variable (family adaptation) and the various independent variables measured in the study. The correlation coefficients as well as the significance values are reported.

Table 5.1.

Correlations between family adaptation and the various independent variables measured.

Variable	r	p
Length of parental relationship	.33	.07
Age Parent 1	.38	.06
Age Parent 2	.12	.60
Age of autistic child	.44*	.02
Years since diagnosis	.22	.23
Occupation classification primary breadwinner	.56**	< .01
Education primary breadwinner	.18	.33
Socioeconomic status	.53**	< .01
Social Support Index (SSI)	.45*	.01
Relative and Friend Support Index (RFS)	.23*	.20
Family Problem Solving and Communication Scale (FPSC)	.65**	< .01
Affirming Communication	.68**	< .01
Incendiary Communication	-.57**	< .01
Family Hardiness Index (FHI)	.76**	< .01
Commitment	.59**	< .01
Challenge	.71**	< .01
Control	.47**	< .01
Family Crisis Oriented Personal Evaluation Scales (F-COPES)		
Social Support	-.01	.98
Spiritual Support	-.05	.81
Mobilising community resources	.34	.06
Redefining the problem	.31	.09
Passive Evaluation	.59**	< .01

Table 5.1.

Continued.

Variable	r	p
Family Time and Routine Index (FTRI): Family Total	.44*	.01
Importance	.09	.70
Child Routines	-.02	.90
Couple Togetherness	.20	.28
Parent-Child Togetherness	.54**	< .01
Family Time Together	.52**	< .01
Meals Together	.31	.10
Family Chores Routines	.14	.45
Relatives Connection Routines	.27	.14
Family Management Routines	.21	.27

* Significant on a 5% level.

** Significant on a 1% level.

As can be seen from the above Table, seventeen of the thirty-two correlations were significant. Most of the significant correlations were positive, while only one was found to be significantly negative (Correlation between family adaptation and incendiary communication scores on the FPSC).

5.5. Regression Analysis

In order to identify which combination of independent variables would best predict the dependent variable (family adaptation), a multiple regression analysis was carried out. A best-subsets analysis was carried out in order to identify the best predictor variables. The combination of independent variables that were identified as being the best predictors of

family adaptation (total scores on the FACI8) were the total scores on the Relative and Friend Support Index, the total scores on the Family Problem Solving and Communication Scale, and the Spiritual Support and Passive Evaluation Subscales on the Family Crisis Oriented Personal Evaluation Scales. Table 5.2 summarises the results of the multiple regression analysis.

Table 5.2.

Regression Summary for Dependent Variable: FACI8 total.

Variable	B	t(27)	p-level
RFS Total	.25	2.53	.0176
FPSC Total	.56	7.38	.0000
F-Copes Spiritual Support	.24	1.48	.1501
F-Copes Passive Evaluation	1.30	7.88	.0000

By looking at the R-value (R = .9099) in Table 5.2 it is clear that there is a strong positive correlation between the true FACI8 scores and the estimated FACI8 scores, using the four independent variables in the Table. We can also see, by looking at the R squared value (R^2 = .8279) that the four independent variables listed above account for approximately 83 % of the variation in FACI8 scores. The p-values listed in the last column of the Table indicate that the B values used to describe this model, apart from F-Copes Spiritual Support and the RFS Total, differ significantly from zero, therefore indicating the importance of including the above-mentioned independent variables in the multiple regression model. Although the B values associated with F-Copes Spiritual Support and RFS, do not differ as significantly from zero as the other two B values in the table, it is essential to include these variables due to the fact that they were identified through the best-subsets analysis.

This section concludes the results of the quantitative part of the study. The discussion will now turn towards the qualitative results.

5.6. Qualitative data

In order to obtain qualitative data from the families participating in the study, the families were asked to answer the following open-ended question: In your own words, what are the most important factors, or strengths, which have helped your family to adapt to living with your autistic child? 33 parents responded to the question and their responses were analysed in order to identify common themes, as well as the prevalence of these themes. The data was analysed through a process of familiarisation, coding and categorising. Inductive reasoning was used in order to identify potential categories and themes from the data.

A summary of the themes identified through the data, and their prevalence, is given in Table 5.3.
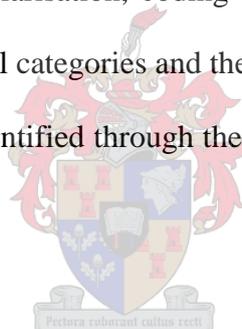
Table 5.3.

Summary of Qualitative Data according to the Parents (n=33)

Resilience Factor	Number of responses
School and treatment programmes*	17
Knowledge about autism	15
Acceptance of diagnosis	13
Support and involvement of extended family	13
Faith in God	13
Advice from experts	9
Love	8
Support and involvement of friends	7
Strong and supportive family base	7

Table 5.3.

Continued.

Resilience Factor	Number of responses
Maintain a positive outlook	6
Hope	5
Treat child as normal	5
Pride due to small improvements	4
Open communication	4
Family recreational activities	4
Support from other parents of autistic children	4
Make child as independent as possible	4
Community support	3
Children are top priority	3
Attention to children	3
Adapt family to accommodate child's needs	3
Healthy parental relationship	3
Listening to child's needs	2
Having other children in the household	2
Working together as a family	2
Stick to basic routine	2
Empathy for child	2
Animals help child to relax	2
Commitment	1
Help child adapt to the family	1
Ignore negative behaviour	1
Setting rules and boundaries	1
Create a safe environment for the child	1
Time alone for parents	1
Provide guidance to the child	1
Provide assistance at the level of the child	1
Patience	1
Recreational activities for the child	1

Table 5.3.

Continued.

Resilience Factor	Number of responses
Special diet for child	1

* Includes doctors, witchdoctors, Zionists, traditional healers, homeopathy, teachers, speech therapists, occupational therapists, and auditory integration.

As can be seen from Table 5.3, those factors reported most often by parents as facilitating the adaptation process following the diagnosis of an autistic child are school and treatment programmes (n=17); knowledge about autism (n=15); acceptance of the diagnosis (n=13); support and involvement of extended family (n=13); and faith in God (n=13).

