

Raising a child with Autism: Exploring family support structures

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DECLARATION

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ABSTRACT

Autism or Autism Spectrum Disorder (ASD) is a condition that, at present, affects approximately one out of every 100 children globally and indications are that the prevalence thereof is steadily on the rise. ASD is a complex neurological condition that impairs social interaction, communication and behaviour. Research on the wide-ranging effects of ASD and its unique characteristics in each child with ASD is widely available. Several studies refer to the fact that ASD has an impact on the family unit, but very few researchers have investigated the support that families from different cultural groups in South Africa are enjoying whilst raising a child with autism. The current situation being what it is means that professionals and families have very little data on the subject and inadequate support is available to address the specific needs of families who are raising a child with autism.

The aim of this study was to investigate the support structures of three families from three different cultural groups in South Africa who were raising a child with autism. The central issue that was researched was the support structures available to parents raising a child with autism, and how parents access that support.

This is a qualitative study within an interpretive research paradigm. In this case study, the methods of data collection comprised semi-structured interviews, observations and reflective journals. This design embraced qualitative research methods that could expose the uniqueness of each family's experience and allowed participants the freedom to express this. The three families, who were purposefully selected for this study, were from different cultural backgrounds. One of the children in each family met the criteria published in the Diagnostic and statistical manual of mental disorders, fourth edition, text revision (American Psychiatric Association,

2000) for Autism or Pervasive Developmental Disorder not Otherwise Specified (PDD-NOS). The study found that the parents in the three families received support from their spouses and the neuro-typical siblings. The families also enjoyed physical support, financial support and emotional support from different sources. Parents reported feeling supported when others show acceptance and understanding of their children's deficits and when such others are prepared to 'go the extra mile'. The three families also perceived information and guidance as a valuable source of support. Even though they had firm support structures in place, they also reported on the lack of support available to them. All three families enjoyed these forms of support, but it was interesting to find out that the families received the support from different sources.

OPSOMMING

Outisme of outisme spektrum versteuring (OSV) is 'n toestand wat tans ongeveer een uit elke 100 kinders wêreldwyd affekteer en daar is aanduidings dat die voorkoms daarvan steeds toeneem. OSV is 'n komplekse neurologiese toestand wat swak sosiale interaksie, kommunikasie en gedrag tot gevolg het. Navorsingsresultate oor die breë gevolge van OSV en die unieke eienskappe daarvan in elke kind met OSV is algemeen beskikbaar. Verskeie studies verwys na die feit dat OSV 'n impak het op die gesinseenheid, maar tot dusver het baie min navorsers die ondersteuning ondersoek wat gesinne uit verskillende kulturele groepe in Suid-Afrika tydens die opvoeding van 'n kind met outisme geniet. Die huidige situasie voorsien professionele mense en gesinne van baie min data oor die onderwerp en onvoldoende ondersteuning is beskikbaar om die spesifieke behoeftes van gesinne met 'n kind met outisme aan te spreek.

Die doel van hierdie studie was om ondersoek in te stel na die ondersteuning wat gesinne in verskillende kultuurgroepe in Suid-Afrika tydens die opvoeding van 'n kind met outisme geniet. Die sentrale ondersoekvraag het betrekking gehad op ondersteuningstrukture vir gesinne met 'n kind met outisme binne hul kultuurgroep, sowel as die wyse waarop die gesinne toegang tot die ondersteuning verkry.

Die studie was kwalitatief van aard binne 'n interpretatiewe navorsingsparadigma en 'n gevallestudie is as navorsingsontwerp gekies. Data is deur middel van semi-gestruktureerde onderhoude, waarnemings en reflektiewe joernale ingesamel. Die kwalitatiewe navorsingsmetodes omvat die uniekheid van elke gesin se ervaring en laat deelnemers die vryheid om uitdrukking daaraan te gee. Drie gesinne is doelbewus vir hierdie studie gekies. Die gesinne moes oor die volgende kenmerke

beskik: Hulle moes uit verskillende kulturele agtergronde (Afrikaan, Wit en Indiër) kom. Hul kind moes voldoen aan die kriteria in die Diagnostiese en Statistiese Handleiding van geestesversteurings, vierde uitgawe, teks hersiening (2000) vir Outisme of pervasiewe ontwikkelingsstoornis nie anders gespesifiseer nie (PDD-NOS). Verskeie etiese beginsels is vir hierdie studie nagekom om te verseker dat die navorsing eties was.

Die studie het bevind dat die ouers in die drie gesinne ondersteuning van hul gades en die neurotipes broers en susters van die kind met outisme ontvang het. Die gesinne het ook fisiese ondersteuning, finansiële steun en emosionele ondersteuning vanuit verskillende bronne geniet. Die gesinne het aangedui dat hul ondersteun voel wanneer hul kinders se afwykings aanvaar word, begrip daarvoor getoon word en andere bereid was om die 'ekstra myl te loop'. Die drie gesinne het ook inligting en leiding as waardevolle bronne van ondersteuning ervaar. Selfs al het die families sterk ondersteuningstrukture in plek gehad, het hulle ook die gebrek aan ondersteuning uitgelig. Al drie gesinne geniet die bogenoemde vorme van ondersteuning, maar dit was interessant om uit te vind dat die families hierdie ondersteuning vanuit verskillende bronne ontvang het.

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List of Acronyms

ASD	Autistic Spectrum Disorder
DSM-IV-TR	Diagnostic and Statistical manual of Mental Disorders, fourth edition, Text Revision
OSV	Outisme Spektrum Versteuring
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
SASSA	South African Social Security Agency
SNAP	Special Needs Adaptive Programme

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CHAPTER 1. INTRODUCTION

1.1. BACKGROUND TO THE STUDY

Caring for a child with autism can be extremely challenging for parents. Research has shown that autism is a severe stressor for parents and has a serious effect on the functioning and well-being of families (Gray, 2006). It has also shown that families that receive support exhibit healthier adaptation to having a child with autism. The strong support needed to raise a child with autism is found in many cultures, but differs regarding the level of support that is present.

Social support is a critical factor that reduces the negative psychological effects of raising a child with Autism Spectrum Disorder (ASD) as well as other disabilities (Bishop, Richler, Cain & Lord, 2007). When professionals in the field of autism ascertain how families from various cultures perceive their need for and access to social support, more effective treatment and education of learners with autism may occur (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). This is particularly relevant for a country as culturally rich as South Africa.

ASD is a pervasive developmental disorder that is generally recognised and diagnosed between the ages of 18 months and three years (Troy, Connolly & Novak, 2007). According to the Diagnostic and Statistical Manual of Mental Disorders (2000) children with autism have low social functioning, impaired communication and repetitive behaviours and interest. They may insist on sameness and show resistance to insignificant changes.

For decades autism was thought to be a rare disorder affecting about four children per 10 000 (Tanguay, 2000). The prevalence of autism increased dramatically over the last number of years. According to Autism South Africa, one out of 100 children in South Africa has an ASD. Autism is becoming a bigger reality for more and more families and the effect it has on family functioning is something that ought to be researched.

Much research on autism focuses on the challenges that parents face whilst raising such children (Bristol, 1984; Gray, 2006; Newsome & Hovanitz, 2006; Sivberg, 2002). This is because autism is considered by many as the most severe childhood disorder with the most complex developmental patterns (Newsome & Hovanitz, 2006). Caring for a child with autism can be challenging, extremely demanding and a severe stressor on family life (Gray, 2006). Such stressors could be caused by the ambiguity of the diagnoses and the severity and the duration of the disorder (Bristol, 1984). Due to the complicated nature of the condition, some parents may consider their abilities to be inadequate in dealing with the behaviour commonly exhibited by children with ASD, such as repetitive behaviour, withdrawal behaviour, self-harm and disruptive behaviour (Mash & Wolfe, 2005). The behaviour is but one challenge that makes social engagement for families with a child with autism difficult, therefore, such families probably have a greater need for support from their social networks, their extended family members and friends to modulate their coping (Tway *et al.*, 2007). Social support also includes the availability of leisure time where they can engage in recreational activities, as well as support from community programmes, professional help and the availability of services and programmes geared towards families with a disabled child. International research has shown that families that

receive such support exhibit healthier adaptation to having a child with autism (Siklos & Kerns, 2006).

According to international research the support that families who raise a child with developmental disabilities receive and have access to differ across cultures and societies. In America, for example, many individuals within the African American culture perceive care-giving for a dependent member as a responsibility to be shared among siblings and extended family members. However, very limited research is available on culture and autism in an African context, as most research regarding autism emanates from Western cultural perspectives (Wilder *et al.*, 2004).

In the five years of working as a tutor and programme manager for autistic children on a home-based intervention programme, I have observed that families from different cultural backgrounds adapt differently to the challenges of raising a child with autism. Though the programme provided the same level of support to all the different families my experience has been that families from some cultural backgrounds received significantly more support from their families and communities than families from other cultures. The purpose of this study was to gain a deeper understanding on the support that families from three different cultural groups in South Africa were receiving whilst raising a child with autism, as well as to understand how they access the support.

Observations whilst working with families from different cultural settings and the knowledge gap that I have experienced in the literature on parent support motivated me to undertake a qualitative study on the types of support that families from various cultural backgrounds receive whilst raising a child with autism.

The study was guided by the following research questions:

- What are the support structures available to parents raising a child with autism?
- How do they access the support?

1.2. SCOPE OF THE RESEARCH

The study was delimited to three families from three different cultural groups in South Africa. The focus of the study was on the support that these families were receiving whilst raising a child with autism, and on understanding how they accessed the support.

1.3. RESEARCH POPULATION

The research populations for this study comprised families raising autistic children. The participants in the study were families whose children receive support from one intervention centre. The sample was selected from a list of parents whose children were attending an intervention centre/school for autistic children. The three families needed to have the following characteristics:

- at least one of their children had to meet the criteria in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) for Autism or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- they had to be from a middle socio-economic social group
- the family unit had to consist of two parents, the child with autism and at least one sibling. I am including neuro-typical siblings into my research sample to explore the role that they are playing in family's support structures.

1.4. RESEARCH METHODOLOGY

My research comprised a qualitative study and was situated in an interpretivist paradigm with its emphasis on experience and interpretation. An interpretivist paradigm is appropriate for researching parents' experiences as it focuses on the "lived experience" where "multiple realities are socially constructed by individuals" (Merriam, 1998, p.4). The aim of this study was to understand the frame of reference of families regarding the support that they receive when raising a child with autism, as well as to find out how these families access the support.

I chose case study research as the research design. A qualitative case study can be defined as an "intensive, holistic description and analysis of a single entity, phenomenon, or social unit" (Merriam, 1998) or "bound system" (Henning, Van Rensburg & Smit, 2004, p. 40). According to Merriam (2002) the case study is a valuable tool for understanding human behaviour in depth. This study consisted of three cases. The bounded systems were three families from three different cultural backgrounds. Because a case study focuses on a single bounded system, the issue of generalisability looms larger here than in other types of qualitative research (Merriam, 2002). However, readers can learn a lot from an encounter with the case through the researcher's narrative description (Merriam, 2002). Henning *et al.* (2004, p. 42) that "case studies require multiple methods" of data collecting in order to truly capture the depth of the case. In this study data were captured through semi-structured interviews, observations and reflective journals. The goal of the semi-structured interview was to provide a detailed qualitative analysis of the support that these three families were receiving whilst raising a child with autism.