Many rated the advice of experts (n=9), love (n=8), the support and involvement of friends (n=7), and a strong and supportive family base (n=7) as important factors in the process of adaptation. Maintaining a positive outlook on life (n=6) and remaining hopeful (n=5) were also rated highly.

The following chapter contains a discussion of the results of this study, with reference to the theories and literature discussed in chapters two and three. It will also include conclusions drawn from the study, as well as suggestions for further research.

CHAPTER 6

DISCUSSION AND CONCLUSIONS

6.1. Introduction

The purpose of this study was to identify the characteristics and resources that families possess that enable them to adapt successfully, and as such, be resilient despite the presence of an autistic child in the family. Theories relating to autistic disorder, as well as resiliency theories were discussed in this respect. The results attained from the statistical analysis of both the quantitative and qualitative data obtained in this study will now be discussed in relation to the above-mentioned theories. In addition, the results of the study will be compared to the findings of previous research. This discussion will be followed by the conclusions drawn from the study, as well as the limitations of the study, and recommendations for further research.
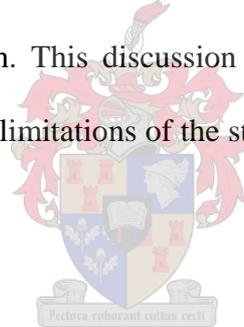
6.2. Discussion

6.2.1. Family demographic variables

Although families in which both parents were present showed higher levels of adaptation (FACI8 scores) than single-parent families (see Figure 5.1), the overlap of the 95% confidence levels indicates that the two family types are not entirely different in terms of their achieved level of adaptation. This finding is of interest, as previous literature has indicated that single-parent families raising a child with autism experience greater feelings of burden and greater difficulties in coping (Powers, 2000). In addition, it was noted that spousal

support, both instrumental and emotional, is of great importance to mothers of autistic children. Mothers who experienced this kind of support reported fewer depressive symptoms, happier marriages and were more accepting of their child with autism (Bristol, 1984; Bristol, Gallagher & Schopler, 1988). Single-parent families most likely lack this source of support and therefore, contrary to the findings of these study, would be expected to exhibit less successful adaptation.

Families in which the child with autism had one or more siblings were found to be better adapted than those with no other children (see Figure 5.2). Although this finding was not statistically significant (p = .21), a definite trend towards increased adaptation as the number of siblings increased, was visible. This finding was also reported by parents in the qualitative data (see Table 5.3). Parents found that having other children in the home helped the family in the adaptation process. Powers (2000) reported that involving the siblings of children with autism in the day-to-day care of the disabled child, as well as in the child's treatment programmes (Howlin & Rutter, 1987) leads to higher self-esteem and feelings of achievement in siblings. This is turn has a positive influence on the family's level of adaptation. According to Cantwell and Baker (1984) this approach is important as it emphasises family strengths rather than weaknesses.

The age of the child with autism also plays a role in family adaptation. A significant positive correlation was found between family adaptation (scores on the Family Adaptability and Changeability Index 8) and the age of the autistic child (see Figure 5.4). This might be indicative of the fact that, after the initial shock and adaptation difficulties associated with having a child with autism, families learn to adapt to the autistic child more successfully over time (Powers, 2000).

6.2.2. Socioeconomic variables

The socioeconomic status of families appeared to play a role in the family's level of adaptation, with families of middle and upper socioeconomic status being better adapted (see Figure 5.3). This may be accounted for by the increased ability of middle and upper class families to afford better treatment for their autistic child. This finding was supported by a positive correlation between socioeconomic status and scores on the FACI8 ($r = .53$, $p < .01$). In addition, a statistically significant positive correlation was found between family adaptation and the occupation of the family's primary breadwinner (see Figure 5.5). This may be related to the fact that higher income jobs yield more funds to be allocated for the treatment of the autistic child. People of higher socioeconomic status and with high-income jobs generally experience greater financial security than those in the lower income brackets.

These findings are further supported by resilience theory. Financial burden is described as a pile-up factor in the Resiliency Model of Adjustment and Adaptation (McCubbin et al., 1996). It therefore adds to the family's demands when faced with a stressful or crisis situation, making adaptation more difficult to achieve. Consequently, financial security may be viewed as a family resource, which may enhance the family's ability to adapt to a crisis situation (McCubbin et al., 1996). Walsh (2003) also identified financial security as an important resource in family resilience.

6.2.3. Social support

A family's level of adaptation is associated with the extent to which families find support in the communities in which they live (see Figure 5.7). This positive correlation was found to be statistically significant ($p = .01$). Social support is an important resource in alleviating the

difficulties associated with having a chronic stressor, such as an autistic child, in the home, and promoting successful adaptation (McCubbin et al., 1996; Walsh, 2003).

Previous research on the mediating effects of social support on the stressors associated with autism is plentiful, and it has been found that family adjustment increases with greater social support (Henderson & Vandenberg, 1992). Social support, including spousal support, relative support, support from friends, support from other parents of autistic children and community services, facilitates the process of accepting the autistic child, marital adjustment (Bristol, 1984), as well as the quality of parenting (Bristol, 1984; Harris & Powers, 1984). In addition, social support has been associated with positive family and child outcomes in families with an autistic child (Rivers & Stoneman, 2003).

The results of the qualitative data support the findings of the Social Support Index. Parents also reported social support as a factor fostering adaptation to having an autistic child in the home (see Table 5.3). Parents reported that access to school and treatment programmes, the support and involvement of extended family, advice from experts, the support and involvement of friends, a strong and supportive family base, support from other parents with autistic children and community support assisted them in the adaptation process.

6.3.4. Patterns of communication

The level of family adaptation is associated with the patterns of communication utilised by the family. Family adaptation is enhanced with affirming communication (see Figure 5.8a, while it declines when incendiary patterns of communication are used (see Figure 5.8b). The quality of the communication within the family provides a good indication of the degree to which families manage tension and strain and obtain a satisfactory level of family functioning,

adaptation and adjustment (McCubbin et al., 1996). Therefore a high quality of communication is associated with better family adaptation (see Figure 5.8c).

McCubbin et al. (1996) describe open communication as an important resource to promote resiliency and ultimately adaptation. Communication processes that are most likely to result in successful family adaptation are characterised by clarity, open emotional expression and collaborative problem solving (Walsh, 2003). When communication is of this quality family members are better able to make sense of the crisis situation, relate to one another truthfully, and make informed decisions. Parents should also be open with their children regarding the crisis situation and develop age-appropriate ways to discuss such situations with them. Open communication fosters empathy and mutual trust, which in turn lead to increased family resilience (Walsh, 2003).

Open communication was reported in the qualitative data (n=4) as a factor that helped families to adapt to the presence of an autistic child. Open and honest communication, as well as emotional expression has also been reported in the literature regarding autism and coping (Powers, 2000). This type of communication promotes an accepting atmosphere in which feelings can be shared, with the outcome of a supportive and nurturing environment. This too contributes to family resilience as families feel a sense of togetherness (Powers, 2000).

6.2.5. Family characteristics

Families who stand together and depend on one another during crisis situations appear to show higher levels of adaptation (see Figure 5.9a). Walsh (2003) reported that a crucial component of family resilience involves approaching a crisis situation as a "shared challenge" (p. 407). She added that the idea of coming together as a family might promote their ability to overcome hardships (Walsh, 2003). In addition, Walsh (2003) described mutual support,

collaboration and commitment as factors that lend towards increased family cohesion, which in turn contributes to more effective family functioning, and therefore increased resilience.

Certain family environments lead to greater acceptance of an autistic child, as well as greater competence in adapting to an autistic child (Bristol, 1984). Families with a supportive environment and a high degree of cohesion typically demonstrate higher degrees of commitment, help, and support for one another. Such families are also more likely to adapt successfully to the presence of a child with autism (Bristol, 1984). Parents in this study reported that being committed to helping their child with autism, working together as a family, and making their children their top priority were all family strengths contributing towards better adaptation (see Table 5.3).

Families who are willing to experience new things, to learn and to be innovative and active, show higher levels of family adaptation (see Figure 5.9b). Such flexibility is an essential process in family resilience (Walsh, 2003). It involves the ability of families to adapt to the stressor, through the reorganisation of patterns of family interaction in such as way as to fit the new demands faced by the family (Walsh, 2003). This view is shared by McCubbin et al. (1996) who report that changes in established patterns of family functioning are crucial for both adjustment and adaptation to occur.

Previous literature on family adaptation in the presence of a child with autism looks at the process of accepting the child's diagnosis as an important step towards family resilience (Powers, 2000). This was also the finding, based on the reports of the parents in this study (see Table 5.3). Mothers who were able to accept their autistic child reported higher levels of marital satisfaction and better adaptation (Bristol, 1987). Parental acceptance of the autistic child results in greater acceptance by siblings (Dyson, Edgar & Crnic, 1989), and better sibling adjustment (Cantwell & Baker, 1984; McHale, Simeonsson & Sloan, 1984).

Families with an internal locus of control showed higher levels of family functioning than those who perceived their lives as being shaped by outside influences (see Figure 5.9c). This finding is concurrent with those obtained by Bristol (1984), and Henderson and Vandenberg (1992). Families experience better adaptation when family members possessed a greater internal locus of control (Henderson & Vandenberg, 1992). This internal attribute influences social support links and the use of certain coping strategies (Bristol, 1984). Those people with an internal locus of control are more likely to engage in behaviours to overcome the adverse effects of the chronic stress of raising an autistic child, and are thus more likely to achieve successful adaptation (Henderson & Vandenberg, 1992).

Higher levels of adaptation were found in families who possess family hardiness (see Figure 5.9d). Family hardiness is a family resource that buffers the effects of stressors and facilitates adaptation over time and refers to a family's internal strengths and durability (McCubbin et al., 1996). Hardiness has been identified as an important resistance and family system resource in the Resilience Model of Adjustment and Adaptation and plays a fundamental role in achieving successful adaptation (McCubbin et al., 1996). It has also been related to sibling adjustment in families with an autistic child, thereby leading to higher levels of family functioning (Dyson et al., 1989).

The importance of love was evident in the parents' reports on resiliency factors in their families (see Table 5.3). Previous literature supports this finding as it emphasises the value of love in the process of adaptation (Powers, 2000), and in more successful family functioning (Howlin & Rutter, 1987; Paluszny, 1979). Families reported that resiliency was fostered by adapting the family to accommodate the autistic child's needs (n=3) and by helping the child to adapt to the family (n=1). Bristol (1984) asserted that interventions regarding the autistic child should promote a family-oriented home, rather than an autistic child-centred home. Families must not only adapt to the child, but the child must be helped to

adapt to the family (Bristol, 1984). As such, the child is incorporated into the existing family structure (Powers, 2000).

A healthy parental relationship leads to better adjustment in families with an autistic child (Rodrigue, Morgan & Geffken, 1993). This was also the finding in this study, based on parental reports (see Table 5.3). Powers (2000) argues that parents should not feel that they must be with their autistic child at all times, and do everything for them. Rather the child should be encouraged to develop skills that will enable him/her to function as independently as possible so as to prevent the child from becoming overly dependent of the parents (Powers, 2000). The parents in this study shared this view and believed that making the child as independent as possible was an important step in the adaptation process.

6.2.6. Problem solving and coping strategies

Families in which members make use of the internal coping strategy of passive evaluation appear exhibit higher levels of family functioning (see Figure 5.10a). Passive evaluation involves accepting the stressful situation (the presence of the autistic child) and not doing anything about it (McCubbin et al., 1996). This finding is interesting as it would be logical to think that families would achieve higher levels of adaptation by actively pursuing solutions to the stressful situation. However, the emphasis here should be on acceptance and not passive acceptance. Participants in the study might have felt that they were doing all they could for their autistic child and have resolved to accept the situation. Acceptance of the child and his/her disorder is an important factor contributing to adaptation to a child with autism (Bristol, 1987; Dyson et al., 1989; Powers, 2000).