The goal of the observations was to help me to move beyond the selective perceptions of the participants and to allow me the opportunity to see things that may routinely escape conscious awareness among the participants (Patton, 1990). Families were also asked to keep a reflective journal.

The qualitative data were analysed according to Thematic Content Analysis. This was completed by means of a step-by-step process outlined by Creswell (1998). Firstly, I transcribed the recordings of the interviews, from which patterns of experiences were noted. Secondly, I included themes from the data. During this process, the data were coded according to relationships between the themes. The next step involved elaboration, which is the process of focusing on the finer distinctions of the themes.

The final step was the interpretation, which meant interpreting the data according to the thematic categories derived from the analysis, including reflexive comments on how subjective experiences may have influenced data collection and analysis. Data collection and analysis were commenced in parallel. The results of data analysis are presented in table form, highlighting the themes and categories that emerged during data analysis.

1.5. ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the University of Stellenbosch before embarking on this research study (Appendix A). Organisational clearance was obtained from the director of SNAP for me to use the organisation's name in the thesis (Appendix B).

Furthermore, participants of research should not suffer harm. As such, certain rules are followed. Participants need to give informed consent to participate (Allan, 2008).

This means that they must be fully informed about the research study and process and assured of protection (Allan, 2008). I had to ensure that participants understood what was being explained to them. The context for this study was not confined to my culture. As such, I had to be culturally sensitive and be well informed about the different cultures involved in the study in order to behave in a respectful way when accessing these settings. I also had to be informed and sensitive about cultural issues that could arise during the fieldwork.

After explaining the relevant details of the study, a written consent form was provided to participants to sign and permission was obtained to record interviews (Appendix C). Confidentiality was to be maintained by means of keeping all the interview recordings, field notes, reflective journals and the signed consent forms locked away at all times and to destroy them after the research was completed. The participants were informed that participation was voluntary and that they were welcome to withdraw at any stage of the research. Confidentiality and acknowledgement of privacy are of the utmost importance.

1.6. TERMINOLOGY

1.6.1. AUTISM

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder that is generally recognised and diagnosed before the age of three years (Twyo, Connolly, & Novak, 2007). Pervasive Developmental Disorders (PDD) include Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified. These Disorders are characterised by severe impairment in several areas of development, including reciprocal social interaction skills and communication skills, or the presence of

stereotyped behaviour, interests, and activities (American Psychiatric Association, 2000; Carr, 2006). Typical problems observed in individuals with autism, include limited eye contact and the absence of appropriate facial expressions and gestures (American Psychiatric Association, 2000). Autism is a spectrum disorder that range from mild to severe according to the variance in characteristics and degree of symptoms.

1.6.2. CULTURE

For the purposes of this study, I define culture as the way of life of a group of people and consisting of predictable patterns of values, beliefs, attitudes and behaviours that are learned and passed from generation to generation (Mandell & Novak, 2005). Garuba and Raditlhalo (2008) also define culture as the set of practices by which meanings are produced and exchanged within a group. According to Erasmus (2008), race is understood biologically in terms of genetic inheritance, descent and physical features, whereas culture is understood as behavioural characteristics as an expression of race. In this study, I will be referring specifically to cultural-racial groups such as African, White and Indian families.

1.7. SUMMARY

In this chapter I have provided background to the study. I presented the research problem and the design for the study. The rest of the thesis is organised as follows. Chapter 2 provides an overview of the literature on autism while Chapter 3 reports in more detail on the research design and methodology. In Chapter 4 the data are presented and discussed. The thesis concludes with Chapter 5, in which I share the findings and make recommendations for further research.

CHAPTER 2. LITERATURE REVIEW

2.1. INTRODUCTION

For decades Autism Spectrum Disorder (ASD) was thought to be a rare disorder affecting about four children per 10 000 (Tanguay, 2000). The prevalence of ASD increased dramatically over the last few decades. Autism South Africa reflects that one in 100 individuals meet the criteria for diagnosis one out of 100 children in South Africa has an ASD. This means that every hour a child is born that will develop ASD in South Africa alone. This equates to approximately 7 665 autistic children born in South Africa in 2010. According to the Centre of Disease Control (2010), incidences of ASD have increased dramatically over the past two decades.

Autism occurs in all racial, ethnic and socio-economic groups, and occurs on average four times more often in boys than in girls (Mash & Wolfe, 2005). Although autism is becoming a bigger reality for many families in South Africa and beyond, understanding of how it influences family functioning remains under researched.

Bronfenbrenner's (1986) theory has had a particularly wide and significant influence in shaping my understanding of how different levels of the system in the social context interact in the process of child development. Understanding a family's ecology, such as who makes up the family, what supports and resources they have, what they enjoy and what they struggle with is a critical piece of the designed intervention's meaningfulness and relevance (Jung, 2010).

According to Jung (2010), the focus has moved from supporting the child to supporting the family, and how support is provided is just as important as what supports are provided. In order for professionals to design an intervention plan, they

need an understanding of what it is that fits families' lives. Professionals providing early intervention need an understanding of the family, its informal and formal resources and its interacting social networks. Understanding the family's ecology is as important to designing intervention as understanding the child's development (Jung, 2010).

In this chapter I undertake a review of the literature that I considered relevant in shaping my understanding of the problem of how autism presents itself in children, as well the effects that autism has on a family's life. After reviewing the literature on the challenges that families experience whilst raising a child with autism, I focus on the different support structures that families install in their lives to help them cope with these challenges.

2.2. PERVASIVE DEVELOPMENTAL DISORDER

Autism is a Pervasive Developmental Disorder (PDD) (American Psychiatry Association, 2000). The understanding of the pervasive developmental disorder includes a group of conditions in which there is delay and deviance in the development of social skills, language and communication, as well as unusual behaviours and interests (Carr, 2006; Mash & Wolfe, 2005). These disorders cause persistent dysfunction in a child's life (Sadock & Sadock, 2003). Furthermore, children with pervasive developmental disorders often exhibit intense particular interest in a narrow range of activities. They are often resistant to changes in their lives and are not appropriately responsive to the social environment. These disorders affect multiple areas of development and are manifested early in life. Included under this classification are Autism, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not

Otherwise Specified (PDD-NOS) (Barlow & Durand, 2009). **Figure 2.1** illustrates the various conditions that are classified as PDD.

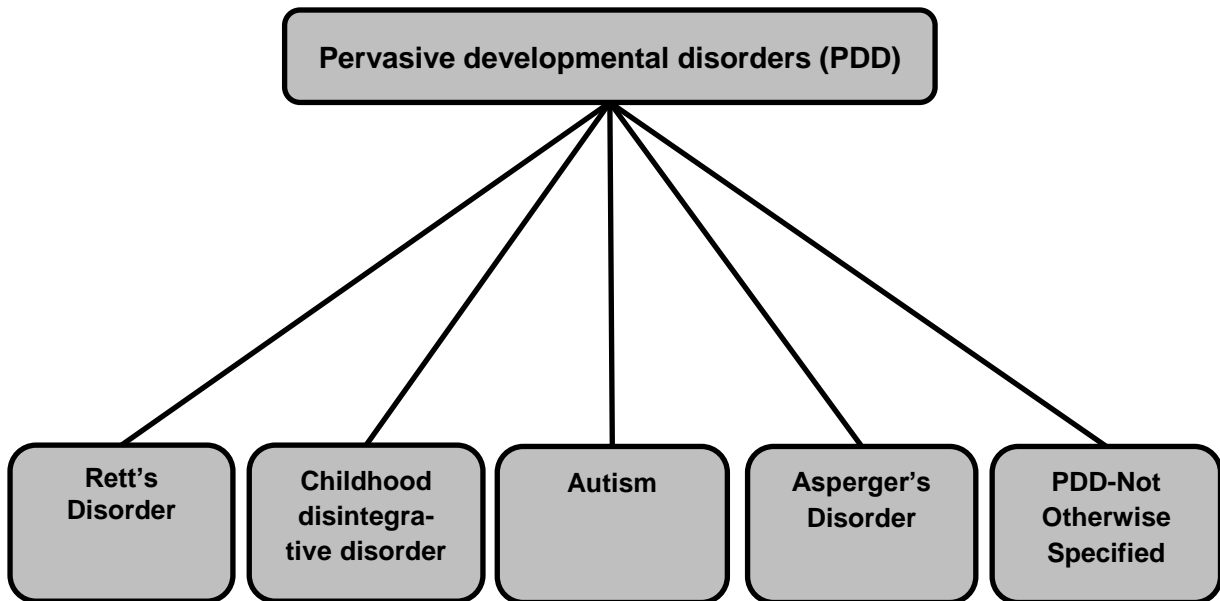


Figure 2.1: Classification of pervasive developmental disorders

Source: American Psychiatric Association (2000)

Before discussing autism, I first focus on the other pervasive developmental disorders. Rett's Disorder is a PDD that is characterised by normal development for at least five months, stereotyped hand movements, a loss of purposeful motions, diminishing social engagement, poor coordination, and decreasing language use accompanied by a deceleration in head growth (Carr, 2006). This disorder appears to occur exclusively in girls. In childhood disintegrative disorder, also known as Heller's syndrome, development progresses normally for the first two years, after which the child shows a loss of previously, acquired skills. The loss is usually in two or more skills, which would be language ability, social responsiveness, play, motor skills, and bladder or bowel control (Carr, 2006).

Those diagnosed with ASD also include pervasive developmental disorder not otherwise specified (PDD-NOS), which is sometimes referred to as high-functioning autism, and Asperger's syndrome, in which affected individual's typically do not display the early language deficits inherent in autistic disorder (Volkmar, Lord, Bailey, Schultz & Klin, 2004). In this study, I use the terms, autism and autism spectrum disorder (ASD) interchangeably when referring to the spectrum of autistic disorders that include autistic disorder, PDD-NOS and Asperger's syndrome.

2.3. AUTISM

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder that is generally recognised and diagnosed between the ages of 18 months and three years (Troy *et al.*, 2007). As articulated in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) typical problems observed in individuals who are autistic, include limited eye contact and the absence of appropriate facial expressions and gestures. Children with autism experience challenges in developing appropriate peer relationships and show a lack of emotional or social reciprocity.

Pervasive Developmental Disorder Not Otherwise Specified is the category that is used when there is a severe impairment in the development of reciprocal social interaction and communication, or stereotypic behaviours, interests and activities, but the full criteria is not met for a diagnosis of Autistic Disorder (American Psychiatric Association, 2000).

Children with autism typically maintain restricted or repetitive behaviours and interests. They show inflexible adherence to non-functional rituals and some children maintain stereotypical and repetitive movement (e.g. flapping of hands), also known

as 'stimming'¹. They are most comfortable with, and may insist on routine, whilst showing resistance to trivial changes (Mash & Wolfe, 2005; Carr, 2006).

According to Hillman (2006) no one behaviour serves as a definitive diagnostic indicator for children with autism as they present with a variety of symptoms across cognitive, emotional and behavioural domains, with language and non-verbal communication skills either absent or significantly delayed (Carr, 2006). Thus, autism is on a spectrum of disorders that affects each individual differently, and with varying degrees of severity.

Lorna Wing's (1995) triad of impairments is useful for explaining the difficulties children with autism experience (see Figure 2.2). The difficulties in areas of development manifest as an impairment of social interaction, language and imagination or flexible thinking (Koudstaal, 2005; Mash & Wolfe, 2005; Carr, 2006), all combined to place tremendous stress on the families of children with autism (Gray, 2006).