The external coping strategy of mobilising community resources is associated with better family adaptation (see Figure 5.10b). Although this correlation was not statistically

significant (p = .06) a definite trend towards increased adaptation with increased mobilisation of community resources is visible. The importance of acquiring community resources to manage stressful situations has been cited in both resiliency theory and previous research regarding adapting to the presence of a child with autism. Parents who feel that vocational, medical and educational resources are accessible to them reported less stress than those who do not have access to such services (Bristol, 1984). Access to community support resources is related to positive family and child outcome in families with an autistic child (Rivers & Stoneman, 2003).

The mobilisation and utilisation of community resources has been identified by McCubbin et al. (1996) as a coping strategy, which promotes maintenance or strengthening of the family unit, as well as the emotional stability and well-being of its members. This in turn facilitates adaptation.

High-information seeking is a coping strategy often employed by parents of autistic children. It enables parents to take positive steps towards helping their autistic child (Rodrigue, Morgan & Geffken, 1990). In this study parents highlighted their knowledge of autism as a positive factor resulting in increased resilience (see Table 5.3). This coping strategy is adaptive as it assists parents in learning how to help their child and prevents the use of maladaptive coping strategies (Rodrigue et al., 1990). The more information parents have about their child's disorder, the more confident they feel in their ability to make a difference in their child's life (Powers, 2000). Knowledge has also been reported by McCubbin et al. (1996) as an important personal resource contributing to successful family adaptation.

6.2.7. Family time and routines

Children with autism have a need for strict adherence to routines (Aarons & Gittens, 1999). Any disruption in their known routines often leads to panic, fear or temper tantrums (Sadock & Sadock, 2003). This aversion to changes in routines results in disruptions in family life as the child may refuse to carry out any activities unless their specific routine is followed (Mash & Wolfe, 2002). This is in contrast with the findings of this study, which show no correlation (see Figure 5.11a) between the family's emphasis on creating predictable routines to promote children's sense of independence and order, and family adaptation (FACI8 scores). This may be due to the fact that, because of their intense need for the preservation of sameness (Nevid, Rathus & Greene, 2000), parents find it important to challenge their children to accept changes in order to prepare them for the unpredictability of everyday life. In terms of the qualitative data very few parents (n=2) reported that sticking to a basic routine was helpful in terms of achieving successful adaptation (see Table 5.3).

Families in which there is an emphasis on creating predictable communications between parents and children showed higher family adaptation (FACI8) scores (see Figure 5.11b). Successful family adaptation is related to parents creating time for all their children (autistic and non-autistic) separately (Bristol, 1984; Powers, 2000), and creating an environment in which children feel safe to express their feelings relating to the child with autism (Tommasone & Tommasone, 2000). Parents reported better sibling adjustment as a result of time spent alone with the non-autistic child (Powers, 2000), which in turn facilitates family adaptation.

This study found that families that emphasise family togetherness showed higher levels (see Figure 5.11c) of family adaptation. The Resilience Model of McCubbin et al. (1996) highlights family celebrations and family time together as important resources

facilitating adaptation. It is also important for parents to have time together for themselves, without any children, as this allows them to invest in their relationship (Bristol, 1984; Powers, 2000), which is beneficial for both the couple and the long-term benefit of the child (Bristol, 1984). Time away from the autistic child was reported as important to the adaptation process by one parent in this study (see Table 5.3.). In previous studies it has shown to be related to higher marital satisfaction (Paluszny, 1979), which is likely to promote family adaptation.

Parents of children with autism have emphasised the importance of routines in the process of successful adaptation (Howlin & Rutter, 1987; Paluszny, 1979). Routines assist parents in organising their time in such a way as to make time for the autistic child, their other children, their spouse and themselves. McCubbin et al. (1996) have also identified family routines as an important family system resource in the adaptation process. This is supported by the findings of this study, which suggest a positive correlation (see Figure 5.11d) between the routines and activities used by families and family adaptation.

Family recreational activities, as well as recreational activities for the child with autism, were rated by parents as important factors in promoting successful family functioning (see Table 5.3). This finding is supported by reports in previous literature that claims that families with an active recreational orientation are more likely to achieve successful adaptation (Bristol, 1984).

6.2.8. Maintaining a positive outlook

Parents reported that maintaining a positive outlook and remaining hopeful were factors that helped them to adapt to have an autistic child (see Table 5.3). The importance of a positive outlook has been documented in resilience theory. Families become resilient when they

actively pursue solutions to their problems, look beyond the hardships surrounding their situation, and focus on making the best of the options available to them (Walsh, 2003).

Families often find it easier to cope when they focus on the small improvements their child makes (Bristol, 1984). Rather than setting long-term goals, parents strive towards short-term goals and take pride in their child's small improvements (Tommasone & Tommasone, 2000). This view was confirmed by the parental reports obtained in this study (see Table 5.3).

6.2.9. Family beliefs

Faith in God was rated by the families in this study as an important factor contributing to adaptation (see Table 5.3). It was found by Bristol (1984) that belief in God and/or adherence to clear moral standards mediates the family hardships by giving meaning and purpose to the sacrifices the family makes in caring for the autistic child. Personal religious beliefs are therefore important in coping with the difficulties related to raising a child with autism. According to McCubbin et al. (1996) shared spiritual beliefs are an essential resistance resource in family adaptation. Belief systems contribute to family resilience by helping families to make meaning out of adversity and to maintain a positive outlook. Most families find comfort, guidance and strength through spiritual resources and religious affiliation, which also plays a part in family resilience (Walsh, 2003).

To conclude this discussion it would be fitting to look at the combination of independent variables that were found to be the best predictors of family adaptation, and should therefore be considered as resiliency factors. Relative and friend support, the quality of communication in the family, and the coping strategies of seeking spiritual support and engaging in passive evaluation of crisis situations, were identified as the most important predictor variables in this study. The significance of these variables on an individual basis has

been shown in the above discussion. It would then be logical to assume that when these factors occur in combination with one another their buffering affects against family crisis would be so much more, and as such higher levels of family adaptation are likely to be achieved.

6.3. Conclusions

Several significant findings emerged from the various statistical analyses conducted. In this section these findings will be considered with reference to theories relating to both autism and family resilience, and the relevant conclusions will be drawn.

While much of the literature on autism and coping focuses on the detrimental effects of the disorder on the family, the families in this study appeared to be relatively well adjusted (indicated by their FACI8 scores). One proposed reason for this trend is that all the families in this sample had access to educational services for their autistic child. The importance of access to schools and other community resources in adaptation was evident in previous research (Bristol, 1984; Factor, Perry & Freeman; Powers, 2000), in resiliency theory (McCubbin, Thompson & McCubbin, 1996; Walsh, 2003), and the results of this study (F-COPES: Mobilising community resources; and the Social Support Index). Due to the limitations based on the homogeneity of the sample in terms of access to educational services, it would be proposed that further research be undertaken to identify resilience factors in families who do not have access to such services.

In addition, the majority of the families in this study were of a high socioeconomic status and employed in higher-income jobs. This implies that they would be likely to have more funds available to invest in educational services for their children. It may be then that it is not so much access to educational services, but access to funds to invest in such services

that is the true mediating factor. It is further recommended that families from lower socioeconomic backgrounds be investigated in order to identify the factors that facilitate their adaptation to having an autistic child.

An interesting finding was the lack of any relationship between family adaptation and the emphasis families place on routines for their autistic child. The literature on autism highlights the importance of routine in the life on an autistic child (Mash & Wolfe, 2002; Nevid, Rathus & Greene, 2000; Sadock & Sadock, 2003). It may be that the absence of a significant relationship between child routines and family adaptation is due to the fact that families want to challenge their children to adjust to the unpredictability of everyday life and therefore place less emphasis on the maintenance of routines. On the other hand, families may be so accustomed to sticking to the rigid routines imposed by the presence of their autistic child that the concept of routines is no longer an issue for them. Further research is recommended to uncover the reasons for this unexpected finding or to shed light on possible extraneous variables that led to this result.

Several factors identified by the Resilience Model of Adjustment and Adaptation (McCubbin et al., 1996) as being important mediating factors in family adaptation were supported by this study. These include social support and the mobilisation of community resources; open communication; and family hardiness, including commitment and an internal locus of control. The Resilience Model therefore provides an effective contextual framework in which resiliency factors specific to families with an autistic child can be understood.

Although this study yielded conclusive results relating to family adaptation to an autistic child it is characterised by a number of shortcomings, some of which have already been discussed. An additional limitation is the size of the sample obtained for the study. Due to problems in gaining direct access to families, as well as time constraints of both the researcher and potential participants, only 34 families took part in the study. This small

sample size calls for caution in generalising the results of the study to all families with an autistic child present in the home. A further limitation of the study is the geographical location of participants. All families participating in the study reside in the Cape Town Metropolitan area in South Africa. This means that additional care must be taken in generalising the results, particularly with regard to families not residing in urban areas. People from rural areas are likely to experience greater difficulty in accessing educational services and may be of lower socioeconomic status than the families participating in this study.

The findings of this study serve a dual role in terms of its utility in facilitating adaptation. Firstly, because many of the findings are supported by already-existing literature, it may serve as confirmation for parents that their efforts are indeed worthwhile. This study confirms that factors, such as accessing social support, taking time away from their child, accepting their child's diagnosis, open emotional expression, family activities and routines, as well as family commitment, are all important resilience factors. As such they are beneficial for the child's well-being, as well as successful family functioning.

Secondly, the results of this study may be used to provide both professionals and parents with insight into how to create a family environment, which will benefit the autistic child, without detriment to the total family system. By providing the child with access to school and treatment programmes, predictable routines, and an atmosphere of open emotional expression, the well-being of the child is enhanced. This is likely to result in better adaptation by the autistic child, and as a result, a more resilient family.

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ADDENDUM 1

QUESTIONNAIRES

The following questionnaires were used:

Biographical questionnaire (includes an open-ended question)

Family Hardiness Index (FHI)

Social Support Index (SSI)

Relative and Friend Support (RFS)

Family Crisis Oriented Personal Evaluation Scales (F-COPES)

Family Time and Routine Index (FTRI)

Family Problem Solving and Communication Scale (FPSC)

Family Adaptability and Changeability Index 8 (FACI8)

BIOGRAPHICAL INFORMATION

All information in this questionnaire is strictly confidential and your information will be anonymously processed.

Please cross the box most appropriate to you, or complete the statement in the space provided:

1. **Living in** …………………………………..…………………………………(town or city)

2. **Family composition**

	Participating Parent	Other Parent	Child at Alpha School	Child 2	Child 3	Child 4
Age						
Gender						

How long ago was your child diagnosed with autism? _____ (completed years)

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

No ☐

Yes ☐ Please give details……………………………………………………………………………………………………

3. Occupation and Education of Primary Breadwinner

Occupation Classification of Primary Breadwinner	Tick
Highly qualified professional, executive, administrative and technical occupations	
Professional, administrative and managerial workers	
Commercially independent	
Lower qualified administrative, technical and clerical with limited supervisory responsibility	
Skilled workers and artisans with trade qualifications	
Routine clerical and administrative workers, service and sales workers	
Semi-skilled production and manual workers	
Not economically active or productive Unskilled production and manual workers	
No response	

Breadwinner's Education	
Attended university	
Trained at Post-matric level (not university)	
Matric	
Apprenticeship	
Primary School Junior Certificate (Std. 8)	
No education	
No response	

What is your home language? Afrikaans ☐   English ☐   Other (specify) …………………….

Thank you again for your co-operation!

OPEN-ENDED QUESTION

In your own words, what are the most important factors, or strengths, which have helped your family to adapt to living with your autistic child?

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Baie dankie vir jou samewerking! / Thank you again for your co-operation!