¹ Stimming refers to self-stimulating behaviour.

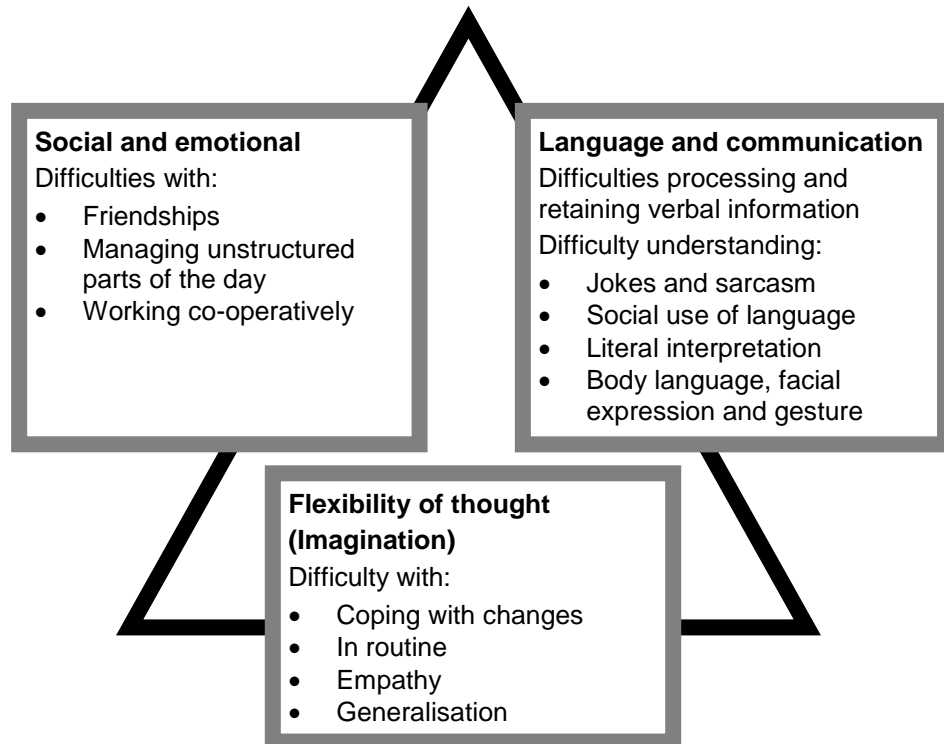


Figure 2.2: Lorna Wing's triad of impairments

Source: www.autism.org.uk

2.4. CHARACTERISTIC FEATURES OF AUTISM SPECTRUM DISORDER

The first characteristic of autism spectrum disorder is an impairment of reciprocal social interaction. Abnormalities in social behaviour that first appear in infancy include the absence of the use of social or emotional gestures. So, for example, pointing to objects to interact or to engage with another person or to share positive emotions such as pleasure and pride, are absent in such children. They also show little interest in peer relationships and show a lack of reciprocity in social relationships and empathy (Carr, 2006; Mash & Wolfe, 2005).

Children with autism fail to show the subtle signs of social relatedness to their parents and other persons and in some cases poor eye contact is a common characteristic (Mash & Wolfe, 2005; Sadock & Sadock, 2003). Autistic children furthermore experience difficulties relating to others or in initiating interaction in an

ordinary and socially acceptable way. According to De Boer (2009), the social behaviour of children with autism typically is the deficit that people notice first. It is the absence of this skill that causes parents the most concern about their child, though it is the most difficult skill for parents to teach (De Boer, 2009).

Wing (1995) identified three typical manifestations of inappropriate social interaction in children with autism, namely aloof and indifferent behaviour, passive behaviour or active but odd behaviour. Children who show aloof and indifferent behaviour appear to be unaware of others (Carr, 2006; Koudstaal, 2005; Mash & Wolfe, 2005). “The overall picture is that of being solitary and withdrawn” (Koudstaal, 2005, p.310). Many children may regard people as objects and are also inclined to engage with people in a mechanical manner, almost exclusively to meet their own needs. For example, they will take or pull a person’s hand, or pull or push any person to the preferred location or desired objects. However, some children are “self-sufficient and will not seek help or permission, and help themselves to whatever they want or desire” (Koudstaal, 2005, p.311).

Children with passive behaviour will accept social contact passively, show some pleasure, but will not initiate spontaneous approaches. Though they may attend to a wide range of activities, they will do so without showing any true interest in the activity and will move from the one activity to the next. These children find it difficult to occupy themselves meaningfully and, in extreme cases, will remain passive most of the time, especially during unstructured times, or will become engaged in repetitive stereotyped behaviour, e.g. spinning objects, rocking themselves, lining up, tapping or throwing objects (Koudstaal, 2005; Mash & Wolfe, 2005). Therefore the full attention of caregivers is required every minute of the day.

Some children display active but odd behaviour (Koudstaal, 2005). These children will “approach others but in an odd, one-sided, bizarre or repetitive way” (Koudstaal, 2005, p.311). Their conversations are usually one-sided, and inappropriate questions are asked repetitively by them, though they pay little or no attention to the reply of the other person (Koudstaal, 2005). Koudstaal explains the reason why children with autism interact differently on the social level is because they experience severe problems in understanding the mental states of others. Children with autism, for example, do not understand that, if they break another child’s toys, it will hurt that child’s feelings. This condition is referred to as mind-blindness.

A second characteristic in the autistic child is impairment of communication and language. Language development in children with autism is usually delayed and the language of children with autism is characterised by a variety of pragmatic abnormalities, including pronominal reversal, echolalia, neologisms and speech idiosyncrasies (American Psychiatric Association, 2000; Carr, 2006; Koudstaal, 2005). “At the severe end of the spectrum, the ability or desire to communicate may be absent” (Koudstaal, 2005, p.313). Children who develop speech often use language in an over-formal, precise and adult-like manner. Vocal intonations may be odd and monotonous and speech delivery may be slow, fast or jerky (Koudstaal, 2005). Such children’s understanding of language is usually of a very literal and concrete nature, which contributes to varying levels of confusion, misunderstanding and anxiety (Koudstaal, 2005; Mash & Wolfe, 2005).

A third characteristic that Wing (1995) identified is that autistic children show an impairment of flexible thinking behaviour. “Like social and communication development, imagination and thinking skills develop differently in that they manifest in an impaired way. Impoverished, restricted imagination and inflexible thinking skills

are demonstrated by their resistance to accepting changes in any context” (Koudstaal, 2005, p.313). Children with autism do not understand the reason when unexpected changes occur therefore; various degrees of repetitive stereotyped activities and behaviour are reflected, e.g. they become preoccupied with unusual objects, interests or rituals. Because children with autism resist change, it is also difficult to anticipate future events (Koudstaal, 2005). As a result, autistic children find it challenging to plan something or to organise themselves. “This leads to a rigid dependence on routines, because they prefer sameness, predictability and order, with no or very few deviations” (Koudstaal, 2005, p.313).

According to Carr (2006) and Koudstaal (2005) play behaviour of children with autism is also affected on many different levels. “Their lack of imaginative play may indicate difficulty in understanding the symbolic value of toys” (Koudstaal, 2005, p.315). As imaginative and pretend play seldom develops spontaneously, it therefore becomes necessary for care givers to guide and teach them to play.

Most autistic children prefer to play on their own and to be occupied with one or more stereotyped and restricted pattern of interest. Some show a preoccupation with unusual objects such as string, sticks, bottle tops, and elastic bands, or, when they lay objects down, arrange such objects in exact lines, or according to shapes, colours or sizes (Koudstaal, 2005, p.314).

The difficulties in areas of development in such children do not only manifest as an impairment of reciprocal social interaction, impairment of language and reciprocal communication and an impairment of imagination and social understanding or flexible thinking, but children with autism also have other commonly associated

features that add to the stress that families experience whilst raising a child with autism.

2.5. COMMONLY-ASSOCIATED FEATURES

Children with autism process sensory, motor and perceptual experiences differently to neuro-typical children. “The way in which they register, modulate and integrate environmental stimuli by means of seeing, hearing, and smelling, tasting, moving around or touching may be affected” (Koustaal, 2005, p.315). Because their senses appear to be so sensitive, it hard for them to be in places with loud noise, strong smells, etc., such as in a supermarket. This could then result in unexpected, negative behaviour (Koustaal, 2005) by the autistic child. Some autistic children will try to regulate or escape the sensory input by covering their ears with their hands, walking on their toes, flapping their hands or jumping up and down (Koustaal, 2005).

Behavioural problems exhibited by children with autism are among the most challenging and stressful issues faced by parents. The problem behaviour that many children with autism display are significant barriers to effective social interaction as well as to educational placement and development (De Boer, 2009), but the undesirable and challenging behaviour of children with autism must be judged as a secondary consequence, rather than as a feature of autism. Difficult behaviour such as socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming and running away are often associated with autism (De Boer, 2009). Challenging behaviour in most cases is a direct result of a lack of understanding. Children with autism in general are resistant to transition and change, because

“sameness provides security”, order and predictability (Koudstaal, 2005, p.316; Mash & Wolfe, 2005).

The research shows that young children with autism have a higher than expected incidence of upper respiratory infections and gastrointestinal symptoms, which cause a lot of discomfort in their bodies. This could also lead to excessive burping, constipation and loose bowel movements (Sadock & Sadock, 2003). The discomfort experienced and the lack of communication skills can also be a reason for showing disruptive behaviour. Furthermore, some children with autism have very fussy eating habits which restrict their diets; while others will compulsively eat anything, even materials like paper, and play dough (Sadock & Sadock, 2003).

2.6. AUTISM AND SECONDARY IMPAIRMENTS

Autism seldom occurs on its own and the complexity of autism increases when secondary impairments are identified (Koudstaal, 2005). According to research on autism, it is possible that it may occur with any other “diagnosable physical, sensory or psychological impairment” (Koudstaal, 2005, p.316). This makes it difficult to separate children diagnosed with severe intellectual impairment from children with severe forms of autism.

Children with intellectual impairments usually show general delays in most areas of development, whereas a typical autistic profile would reflect relatively better developed motor skills as opposed to poorly developed language and social abilities (Koudstaal, 2005, 316).

Many children with autism also suffer from epilepsy and exhibit high levels of anxiety (Carr, 2006; Koudstaal, 2005).

Conditions such as obsessive-compulsive disorder, attention deficit hyperactivity disorder, schizoid personality disorder and non-verbal learning disability, as well as Tourette syndrome, are sometimes confused with autistic spectrum disorders. In spite of the many similarities between the above-mentioned conditions and autism, the underlying difficulties are different (Koudstaal, 2005, p.317).

2.7. CHALLENGES THAT PARENTS FACE WHILST RAISING A CHILD WITH AUTISM

Many research studies on autism focus on the challenges that parents face whilst raising such children (Bristol, 1984; Gray, 2006; Newsome & Hovanitz, 2006; Sivberg, 2002). This is because autism is considered by many as the most severe childhood disorder with the most complex developmental patterns (Newsome & Hovanitz, 2006). Caring for a child with autism can be challenging, extremely demanding and a severe stressor on family life (Gray, 2006). Such stressors could be the result of the ambiguity of the diagnoses, the severity and the duration of the disorder and the child's lack of adherence to social norms (Bristol, 1984).

Studies on parents wellbeing shows that parents who have a child with autism report higher levels of parental stress and psychological distress than parents of children without autism (Sivberg, 2002) and parents of children with other neuro-developmental disabilities (Pottie & Ingram, 2008). Several factors have been proposed to account for the higher levels of stress of parents with a child with autism, including the uncertainty surrounding autism diagnosis, the long-term prognosis of individuals with autism, the stressful nature of autistic symptoms and associated behaviour problems, and the lack of public understanding of and

tolerance for the behaviour of children with autism (Hartley, Barker, Seltzer, Greenberg, & Bolt, 2010). The findings of such studies show that most parents experience intense confusion during the period before they receive an official diagnosis. Although the quest to help their child may alleviate some negative feelings, the stress increases when parents realise that there is no cure for autism (Altiere & Von Kluge, 2009). Hartley *et al.* (2010) have also found that parents of children with ASD experienced a prolonged period of vulnerability to divorce which, in part, is attributed to the constant high level of parenting demands and stress and subsequent lack of attention to one's spouse when raising a child with autism. The significantly higher prevalence of divorce among parents of children with autism (23,53%) than among parents of children without a disability (13,81%) (Hartley *et al.*, 2010) is evidence of the high levels of stress that these families are experiencing.

2.8. SUPPORT TO THE FAMILY STRUCTURE

The literature on support makes a distinction between formal and informal support (Jung, 2010). Formal support is usually provided by people and groups of people that are formally organised for the purpose of responding to particular family needs (Dunst, 2000). Examples of formal support include health care providers, medical specialists, therapists and early intervention programmes (Jung, 2010). Informal support refers to the people who normally form part of the family's lives (Jung, 2010). Examples of those who provide informal support include extended family, neighbours, friends, churches and recreational clubs (Jung, 2010).

Research shows that families find support most helpful when it is part of the informal social support network (Jung, 2010). Social support has been identified as a critical factor that reduces the negative psychological effects of raising a child with autism

(Jung, 2010). Families usually receive much of their needed support through their informal social networks – their families and friends (Jung, 2010). Families who are lacking a sense of emotional support can feel isolated, experience higher levels of stress (Jung, 2010), hopelessness (Cattell, 2001) or depression (Ray & Street, 2005). An important part of emotional support for some families is parent-to-parent support. Being able to identify and use sources of emotional support is fundamental to a family's feeling of confidence, sense of control, and self-worth (Cattell, 2001; Ray & Street, 2005).

Informal support has been found to be especially important for mothers raising a child with autism (Altiere & Von Kluge, 2008). Lindblad, Holritz-Rasmussen and Sandman (2007) have found that support received from social networks was experienced as being more efficient in reducing stress than formal support. According to them, valuable informal support is experienced when the mother is able to share concerns about her autistic child with other mothers in the same situation. Mothers receive more practical and emotional support from these social networks than from the professional networks (Lindblad, *et al.*, 2007).

Altiere and Von Kluge (2008) also found informal support to be effective in reducing stress among mothers of children with ASD. Mothers of children with ASD who perceived receiving higher levels of support, from spouses and relatives, report lower levels of depression-related somatic symptoms and fewer marital problems (Altiere & Von Kluge, 2008; Ekas, *et al.*, 2010). Ekas, *et al.* (2010) have found that mothers first turn to their spouses for support, then to their immediate family and finally to other parents of children with disabilities. However, it is possible that a spouse may be equally distressed and unable to provide effective support and that extended family or close friends may be more beneficial in promoting a mother's well-being (Ekas, *et*

al., 2010). Although there is empirical support for the importance of informal support for mothers of a child with autism, there is little research on the importance of informal support for fathers (Altiere & Von Kluge, 2008).

Lee and Gardner (2010) researched the importance of grandparents as informal supporters. In several studies (Lee & Gardner, 2010; Lindblad *et al.*, 2007) grandparents were found to be the primary source of support to parents. However, conflicts between parents and grandparents concerning the child's care could be a source of stress for parents. According to Lindblad *et al.* (2007), parents have reported that grandparents' acceptance of the child's disability and their treatment of the child as equal to the other siblings was of great supportive value to parents. Grandparents' emotional support appears to have a strong impact on the parents' emotional and physical wellbeing (Lee & Gardner, 2010).

The support that families who raise a child with developmental disabilities receive and have access to might be different in the various cultural groups and for different societies (Wilder *et al.*, 2004). In the USA, for example, African Americans often turn to family, friends and religious groups before seeking professional help and typically access services less frequently than other cultural groups in America (Wilder *et al.*, 2004). Wilder *et al.* (2004) found that, in African American culture, care-giving for a dependent member is perceived as a responsibility to be shared among siblings and extended family members. An Indian study reported that some families choose to have another child after their child with autism was born, for the explicit purpose of having someone to care for the child with autism after the parents' death (Daley, 2002). Very limited research is available on culture and autism in an African context, with most research regarding autism emanating from Western cultural perspectives (Dyches *et al.*, 2004).

Gray's (2002) qualitative findings demonstrate that social support is an integral part of the coping milieu in families with a child with autism. However, positive and negative coping mechanisms mirror each other. The family, for example, may gain support through interaction with family members and friends. On the other hand, they may withdraw from, or lack the time for, important social support activities (Altiere & Von Kluge, 2008). Thus, families with a child with autism may gradually lose their friends because of their limited availability for socialising (Altiere & Von Kluge, 2008; Schall, 2000).

Although many studies have been conducted on the support needed by families who are raising a child with autism (Altiere & Von Kluge, 2008; Gray, 2006; Tway, *et al.*, 2007), few have focussed on the unique support types within the various cultures. It is such information that could contribute to the knowledge base concerning the support that families with autistic children are receiving.

2.9. SUPPORT AND FAMILY STYLES

A well-functioning family has a good balance of adaptability and cohesion (Seligman & Darling, 1997). Acquiring new resources, for example social support; learning new coping behaviours; and changing the way a situation is interpreted, may restore the balance in the family system. "Although families establish functioning styles early, it is likely that these rules change significantly upon discovery that their child has autism" (Altiere & Von Kluge, 2008, p.84).

A family raising a child with autism must make significant adjustments to cope and function at an adequate level. "As surely as the functioning of the family affects the child, the development of the child affects the functioning of the family" (Altiere & Von Kluge, 2008, p.84).

Altieri and Von Kluge (2008, p.84) refer to Minuchin (1974) who defines the extremes on the continuum of cohesion in families as enmeshment and disengagement. According to Minuchin (1974), highly enmeshed families are overly involved with and protective of their children's lives, which can have a detrimental effect on the child because there may not be adequate promotion of growth and independence. On the opposite end of the cohesion continuum are disengaged families which have rigid boundaries around their family roles. Minuchin (1974) suggests that these families are under-involved because involvement causes anxiety. The child with a disability in this type of family would be free to develop independence, when able, but may not receive the attention and protection that would be available in a more engaged family.

Given this, Bristol (1984) theorised that families with a child with autism are close-knit; able to express emotions; supportive of one another; and involved in outside recreational activities. This combination of characteristics is found in a family that functions between extreme enmeshment and disengagement and such a family may better adapt to the stress of caring for a child with autism.

Adaptability measures the family's ability to change in response to a stressful situation (Olson, Russel & Sprenkle, 1980 sited in Altieri & Von Kluge, 2008, p.84). On one extreme of the adaptability continuum is the rigid family. They resist change even in response to large stressors. This type of family typically believes that the father or husband is the head of the household and does not assist with the household responsibilities or childcare. This places a larger burden than normal on the mother and may result in her having little time for herself or for other members of the family. On the other end of the continuum are chaotic families, those that are characterised by unstable or unpredictable

change. In chaotic families, the rules may be constantly changing. There may be no consistent leader and frequent role changes. One cannot dismiss the value of the ability to change with the occurrence of sudden stressors, but this family style lacks the consistency needed when caring for a child with autism.

2.10. SUMMARY

The relevant literature on Pervasive Developmental Disorders (PPD) and the characteristic features of Autism Spectrum Disorders (ASD) have been reviewed in this chapter. The reviewed literature addresses the challenges that parents face whilst raising a child with autism and the support to family structure. In the next chapter, the research design and methodology for the study are presented and discussed.

CHAPTER 3. RESEARCH DESIGN AND METHODOLOGY

3.1. INTRODUCTION

In this chapter, the research design and methodology for the current study are presented and discussed. The chapter commences with an introduction to the research paradigm that was selected for the study. The researcher then proceeds to describe the research process and the specific data collection methods that were considered suited to generating relevant data to respond to the research questions. The data processing techniques, methods of establishing data interpretation, as well as ethical issues are explained. The chapter concludes with a summary of what was discussed in the chapter.

3.2. INTRODUCING THE RESEARCH

This qualitative research study is situated in an interpretivist paradigm. Qualitative research methods allow for certain phenomena to be explored in greater depth. They enable the researcher to examine a selected phenomenon from the perspectives of those involved (Patton, 2002). According to Merriam (2009), qualitative research is distinguished from quantitative research by its search for meaning and understanding. In qualitative research, the researcher is the primary instrument of data collection (Merriam, 2009). Silverman (2010) argues that qualitative studies place emphasis on the subjective world of people and the understanding of human experience. In this study, the support that families from three different cultural groups in South Africa are enjoying whilst raising a child with autism was investigated. In order to investigate the support structures of parents who are raising a child with autism, an interpretive qualitative research process was undertaken.

Silverman (2010) explains that the aim of the interpretive paradigm is to understand the nature of the participants' setting, what their lives are like, what is happening to them and what their understanding of the research problem is. An interpretivist paradigm was appropriate for researching parent's experiences in raising a child with autism as I planned to focus on their lived experiences as parents of a child with autism. My understanding of reality is that "multiple realities" are socially constructed by individuals (Merriam, 2009). Gaining insight into participants' unique experiences and meanings attributed to such experiences is the defining characteristic of the basic interpretive paradigm (Merriam, 2009).

3.3. RESEARCH DESIGN

According to Merriam (1998), a research design resembles a focused guide for carrying out an inquiry. The research design or map is a logical plan for getting from an initial set of questions towards answers or conclusions to these questions (Merriam, 1998). However, in qualitative inquiry, the term design poses a paradox. On the one hand, it involves planning for certain broad contingencies to emerge, without an indication of exactly what will be done (Merriam, 1998; Patton, 2002). The challenge was to figure out an appropriate design and the most useful research methods for this specific situation (Merriam, 1998; Patton, 2002), which was to gain access to parents' worlds to study and make meaning of the type of support that they experience in their daily lives with raising their child with special needs.

I decided on a case study for the research design. In Merriam (2009) the author defines a qualitative case study as an intensive, "holistic description and analysis of a single entity, phenomenon, or social unit" or "bounded system" (Henning, *et al*,

2004, p.40). The definition stipulates that case studies are intensive and comprise detail, richness, completeness and variance (Flyvbjerg, 2011).

Merriam (2002) argues that the case study is a valuable tool for understanding human behaviour in depth. By concentrating on a single phenomenon or entity, the researcher aims to uncover the interaction of significant characteristics of the phenomenon. In the three cases investigated in this study, the significant factors would be those that interact or support the families, for example other members of the extended family, friends and professional services.

The case study focuses on “holistic description” and explanation (Merriam, 1998, p.27). The case study can be further defined by its special features. Qualitative case studies are characterised as being “particularistic, descriptive and heuristic” (Merriam, 1998, p29).