SSI

Please rate the following statements as they apply to your family	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	*Official use*
1. If I had an emergency, even people I do not know in this community would be willing to help						
2. I feel good about myself when I sacrifice and give time and energy to members of my family						
3. The things I do for members of my family and they do for me make me feel part of this very important group						
4. People here know they can get help from the community if they are in trouble						
5. I have friends who let me know they value who I am and what I can do						
6. People can depend on each other in this community						
7. Members of my family seldom listen to my problems or concerns; I usually feel criticised						
8. My friends in this community are a part of my everyday activities.						
9. There are times when family members do things that make other members unhappy						
10. I need to be very careful how much I do for my friends because they take advantage of me.						
11. Living in this community gives me a secure feeling						
12. The members of my family make an effort to show their love and affection for me.						
13. There is a feeling in this community that people should not get too friendly with each other						
14. This is not a very good community to bring children up in						
15. I feel secure that I am as important to my friends as they are to me						
16. I have some very close friends outside the family who I know really care for me and love me						
17. Member(s) of my family do not seem to understand me; I feel taken for granted						

RFS

DIRECTIONS: Decide for your family whether you: STRONGLY DISAGREE; DISAGREE; are NEUTRAL; AGREE;

 or STRONGLY AGREE with the statements listed below. Indicate your choice in the appropriate space.

We cope with family problems by:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Official use
1. Sharing our difficulties with relatives						
2. Seeking advice from relatives						
3. Doing things with relatives (get togethers)						
4. Seeking encouragement and support from friends						
5. Seeking information and advice from people faced with the same or similar problems						
6. Sharing concerns with close friends						
7. Sharing problems with neighbours						
8. Asking relatives how they feel about the problems we face						

FPSC

When our family struggles with problems or conflicts which upset us, I would describe my family in the following way:	False	Mostly False	Mostly True	True
1. We yell and scream at each other	0	1	2	3
2. We are respectful of each others' feelings	0	1	2	3
3. We talk things through till we reach a resolution	0	1	2	3
4. We work hard to be sure family members are not hurt, emotionally or physically	0	1	2	3
5. We walk away from conflicts without much satisfaction	0	1	2	3
6. We share with each other how much we care for one another	0	1	2	3
7. We make matters more difficult by fighting and bring up old matters	0	1	2	3
8. We take time to hear what each other has to say or feel	0	1	2	3
9. We work to be calm and talk things through	0	1	2	3
10. We get upset, but we try to end our conflicts on a positive note	0	1	2	3

FHI

DIRECTIONS: Please read each statement below and decide to what degree each describes your family. Is the statement FALSE, MOSTLY FALSE, MOSTLY TRUE, TRUE, or NOT APPLICABLE about your family? Please indicate your choice in the appropriate space.

| IN OUR FAMILY …..	False	Mostly False	Mostly True	True	Not Applicable	Official use
1. Trouble results from mistakes we make						
2. It is not wise to plan ahead and hope because things do not turn out anyway						
3. Our work and efforts are not appreciated no matter how hard we try and work						
4. In the long run, the bad things that happen to us are balanced by the good things that happen						
5. We have a sense of being strong even when we face big problems						
6. Many times I feel I can trust that even in difficult times that things will work out						
7. While we don't always agree, we can count on each other to stand by us in times of need						
8. We do not feel we can survive if another problem hits us						
9. We believe that things will work out for the better if we work together as a family						
10. Life seems dull and meaningless						
11. We strive together and help each other no matter what						
12. When our family plans activities we try new and exciting things						
13. We listen to each others' problems, hurts and fears						
14. We tend to do the same things over and over …. it's boring						
15. We seem to encourage each other to try new things and experiences						
16. It is better to stay at home than go out and do things with others						
17. Being active and learning new things are encouraged						
18. We work together to solve problems						
19. Most of the unhappy things that happen are due to bad luck						
20. We realise our lives are controlled by accidents and luck						
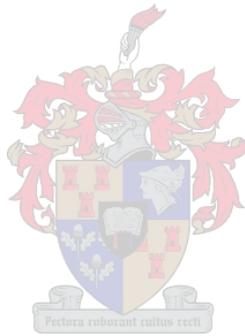
F-COPES

DIRECTIONS

First, read the list of "Response Choices" one at a time.

Second, decide how will each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then select the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then select the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3 or 4 to indicate how much you agree or disagree with the statement about your response.

1	2	3	4	5
Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

___   1. Sharing our difficulties with relatives

___   2. Seeking encouragement and support from friends

___   3. Knowing we have the power to solve major problems

___   4. Seeking information and advice from persons in other families who have faced the same or similar problems

___   5. Seeking advice from relatives (grandparents, etc.)

___   6. Seeking assistance from community agencies and programs designed to help families in our situation

___   7. Knowing that we have the strength within our own family to solve our problems

___   8. Receiving gifts and favors from neighbours (e.g. food, taking in mail, etc.)

___   9. Seeking information and advice from the family doctor

___   10. Asking neighbours for favors and assistance

___   11. Facing the problems "head-on" and trying to get a solution right away

___   12. Watching television

___   13. Showing that we are strong

___   14. Attending church services

___   15. Accepting stressful events as a fact of life

___   16. Sharing concerns with close friends

___   17. Knowing luck plays a big part in how well we are able to solve family problems

___   18. Exercising with friends to stay fit and reduce tension

___   19. Accepting that difficulties occur unexpectedly

___   20. Doing things with relatives (get-together, dinners, etc.)

___   21. Seeking professional counseling and help for family difficulties

___   22. Believing we can handle our own problems

___   23. Participating in church activities

___   24. Defining the family problem in a more possitive way so that we do not become too discouraged

___   25. Asking relatives how they feel about problems we face

___   26. Feeling that no matter what we do to prepare, we will have difficulty handling problems

___   27. Seeking advice from a minister

___   28. Believing if we wait long enough, the problem will go away

___   29. Sharing problems with neighbours

___   30. Having faith in God
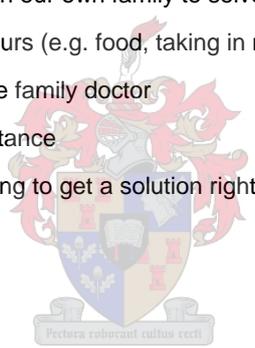
FAMILY FUNCTIONING
FACI8

Instructions

Decide how well each statement describes what is happening in your family. In the column headed **Now**, circle the number which best describes how often each thing is happening right now. In the column headed **Like**, circle the number which best describes how often you would like each thing to happen in your family.

In my family…										
	Now					*Like*				
	Never	Sometimes	Half the time	More than half	Always	Never	Sometimes	Half the time	More than half	Always
1. In our family it is easy for everyone to express his/her opinion.	1	2	3	4	5	1	2	3	4	5
2. It is easier to discuss problems with people outside the family than with other family members.	1	2	3	4	5	1	2	3	4	5
3. Each family member has input in major family decisions.	1	2	3	4	5	1	2	3	4	5
4. Family members discuss problems and feel good about the solutions.	1	2	3	4	5	1	2	3	4	5
5. In our family everyone goes his/her own way.	1	2	3	4	5	1	2	3	4	5
6. Family members consult other family members on their decisions.	1	2	3	4	5	1	2	3	4	5
7. We have difficulty thinking of things to do as a family.	1	2	3	4	5	1	2	3	4	5
8. Discipline is fair in our family.	1	2	3	4	5	1	2	3	4	5
9. Family members feel closer to people outside the family than to other family members.	1	2	3	4	5	1	2	3	4	5
10. Our family tries new ways of dealing with problems.	1	2	3	4	5	1	2	3	4	5
11. In our family, everyone shares responsibilities.	1	2	3	4	5	1	2	3	4	5
12. It is difficult to get a rule changed in our family.	1	2	3	4	5	1	2	3	4	5
13. Family members avoid each other at home.	1	2	3	4	5	1	2	3	4	5
14. When problems arise, we compromise.	1	2	3	4	5	1	2	3	4	5
15. Family members are afraid to say what is on their minds.	1	2	3	4	5	1	2	3	4	5
16. Family members pair up rather than do things as a total family.	1	2	3	4	5	1	2	3	4	5

FTRI

Instructions

First, read the following statements and decide to what extent each of the routines listed below is false or true about your family: **False (0), Mostly False (1), Mostly True (2), True (3).** Please circle the number (0, 1, 2, 3) which best expresses your family experiences.

Second, determine the importance of each routine to keeping your family together and strong: **NI = Not Important, SI = Somewhat Important, VI = Very Important.** Please circle the letters (NI, SI, or VI) which best express how important the routines are to your family. If you do not have children, relatives, teenagers, etc., please circle NA = Not Applicable.

Routines	False	Mostly False	Mostly True	True	How Important to keeping the Family Together and United			
					Important to family			Not
					Not	Somewhat	Very	applicable
1. Parent(s) have some time each day for just talking with the children	0	1	2	3	NI	SI	VI	NA
2. Working parent has a regular play time with the children after coming from work	0	1	2	3	NI	SI	VI	NA
3. Working parent takes care of the children some time almost every day	0	1	2	3	NI	SI	VI	NA
4. Non-working parent and children do something together outside the home almost every day (e.g., shopping, walking, etc.)	0	1	2	3	NI	SI	VI	NA
5. Family has a quiet time each evening when everyone talks or plays quietly	0	1	2	3	NI	SI	VI	NA
6. Family goes some place special together each week	0	1	2	3	NI	SI	VI	NA
7. Family has a certain family time each week when they do things together at home	0	1	2	3	NI	SI	VI	NA
8. Parent(s) read or tell stories to the children almost every day	0	1	2	3	NI	SI	VI	NA
9. Each child has some time each day for playing alone	0	1	2	3	NI	SI	VI	NA
10. Children/teens play with friends daily	0	1	2	3	NI	SI	VI	NA
11. Parents have a certain hobby or sport they do together regularly	0	1	2	3	NI	SI	VI	NA
12. Parents have time with each other quiet often	0	1	2	3	NI	SI	VI	NA
13. Parents go out together one or more times a week	0	1	2	3	NI	SI	VI	NA
14. Parents often spend time with teenagers for private talks	0	1	2	3	NI	SI	VI	NA

Routines	False	Mostly False	Mostly True	True	How Important to keeping the Family Together and United			
					Important to family			Not
					Not	Somewhat	Very	applicable
15. Children have special things they do or ask for each night at bedtime (e.g. story, good-night kiss, hug, etc.)	0	1	2	3	NI	SI	VI	NA
16. Children go to bed at the same time almost every night	0	1	2	3	NI	SI	VI	NA
17. Family eats at about the same time each night	0	1	2	3	NI	SI	VI	NA
18. Whole family eats one meal together daily	0	1	2	3	NI	SI	VI	NA
19. At least one parent talks to his or her parents regularly	0	1	2	3	NI	SI	VI	NA
20. Family have regular visits with the relatives	0	1	2	3	NI	SI	VI	NA
21. Children/teens spend time with grandparent(s) quite often	0	1	2	3	NI	SI	VI	NA
22.We talk with/ write to relatives usually once a week	0	1	2	3	NI	SI	VI	NA
23. Family checks in or out with each other when someone leaves or comes home	0	1	2	3	NI	SI	VI	NA
24. Working parent(s) comes home from work at the same time each day	0	1	2	3	NI	SI	VI	NA
25. Family has certain things they almost always do to greet each other at the end of the day	0	1	2	3	NI	SI	VI	NA
26. We express caring and affection for each other daily	0	1	2	3	NI	SI	VI	NA
27. Parent(s) have certain things they almost always do each time the children get out of line	0	1	2	3	NI	SI	VI	NA
28. Parents discuss new rules for children/teenagers with them quite often	0	1	2	3	NI	SI	VI	NA
29. Children do regular household chores	0	1	2	3	NI	SI	VI	NA
30. Mothers do regular household chores	0	1	2	3	NI	SI	VI	NA
31. Fathers do regular household chores	0	1	2	3	NI	SI	VI	NA
32. Teenagers do regular household chores	0	1	2	3	NI	SI	VI	NA

SCORING OF QUESTIONNAIRES

Biographical questionnaire (this includes the open-ended question)
Please identify the respondents in your interview; report their responses as accurately as possible. In other words, take note of responses that are not obvious or clear, for example: "I said to myself that I could overcome a crisis".