Particularistic means that case studies focus on a particular situation or phenomenon. The case is important for what it reveals about the phenomenon and for what it might represent. This specificity of focus makes it an especially good design for practical problems – for questions, situations or puzzling occurrences arising from everyday practice (Merriam, 1998, p29).

“Case studies concentrate attention on the way particular groups of people confront specific problems, taking a holistic view of the situation” (Shaw, 1978 cited in Merriam, 1998). But, situations and context differ for people. The support that families who raise a child with developmental disabilities receive and have access to are not the same. It is influenced by factors such as culture, race, societal issues and class. Therefore the case study research design was expected to facilitate gaining a deeper understanding of the support that each specific family was enjoying.

Qualitative case studies can be further defined by arranging them into categories or types based on disciplinary orientation or function, that is, whether meant to describe, interpret, or evaluate some phenomenon or to build theory. For the purpose of this study, I chose a collective case study. In a collective case study, one issue or concern is selected, but the inquirer selects multiple case studies to illustrate the issue (Creswell, 2007; Silverman, 2010). This study consists of three case studies representing three families, each of which is raising a child with autism. Though all three families are from the same socio-economic class, they were purposively selected from different cultural groups.

The strength of using a case study as the research design is that it offers insights and illuminates meanings that expand the readers' experience and readers can learn vicariously from an encounter with the case through the researcher's narrative description (Merriam, 2002).

3.4. PARTICIPANTS

The participating families were selected from a list of names of families whose children are attending an intervention centre for autistic children. To access the list, written permission for access was sought from the directors of SNAP (Appendix B).

Families of various races who were of the same socio-economic standing make use of this centre's services. Three racially different families who still live in racially homogenous communities were approached to participate in the study (Contexts of participants is provided in section 4.2.). In a South African context, these families would be racially defined as families who, pre-1994, were classified as African-, White-, and Indian families.

3.5. DATA COLLECTION

Case studies require “multiple methods of data collecting” in order to truly capture the case in some depth (Henning, *et al*, 2004, p.42). This study incorporated methodological triangulation using three qualitative methods of data collection, namely semi-structured interviews, observations and reflective journals. Triangulation technique is used by qualitative researchers to ensure that the data is rich and comprehensive (Creswell, 2007; Parker, 2005).

3.5.1. QUALITATIVE INTERVIEWING

The primary method of data collection is interviewing. Qualitative interviewing is also known in qualitative literature as personal interviewing or semi-structured interviewing. Semi-structured interviewing is devoted to asking open-ended questions that offer participants the opportunity to respond in their own words and to express their unique personal perspective (Patton, 2002). Kvale (2010, p.8) has defined semi-structured interviewing as “an interview with the purpose of obtaining descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena”. An interview is a way of constructing knowledge through interaction with the participants. By means of the semi-structured conversation the researcher is allowed the opportunity to question and gain insight into the experiences of the interviewee without being overly directive, which may restrict the participant’s responses (Parker, 2005). The research interview might be an enriching experience for participants because the interviewer shows an interest in them; is sensitive to their feelings; and attempts to understand their experiences (Kvale, 2010).

An interview guide was used during the semi-structured interviews. An interview guide provides topics or subject areas within which the interviewer explores, probes and asks questions that will elucidate and illuminate that particular subject. Thus, the interviewer remains free to build a conversation within a particular subject area, to word questions spontaneously, and to establish a conversational style, but with the focus on a particular subject that has been predetermined (Patton, 2002). One advantage of semi-structured interviews is that they are as “task-orientated as structured interviews and as adaptable as unstructured interviews” (DiCicco-Bloom and Crabtree, 2006). The interview guide that was designed is attached as Appendix D.

According to Merriam (1998), the goal of qualitative interviewing is to capture how those being interviewed view their world and to capture the complexities of their individual perceptions. The interview was constructed in such a way that the questions tapped into the informal support families receive from their partners, extended family members and friends (Appendix D).

The interviews were conducted in the comfort of the participants’ own house. Both parents from each family were interviewed. The interviews were approximately 60 minutes long. With consent from the participants, all interviews were audio-taped and transcribed (Appendix C). Notes made by the interviewer during the interviews were used to ensure that the interviewer’s understanding of what the interviewees were conveying was accurate.

3.5.2. OBSERVATIONS

The second method used for data collecting is observation. “Through direct observations, the inquirer is better able to understand and capture the context within

which people interact” (Patton, 2002, p.262). According to Patton (2002, p.262), “understanding context is essential to a holistic perspective”. Patton (2002) argues that first-hand experience with a setting and the people in the setting allows an inquirer to be open, discovery orientated and inductive because, by being on-site, the observer has less need to rely on prior conceptualisations of the setting.

For this study, the three families’ everyday activities, such as the bath time of the child, dinner and the children’s bedtime routines were observed. Having worked in the families’ homes for the last couple of years, my presence in the home was perceived as a normal occurrence. This allowed me the opportunity to pay close attention to the interaction between family members and to the role that their support was playing within the family. The goal of the observations was to “facilitate moving beyond the selective perceptions of the parents about the support that family provide and to allow the opportunity to see things that may routinely escape conscious awareness among the participants” (Patton, 2002).

3.5.3. REFLECTIVE JOURNAL

The third method that was used was reflective journals. Both parents of each family were asked to keep a reflective journal. The aim of the reflective journals was to allow the parents the opportunity to reflect on their support structures and to add any additional information that was not explored during the interviews. The template for the reflective journal (see Appendix E) was e-mailed to the participants beforehand. The participants completed the reflective journals electronically and e-mailed it back to the researcher.

After the data had been collected, the process of data analysis took place (Boeije, 2010). In qualitative research the process of data collection and analysis is a

dynamic process and changes may therefore occur during the process (Taylor & Bogdan, 1998).

3.6. DATA ANALYSIS

Gibbs (2007) argues that data analysis implies that data is somehow transformed from a substantial amount of qualitative data to refined interpretations thereof. The qualitative data were analysed according to the Thematic Content Analysis process (Creswell, 2007). Thematic content analysis entails a descriptive representation of data. If the analysis is carried out satisfactorily, it will portray the thematic content of transcripts, and other texts. The researcher groups and extracts common themes from the texts in order to give expression to the harmony of voices across participants (Creswell, 2007). As the aim of the study was to understand the frame of reference of families from different cultural groups regarding the support that they were receiving while raising a child with autism, thematic content analysis was useful in picking up unities across participants. This was achieved through a step-by-step process outlined by Creswell (2007).

Firstly, as illustrated in **Figure 3.1**, the recordings of the interviews were transcribed, and patterns of experiences were noted from the transcripts. To form a general understanding, all the data were accounted for by repeatedly reading and reflecting on the transcripts, reflective journals and field notes while keeping the research problem in mind.

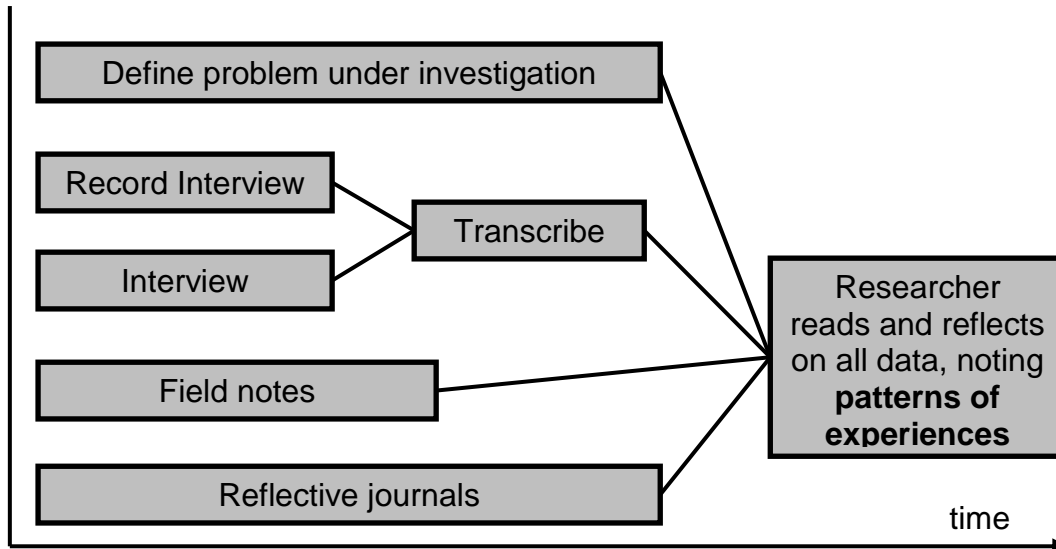


Figure 3.1: Data analysis: phase 1

Secondly, as illustrated in **Figure 3.2**, the researcher included themes from the data. The data were coded according to relationships between one and more of the themes. The next step involved elaboration, which is the process of focusing on the finer distinctions of the themes. The themes were linked with information from the literature study in order to gain a deeper understanding of the participants' experience of the level of support that they were receiving whilst raising a child with autism.

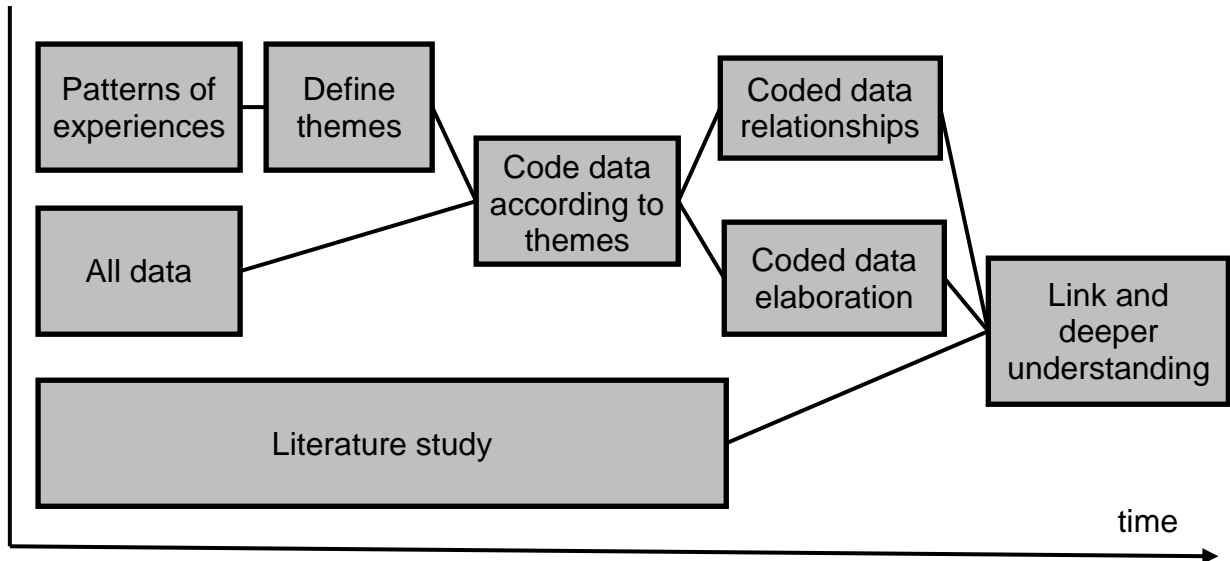


Figure 3.2: Data analysis: phase 2

The final step was interpretation, which involved interpreting the data according to the thematic categories derived from analysis, including reflexive comments on how subjective experiences may have influenced data collection and analysis, as illustrated in **Figure 3.3**. Data collection and analysis commenced in parallel. Transcriptions and analysis were done solely by the researcher.

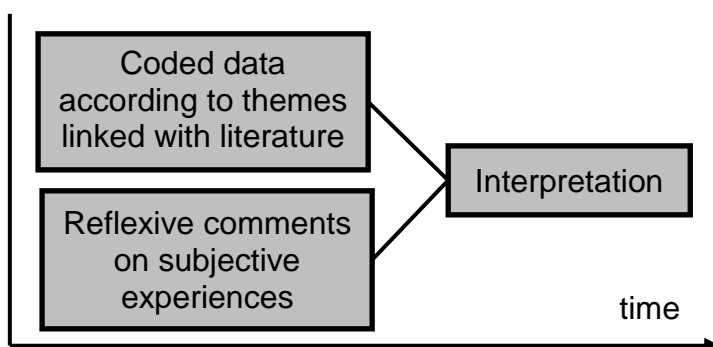


Figure 3.3: Data analysis: phase 3

3.7. TRUSTWORTHINESS AND CREDIBILITY OF DATA

A research process informed by the importance of validity and reliability in qualitative research was followed. This was to enhance the trustworthiness of and the accurate reflection of the participants' thoughts and perceptions, thereby lending credibility to the research findings. Qualitative methods need to ensure trustworthiness of the findings and that the findings occur as the researcher says they did (Creswell, 2007). I ensured that the participants were not forced in any way and that they had every opportunity to express their true feelings.

The interviews were audio taped and transcribed ensuring accuracy of the data collected. To ensure that the results of the data analysis accurately reflected the essence of interviews, the participants had an opportunity to comment on the extent to which the themes extracted accurately reflected the theme of the interviews and their reflective journals. According to Creswell (2007) this is referred to as respondent validation and is a method used to improve the thoroughness of qualitative research methods.

Furthermore, this study incorporated "methodological triangulation" using three qualitative methods of data collection which increased the trustworthiness and credibility of the data collected (Creswell, 2007; Parker, 2005). Triangulation facilitates validation of the data through verification across more than two sources. It refers to the application of several research methodologies in the study of the same phenomenon (Creswell, 2007).

3.8. REFLEXIVITY

According to Bloor & Wood (2006), reflexivity refers to an awareness of the self in the research situation and the role the researcher plays in constructing that situation. The researcher's own views, beliefs and biases are often raised during the research process, and thus care was taken when interpreting and collecting the data. An important requirement for the qualitative researcher is to have a critical awareness of the self. I was therefore aware of how I might project my own subjective views onto the research, particularly because of working in the family's homes before. I was also aware of how I was experienced by participants and consistently ensured that the meaning of the information shared was not changed.

Because I had been working in the field of autism for at least six years, I, as the researcher, was approaching the families as an insider, which could have impacted on the depth of disclosures made by participants. Because the participants view me as an insider, it is possible that I, made the participants feel more comfortable about disclosing information, which enabling me to gather comprehensive and rich data.

3.9. ETHICAL CONSIDERATIONS

Ethics form a vital part of qualitative research as it involves "collecting data from people, about people" (Creswell, 2009, p. 87). Ethical considerations should therefore be an essential part of the planning and implementation of the research process (Mertens, 1998). This provides a framework that guides research into being non-harmful to participants and respect of their status as human beings (O'Leary, 2010). As I was allowed into the world of the participants, I had to protect them,

develop trust with them, promote integrity and guard against misconduct (Creswell, 2009).

Sound ethical conduct is of vital importance when research is conducted on sensitive topics and across cultural boundaries. The population for the study was not confined to my cultural group only. As such, I had to be culturally sensitive and was well informed about the different cultures in order to behave in a respectful way when accessing these settings. I adhered to the ethical obligation to ensure personal competence and adequacy in undertaking this study. I made counselling sessions available with a counselling psychologist who is experienced in working with families with autistic children to counsel participants who might require counselling after having engaged in this research.

Ethical clearance was obtained from the University of Stellenbosch before embarking on this research study (Appendix A). Organisational clearance was obtained from the director of SNAP for me to use the organisation's name in the thesis (Appendix B). Participants were presented with a consent form including a participant information sheet summarising what their participation would entail (Appendix C). The respondents had to give informed consent to participate. This means that the participants were fully informed about the research study and process and the protection of participants were ensured. I made sure that the families understood what was being explained to them. After explaining the relevant details of the study a written consent form was provided to participants to sign. This also covered permission to record the interviews (Appendix C).

All the participants were reminded that their participation was voluntary and that anonymity and confidentiality would be maintained. They were informed of their right

to withdraw from the study at any stage and it was explained that confidentiality would be maintained by means of keeping all records of their participation (the interview recording, field notes, reflective journals and the signed consent form) locked away at all times and that it would be destroyed after the research was completed. Documents and recordings will be destroyed at the end of the research process. As confidentiality and acknowledgement of privacy are of the utmost importance, participants were also assured that they would be anonymous.

3.10. SUMMARY

In this chapter the research process utilised to conduct this study has been described. This commenced with a description of qualitative research. I described the research design and I justified the choice of data collection methods. The data analysis techniques that allow for the categorisation of data collected during this study were explained. To conclude this chapter and ethical considerations were discussed. The following chapter is focused on expanding on themes derived from data categories, to be followed by a detailed discussion of the findings of the research.

CHAPTER 4. PRESENTING THE DATA

4.1. INTRODUCTION

While researchers have collected extensive data quantifying the numerical measurable experiences of the support structures of families with children with autism, families have not had ample opportunity to tell their story. A gap identified in research, especially as it pertains to South African research, is created by the lack of research on the meaning these families attribute to the lives they live. Raising a child with autism is difficult and unique regarding all aspects of child rearing: Parents have to put unique support structures in place. In this study I have therefore investigated the support structures from which three South African families draw help to cope with the challenges of raising a child with autism.

This study made use of methodological triangulation using three qualitative methods of data collection, namely semi-structured interviews, observations and reflective journals, to ensure that the account was rich, and comprehensive (Creswell, 2007; Parker, 2005). A descriptive representation of data was produced by means of Thematic Content Analysis (Creswell, 2007). The step-by-step process outlined by Creswell (2007) was followed. First, all the data were accounted for. The recordings of the interviews were transcribed, as were the other field notes. By repeatedly reading and reflecting on the transcripts, reflective journals and field notes while keeping the problem under investigation in mind, common themes could be extracted from the texts.

During the process of data reduction the data was coded and the coding process allowed themes to emerge and patterns of experiences to be noted. The next step involved elaboration, which is the process of focusing on the finer nuances of the themes. The themes were then linked to the literature to gain deeper understanding of the issue under investigation. The final stage was interpretation, which involved interpreting the data according to the thematic categories obtained from the analysis and reflexive comments on how subjective experiences may have influenced data collection and analysis.

4.2. INTRODUCING THE PARTICIPANTS

Three middle-class families were purposively selected for this study. The three families were identified as information-rich families whose children were involved in the Special Needs Adapted Programme for autistic children (SNAP) at an intervention centre. These three families were of different racial groups and still lived in racially homogenous communities. Though this is not a cross-cultural study, their selection is justified by my understanding that separate development in South Africa might have led to different support structures for different race and ethnic groups. I do not hold these individual families up as representative of their respective ethnic and racial groups. Each of these purposively selected families had to meet the criteria as stipulated on page four of Chapter 1.

4.2.1. FAMILY BOTHA

Family Botha is a white family who speak both English and Afrikaans. Their eleven-year-old son, Ethan was diagnosed with autism at the age of thirteen months. He was born with his foot folded up against his shin and a tumour in his neck and has been receiving therapy since birth. He is currently attending the SNAP special needs

school where he is following a mainstream curriculum in the mornings and receives one-on-one tutoring in the afternoons. He has a younger sister who is eight years old. Family Botha lives in one of the northern suburbs of the Cape Town where the Afrikaans influence is still very strong. The father is Afrikaans-speaking while the mother is English-speaking. By mutual agreement the parents have chosen English as the family language. This decision was taken because language development is one of the areas of impairment in autistic children. Both parents are working. The father is a managing director at a publishing house while the mother is an English lecturer at a tertiary institution.

4.2.2. FAMILY NAIDOO

Family Naidoo is an Indian Muslim family. Their seven-year-old daughter Danna was diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS). She stopped taking her feeds at six weeks and started showing pervasive developmental delays with typical spectrum traits. She has been receiving physio- and occupational therapy since she was only a few months old. She received intensive one-on-one tutoring from SNAP and is now attending a remedial school in the southern suburbs of Cape Town. She has a younger brother who is five years old. The family lives in the southern suburbs of Cape Town in an area that has strong cultural influences. The father works as a mechanical engineering manager. Though the mother used to manage her father's business, she has now decided to dedicate more of her time to her children.

4.2.3. FAMILY DARAMOLA

Family Daramola is a Shona-African family. Their four-year-old son, Dubbie, was diagnosed with autism at the age of 28 months. He is currently following a mainstream curriculum in the mornings and receives one-on-one tutoring in the

afternoons at SNAP Education. They live in the southern suburbs of Cape Town. The family immigrated to South Africa a few years ago, though the children's grandparents still live in Zimbabwe. The family is following modern Shona traditions, though they identify with the Christian value system. Both parents are electrical engineers. The father works at a software company and the mother works as a program manager. The table below sets out the demographic information collected about the three families. All the names used in the thesis are pseudonyms that were assigned to the participants.

Table 4.1: Demographic Information of three families

Attributes	Family Botha	Family Naidoo	Family Daramola
Racial- religious cultural group identified with	White , Christian, Afrikaner/English	Indian, Muslim, English	Shona-African, English/Shona
Child with autism	<ul style="list-style-type: none"> ○ Ethan ○ 11-year-old boy ○ Diagnosed with Autism and had co-morbid physical deficits at birth 	<ul style="list-style-type: none"> ○ Dubbie ○ 7-year-old girl ○ Diagnosed with Pervasive Developmental disorder not otherwise specified (PDD NOS) 	<ul style="list-style-type: none"> ● Danna ● 4-year-old boy ● Diagnosed with Autism
Neuro-typical sibling	<ul style="list-style-type: none"> ● 7-year-old sister 	<ul style="list-style-type: none"> ● 5-year-old brother 	<ul style="list-style-type: none"> ● 11-year-old brother

4.3. PRESENTATION OF THEMES

The themes that emerged after the coding of the data are presented in this section. The conceptual framework of support is illustrated in **Figure 4.1**. The themes were refined into categories and are presented as the eight categories in **Table 4.2**. These themes mentioned above are outlined in this table, along with quotations from interview transcripts to illustrate points and to support the findings.