Family Hardiness Index (FHI)
Responses are accorded the following values: False = 0; Mostly false = 1; Mostly true = 2; True = 3; Not applicable = 0
    [NB The values of items marked * must be reversed; in other words, a 0=3; 1=2; 2=1; 3=0]

Summarise the responses for the following subscales:

Commitment (to life):	4, 5, 6, 7, 8*, 9, 11, 18
Challenge (life is a ...):	12, 13, 14*, 15, 16*, 17
Control (to have):	1*, 2*, 3*, 10*, 19*, 20*
Total:	Ad the amounts of the three sub-scale scores

Social Support Index (SSI)
Responses are accorded the following values: Strongly disagree =0; Disagree =1; Neutral =2; Agree =3; Strongly agree =4
    [NB The values of the items marked * must be reversed: 0=4; 1=3; 2=2; 3=1; 4=0]

Only summarise the responses for a total score (items 7*, 9*, 10*, 13*, 14*, 17* must be reversed)

Relative and Friend Support (RFS)
Responses have the following values: Strongly disagree =1; Disagree =2; Neutral =3; Agree =4; Agree strongly =5

Only summarise the responses for total score

F-COPES

Responses are weighted as indicated on the questionnaire. Take note that **item 18** is taken into account in neither the subscales nor the total score. Summarise scores for subscales and totals.

Have social support:	1, 2, 5, 8, 10, 16, 20, 25, 29
Reformulate:	3, 7, 11, 13, 15, 19, 22, 24
Seek spiritual support:	14, 23, 27, 30
Utilisation of family support:	4, 6, 9, 21
Passive evaluation:	12*, 17*, 26*, 28*

                    [the scores of the last subscale must be reversed: 1=5; 2=4; 3=3; 4=2; 5=1]

FAC18

 Attachment: Items 2, 5, 7, 9, 12, 13, 15, 16 score in the reverse direction, that is 1=5, 2=4, 3=3, 4=2 and 5=1
 Changeability: Items 1, 3, 4, 6, 8, 10, 11, 14. Normally add up
Sub-scale scores are obtained by adding up of indicated choices
Add the sub-totals for Attachment and Changeability and devide by 2 to obtain a FACI8 score:
Changeability_____ + Attachment _____ = _____ / 2 = _____ FACI8 score.

Family Times and Routines Index (FTRI)

There are two scores:

1. The extent to which each of the routines is true for the family: Sum the numerical values of the items selected
(i.e. 0 = False, 1 = Mostly False, 2 = Mostly True, 3 = True) to get a total Family Routines score

2. The degree to which the respondent values or views the routines as important: Sum the numerical values of the items selected (i.e. 0 = Not Important, 1 = Somewhat Important, 2 = Very Important, 0 = Not Applicable).

Sub-scale scores are a summation of the relevant items (as it is true for the family):

1 Child routines -	Items 9, 10, 15, 16	2 Couple's togetherness -	Items 11, 12, 13, 25
3 Meals together –	Items 17, 18	4 Parent-child togetherness -	Items 1, 2, 3, 8, 14
5 Family togetherness -	Items 5, 6, 7, 26	6 Relative's connection -	Items 19, 20, 21, 22
7 Family chores -	Items 29, 32	8 Family management -	Items 23, 27, 28, 30, 31

Family Problem Solving Communication (FPSC)

The FPSC may be scored in three ways:

1: To calculate Affirming Communication only: Sum items 2, 4, 6, 8, 10

2: To calculate Incendiary Communication only: Sum items 1, 3, 5, 7, 9. Reverse items 3 and 9 before summing (i.e 0 = True, 1 = Mostly True, 2 = Mostly False, 3 = False)

3: To calculate total score: Sum all items, but first reverse items 1,5 and 7 (**not** 3 and 9)
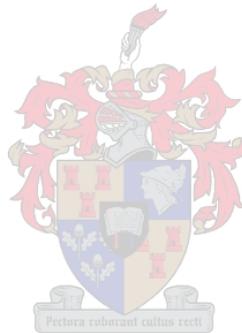
TABLE OF CODES FOR DATA SETS

M.S = Marital status 1 = Unmarried 2 = Married 3 = Separated 4 = Divorced 5 = Other
L.P.R = Length of parental relationship
A.P1 = Age parent 1
G.P1 = Gender parent 1 1 = Male 2 = Female
A.P2 = Age parent 2
G.P2 = Gender parent 2 1 = Male 2 = Female
G.C = Gender autistic child 1 = Male 2 = Female
A.C = Age autistic child
N.S = Number of siblings
Diag = Years since diagnosis
OC.PB = Occupation classification primary breadwinner 0 = No response 1 = Not economically active or productive 2 = Unskilled production and manual workers 3 = Semi-skilled production and manual workers 4 = Routine clerical and administrative workers, service and sales workers 5 = Artisans and skilled workers with trade qualifications 6 = Lower grade administrative, technical and clerical 7 = Independent commercial 8 = Professional, administrative and managerial workers 9 = Top professional, executive, administrative and technical occupations
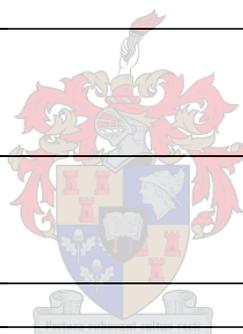
Edu.PB = Education primary breadwinner
0 = No response
1 = None at all
2 = Primary School
3 = Junior Certificate
4 = Apprenticeship
5 = Matric
6 = Post-Matric training (not university)
7 = University attendance
SES = Socioeconomic status
1 = Lower
2 = Middle
3 = Upper
HL = Home language
1 = English
2 = Afrikaans
3 = Other