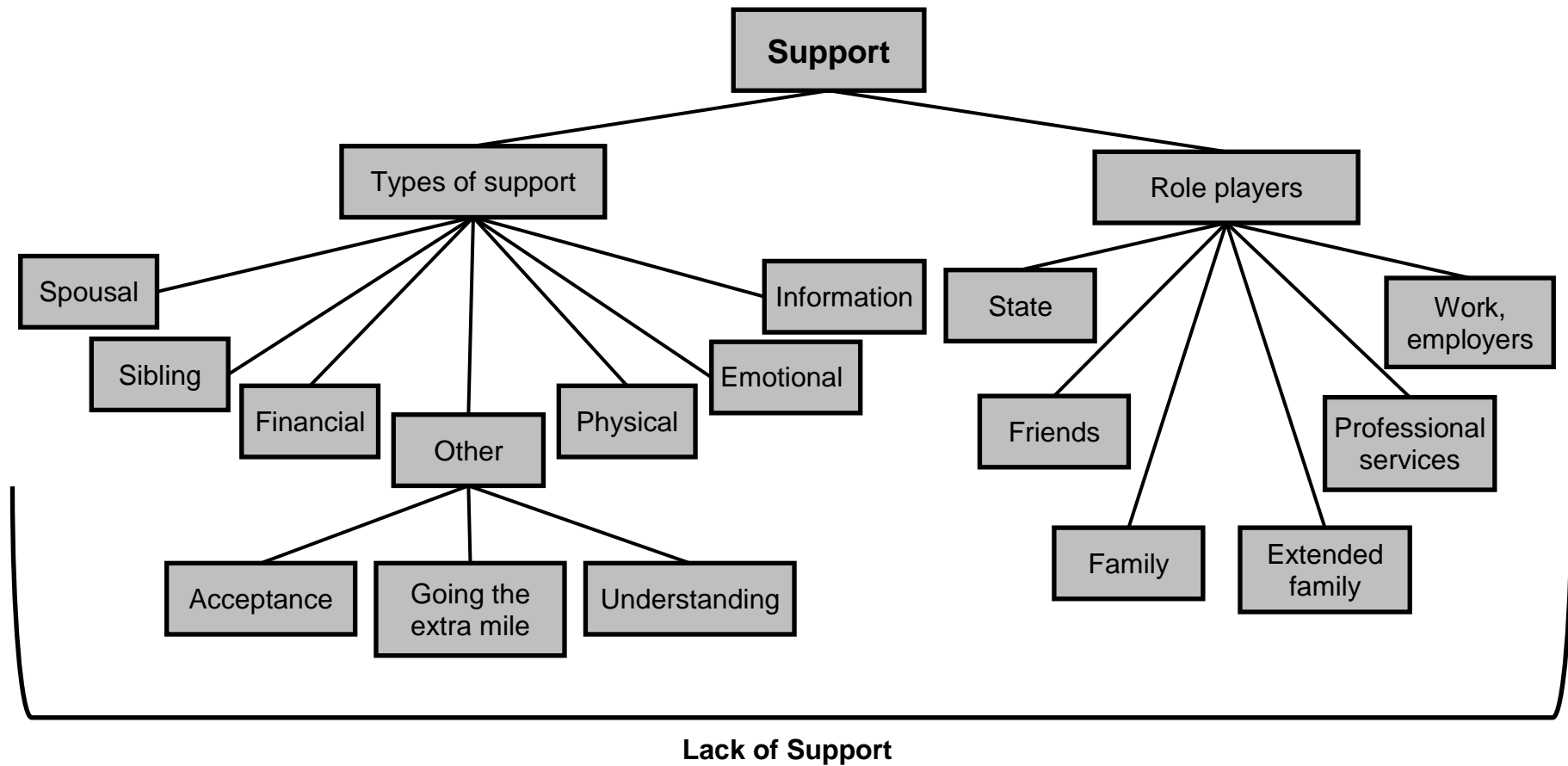


Figure 4.1: Conceptual framework of support

Table 4.2: Conceptual framework

Categories: Support	From whom?	Themes	Examples
Spousal Support		<ul style="list-style-type: none"> • Sharing children and home responsibilities • Allowing each other free time • Together in this 	<ul style="list-style-type: none"> • <i>“When one of us is busy with the kids the other one will work and do whatever needs to be done in the house.”</i> • <i>“I believe that it is because we give each other personal time, that we are able to cope.”</i> • <i>“to be able to deal with it together.”</i>
Sibling Support		<ul style="list-style-type: none"> • Playing with autistic sibling • Leading the way • Sharing responsibilities 	<ul style="list-style-type: none"> • <i>“He really helped Danna a lot with the social aspect, they played well together.”</i> • <i>“Danna will not attempt to climb or step into the place but the moment he came in the picture she used to follow him everywhere and that is good for her.”</i> • <i>“She is like a second mother to him. She was telling him to sit and when he ran away she would say come back here.”</i>
Physical Support	<ul style="list-style-type: none"> • Professional services • Extended family (grandparents and siblings) • Work 	<ul style="list-style-type: none"> • Helping with transport (Doing more than what is expected) • Food sharing arrangement • Looking after children • Flexible work conditions 	<ul style="list-style-type: none"> • <i>“On days when I was not able to take Danna to school, her teacher would offer to take her.”</i> • <i>“Because they are pensioners and have more time, so most of the days they cook.”</i> • <i>“Sometimes you just wish that someone can take your kids for two hours.”</i> • <i>“...he allowed the adjustments to accommodate my needs.”</i>
Financial Support	<ul style="list-style-type: none"> • Professional services • Friends and work colleagues • Extended family (grandparents and siblings) 	<ul style="list-style-type: none"> • Providing pro-bono services • Contributing to therapy fees • Contributing to therapy fees • Smaller family responsibilities 	<ul style="list-style-type: none"> • <i>“...our occupational therapist treated Ethan for free for almost a year as a gift to us.”</i> • <i>“...a work colleague covering a third of Ethan’s SNAP cost per month”</i> • <i>“sold shares and gave up part of his pension”</i> • <i>“...contributions to the upkeep of our parents is less, due to our additional cost with Dubbie.”</i>
Emotional Support	<ul style="list-style-type: none"> • Professional services • Friends and extended family 	<ul style="list-style-type: none"> • Check-up phone calls • Enquiring about progress 	<ul style="list-style-type: none"> • <i>“Our neurologist has been very available to e-mail her or phone”</i> • <i>“...our GP even phoned once or twice to hear how it is going.”</i> • <i>“We’ve had emotional support from our siblings in the sense that they would ask how things are going.”</i> • <i>“They are checking in on his progress and how he is doing.”</i> • <i>“... text messaging a friend saying, he is having a terrible day or just</i>

		<ul style="list-style-type: none"> • Understand when having a bad day • Available to listen 	<p><i>chat to somebody who has an idea. That really helps.</i></p> <ul style="list-style-type: none"> • <i>“The grandparents are in Zimbabwe but they are very available, you can call them and blow off steam, and they are always there to consult.”</i>
Other Support – Acceptance, Understanding and going the extra mile	<ul style="list-style-type: none"> • Professional services • Friends, work colleagues and extended family 	<ul style="list-style-type: none"> • Going the extra mile • Accepting and understanding the child’s deficits • Engaging with the child • Accepting and understanding the child’s deficits 	<ul style="list-style-type: none"> • <i>“They aren’t just tutors, they love him and they are becoming part of the family.”</i> • <i>“SNAP is just so different. They support us just by appreciating his condition.”</i> • <i>“she spends ages reading him the same stories over and over again and relates to him.”</i> • <i>“When our son goes on and on about the same thing they will really patiently answer his questions.”</i>
Information as Support and Guidance	<ul style="list-style-type: none"> • Professional services • Friends and work colleagues 	<ul style="list-style-type: none"> • Providing useful information • Providing a plan of action and reassurance • Sharing practical advice 	<ul style="list-style-type: none"> • <i>“She supported me emotionally because she was giving me information and skills to help my child.”</i> • <i>“Just to hear the fact that you put a plan together, that is important.”</i> • <i>“I think some technical support that I got was from my colleague and his wife. They also got a child that is special needs and he works with me. So we would exchange notes and compare it.”</i>
Lack of Support	<ul style="list-style-type: none"> • Professional services • Friends and work colleagues • Extended family (grandparents and siblings) • State 	<ul style="list-style-type: none"> • Not experience in dealing with autism • Not understanding the condition • Not understanding the condition • Not understanding the condition 	<ul style="list-style-type: none"> • <i>“Our experience with a school for disabled children was really bad. They didn’t get what autism was about.”</i> • <i>“I got a long with our paediatrician, but she was clueless with Danna.”</i> • <i>“You know even I got very good friends that I work with and if they invite us to a braai at their house. They know Danna is special needs but they don’t know what to do with her.”</i> • <i>“They will never spend time with him. It’s like they don’t know how to relate to him.”</i> • <i>“But all our other siblings, I mean I don’t think they really understand what it means to be autistic.”</i> • <i>“Even our family, they don’t even talk to her. They don’t know how to interact.”</i> • <i>“The lack of state support is shocking. You would think that the state would look after you in some way.”</i> • <i>“You know there are no schools for autistic children – or very few.”</i>

4.4. SPOUSAL SUPPORT

The first theme is that of spousal support. The Botha, Naidoo and Daramola families reported that autism brought out the best in them and that it has bonded them closer together than they had been before. The parents describe their respective partners as each other's primary support structure and they do not think they could have coped without having such a strong marriage.

The data revealed many different ways in which the spouses in the three families supported one another. One of the themes that emerged was their shared responsibility for children and home. The data showed that the spouses in all three families took on active roles in raising their children. The mothers reported that their spouses were very supportive. According to Mrs Botha, "When one of us are [sic] busy with the kids the other one will work and do whatever needs to be done in the house." All three mothers furthermore reported that their husbands shared child rearing responsibilities with them. The mothers' data on how the fathers shared in the household responsibilities are displayed in **Table 4.3**.

Table 4.3: Quotes verifying spousal support

Family	Quotes verifying spousal support
Botha	<ul style="list-style-type: none"> • "He is not the kind of dad who leaves the child duties to me and does his own thing." • "He helps to get our autistic son ready for school in the morning and he plays play-station with him every night." • "He helps around the home a lot. He folds the laundry and washes the dishes many evenings." • "When we are all together at a family gathering at Christmas times, my husband and me will take turns looking after him."
Naidoo	<ul style="list-style-type: none"> • "When Danna didn't want to feed. He would come home and take her from me because I couldn't anymore because I had her all day."
Daramola	<ul style="list-style-type: none"> • "He will get here and make sure he is bathed and in the morning I don't get Dubbie dressed." • "He does all of that and takes Dubbie to school." • "Changing his diapers."

According to Mrs Daramola, the role that her husband plays deviates from what is expected of Shona husbands. According to her, her husband has supported her by stepping out of the traditional Shona father role. In the Shona culture it is the mother's sole responsibility to raise and look after the children.

In our culture men don't get involved in the child care as much as my husband gets involved with the children, most importantly with Dubbie. He is really just hands on and that is not typical. I mean a Shona man would not normally be found to do that.

Another way in which these spouses supported one another, was through allowing each other free time. According to Gray (2006), caring for a child with Autism can be challenging, extremely demanding and a severe stressor on family life. The three families reported that, in order to deal with the challenges of raising a child with autism, they needed to support each other by allowing each parent to have some free time for himself or herself. According to the Botha's:

It is important for us to give each other a few hours a week to do something that is important to us. I believe that it is because we give each other personal time, that we are able to cope.

The three families have developed interesting strategies for allowing each other free time. Family Botha, for example, would alternate the days on which one spouse could sleep late. In family Botha's case, Ethan does not sleep well and the only time to make up for that is over the weekend. On a Saturday and Sunday morning Mr Botha looks after the children to allow his wife to get extra sleep and on a Saturday and Sunday afternoon Mr Botha will get free time to sleep. Every Monday evening Mr Botha also looks after the children when his wife has to join the university choir to "do something that's just for her". Mr Botha has a close relationship with his father and it is very important for him "to have time to spend with him".

This also happens in family Naidoo's case, as they also allow each other time to do their own things. Mrs Naidoo has formed close friendships with other mothers from Danna's Moms and Tots group and Mr Naidoo allows her free time to spend with her friends. This is a reciprocal process, as Mrs Naidoo also pointed out: "We know each other and when I could see he has reached his limits, and then I would say, just go and relax in front of the TV."

4.4.1. TOGETHER IN THIS

Throughout the interviews it became clear that the spouses of all three families felt supported because they were part of a couple and as such were not alone in this situation. According to the Daramolas, what made it possible for them to cope with the challenges of raising a child with autism is that they deal with the challenges as a couple, and that they "support each other a lot". So too with the Botha's; Mr Botha reported that "My wife and I kind of made a pact that we will be there for each other." This mindset is also evident in Mrs Naidoo's comment that "It wasn't my problem or his problem, it was ours together. We were both parents and that's what pulled us through".

4.4.2. SIBLING SUPPORT

All three family units consisted of the parents and two children. What the data show is that the neuro-typical siblings play an important role in the family support structure through their involvement with their autistic sibling. Abnormalities in social behaviour are among the core deficits in children with autism. Such children show little interest in peer relationships and show a lack of reciprocity in social relationships and empathy (Carr, 2006; Mash & Wolfe, 2005). Children with autism fail to show the subtle signs of social relatedness to their parents and other persons (Mash & Wolfe, 2005; Sadock & Sadock, 2003). They experience difficulties relating to others or in

initiating interaction in an ordinary and socially acceptable way. According to De Boer (2009), the social behaviour of children with autism typically is the deficit that people notice most often. It is the skill that parents are most concerned about in their child, though it is the most difficult skill for parents to teach (De Boer, 2009). The three families have expressed how pivotal a role their neuro-typical child played in their support structure. The Daramola family's neuro-typical child played with his autistic sibling. Mr Daramola reported that they often spent the entire Saturday and Sunday together playing and sometimes he would find them on the sofa, curled up under a blanket watching television.

The support that siblings offer by playing with their autistic sibling is two-fold. Firstly, having the neuro-typical sibling playing with the autistic sibling addresses and develops one of the core delayed areas of children with autism. The Naidoo family expressed it as follows: "He really helped Danna a lot with the social aspect, they played well together." By playing together, siblings teach their autistic siblings to interact appropriately with other people and to relate to them. In this way the neuro-typical siblings are modelling appropriate behaviour, a skill that is normally addressed only in therapy.

This data was validated by my observations during home visits. On one visit to the Naidoo family's home, Danna was playing a game with her younger brother on their computer. She was able to interact with him while he was teaching her valuable skills, for example how the rules of the game works, taking turns and to be competitive. During bath time at the Botha family's house I observed how Ethan's sister would also come and entertain him while he was in the bath. She would play guessing games with him, for example "Monster-monster of the mountains", a game that is developing his abstract reasoning, another core deficit in children with autism.

The parents expressed the view that raising a child with autism to be very tiring. As Mrs Botha says:

The biggest problem is living with this constant tiredness, the feeling that you can never rest, you can never relax or take a break.

In these families, the neuro-typical child often stands in for the parent; thus giving the parent some breathing space. Having a neuro-typical sibling playing with the autistic child and keeping him busy frees the parent to do other things; it allows parents to have some time for themselves and for doing what needs to be done. In the Botha family, the sister is sometimes remunerated to keep her autistic sibling occupied.

A theme that emerged was how the other siblings serve as role models and initiators of new things that can be tried. Children with autism are generally resistant to transition and change, because 'sameness' provides security, order and predictability (Mash & Wolfe, 2005; Koudstaal, 2005). This trait prevents children with autism from trying out anything new, which can be very restrictive to normal family routine and outings. During the interviews, parents relayed information on how their neuro-typical child was supporting them by "showing [their] autistic child the light and leading the way". In family Naidoo's case, Danna's brother has been an inspiration to her in many ways. When Danna and her brother used to go to the indoor play centre, Danna would not attempt to climb on any of the apparatus or even put a foot on the playground, but when her brother got older and discovered all the fun things that could be done on the playground, Danna started following him everywhere, and trying out the apparatus.

The siblings do not only model appropriate behaviour; they also convince their autistic sibling to try out new things with them. Family Naidoo reported how Danna's brother would help her:

If he wants to do something he will convince her and convincing her is good for her because then she realise that it's not so bad. Even riding a bicycle. When they got their bikes, she wasn't into riding her bike. But he loves cycling and he would say let's get outside and go to the park and initially she didn't want to but as he carried on she cycled a bit. Everything, so many things she does today is because of him.

What the findings show is that the siblings not only teach their autistic siblings valuable skills that are normally addressed in therapy, but also broaden their sibling's worlds. This, in turn, indirectly provides the family with an additional support structure and invites the family and more specifically their child with autism to be less restrictive in their behaviour.

This was also confirmed during my observations. Danna's brother would convince her to things, for example to watch a television programme that she was scared of. Danna did not like robots but he convinced her to watch the programme with him. When she eventually agreed and started watching programme, she also enjoyed it.

Both the Botha and the Daramola family have reported that their neuro-typical children are taking on some of the responsibilities of looking after their autistic sibling.

Table 4.4: Quotes verifying sibling support

Family	Quotes verifying sibling support
Botha	<ul style="list-style-type: none"> • “She is like a second mother to him. She was telling him to sit and when he ran away she would say come back here.” • “She is like a little tutor to him, telling Ethan to change the topic or finish talking about this.”
Daramola	<ul style="list-style-type: none"> • “He participates in the looking after him. Outdoors he is very aware of where Dubbie is and he is going after him when he is running off.”

The neuro-typical siblings who are older, like the Daramola brother, often help out with the responsibilities of the household. In the Daramola household, the older sibling also does specific chores to share our responsibilities among the family members. “He got his chores that he gets paid to do like washing dishes that is relieving our work load in a way.”

4.4.3. PHYSICAL SUPPORT

Sivberg (2002) found that parents who have a child with autism report higher levels of parental stress and psychological distress than parents of children without autism. Several factors have been proposed to account for the higher levels of stress experienced by these parents, including the long-term prognosis of individuals with autism and the stressful nature of autistic symptoms and associated behaviour problems (Hartley, Barker, Seltzer, Greenberg & Bolt, 2010). The interviews conducted for the current study, revealed how the three participating families value the physical support they were given as it provided relief from the stressors of raising a child with autism.

Lee and Gardner (2010) exclusively examined grandparents’ importance as informal supporters, but other studies (Lindblad, Holritz-Rasmussen & Sandman, 2007), also

indicated that grandparents were the primary source of support. This finding of the current study partially supports these findings. In this study physical support from extended family members such as grandparents was provided only in the case of the Botha family, who described both their parents as “their next line of support”. This was an experience not shared by the other two families. According to the Naidoo family in the Indian culture, it is the children’s responsibility to look after the grandparents. As such, they do not burden their parents with their problem. The Daramola family also explained that the natural thing to do in their culture is for the siblings to all contribute money to look after the grandparents. Even though their parents were very available for emotional support, it was not common for them to be physically involved in the support structure. In both the Daramola and the Naidoo family’s case, the grandparents lived far away, which also contributed to some extent to their limited involvement in the support network.

Because raising a child with autism requires so much time from their care givers, the grandparents in the Botha family have supported them by relieving them from some of the physical everyday duties, such as food preparation. This family has a food sharing arrangement with the grandparents who cook the meals while they make a financial contribution.

Because they are pensioners and have more time, so most of the days they cook. I cannot measure the time they have saved me in cooking and shopping-for-food hours.

In the white Afrikaans-speaking cultural group, meeting on Sundays for a family lunch is a common ritual. Thus, the Botha family are released from cooking responsibilities on that day, whereas this is not the case for the other two families.

Raising a child with autism means that parents' schedules are filled up with therapy sessions for the autistic sibling. When parents are raising two children, it can be a challenging task to get everyone where they need to be. The Botha family reported that they enjoyed a lot of physical support from their parents in this regard, in that the grandparents would step in to fetch the children from school and take them to extra-mural activities or therapy on days when neither one of the parents could get home in time to do it.

In the absence of, or in addition to grandparent or extended family support, the families enjoyed the same sort of physical support from professional services. The physical support offered by professional persons was often extended beyond that which they were paid for. Ethan's tutor, for example, took him to SNAP every day. Mrs Botha would take Ethan to his sister's school and his tutor would fetch him when she dropped her children off at the school and take him to SNAP. The Naidoo family enjoyed the same sort of support from professionals. Danna's school teacher also gave them a lot of help. On days when Mrs Naidoo was not able to take Danna to school, her teacher would offer to take her.

As already stated, raising a child with autism can be extremely demanding on parents' time. All the adults spoke about their need to sometimes just have a break from their responsibilities. As Mrs Naidoo phrased it, "Sometimes you just wish that someone can take your kids for two hours". However, finding someone to take care of a child with autism can be complicated. A very specific person who is able to deal with the challenge of an autistic child is needed, and it also takes a very specific person that the autistic person will warm up to. Sometimes parents even find support in someone looking after the neuro-typical sibling to allow the parent to give full

attention to the demanding needs of their autistic child. This was the case for the Naidoo family.

Our domestic nanny was more of a support to Danna's sibling. Danna wouldn't allow her to do anything, it take [*sic*] very long for her to warm up to someone.

All three families could rely on individuals whom they trusted who could step in when they needed to escape from their situation. Such individuals included the Botha's parents, a teacher, or the professional support environment. Even though it is difficult for parents to find someone to look after their children, they did enjoy physical support from family members and professionals. The Botha family received much physical support in this regard from their parents, as revealed in the statements quoted in **Table 4.5**.

Table 4.5: Quotes verifying physical support

Family	Quotes verifying physical support
Botha	<ul style="list-style-type: none"> • "When my second child came, they would come and fetch her for a few hours so I can work with our autistic child." • "When I wasn't feeling well, they would look after him." • "My mom will be the one that puts them to bed and read [<i>sic</i>] them stories, when we need to go out." • "My dad would come every Wednesday and spend the morning with him, look after him and play with him." • "My folks do let us go out every now and again."
Naidoo	<ul style="list-style-type: none"> • "Bringing Danna over, playing with her, taking care of her and looking after her." • "Danna's teacher tends to help out some weekends. When we need to go out she will come and baby sit. So to me that type of support is great, when we need a time-out then she is there to do that."
Daramola	<ul style="list-style-type: none"> • "Also we are both working full day so Dubbie is able to be at the centre for the whole day. So the fact that the hours of the centre coincide with our work hours is really helpful so we don't need to find alternative childcare for him, which in itself is very difficult to find for a special needs child."

In all three families the parents are full-time employees. Due to their challenging circumstances, all could report on situations when they have had to renegotiate work schedules due to their personal challenges. The families have all expressed how they were physically supported by their employers because they understood their circumstances and allowed practical alterations to their job descriptions to accommodate their physical needs. Mr Botha described his employer as very understanding: “She is actually very empathetic and does her best to support me, for example when my son needs to go and see a specialist then she will give me off.”

This was the situation for Mr Daramola, too. He had to renegotiate his working hours to fit that of the centre where Dubbie attends. He also experienced his employer as accommodating as “...he allowed the adjustments to accommodate my needs”. Mr Daramola also mentioned that there are very few institutions that are geared to work with autistic children, which often means that parents need to move closer to these specialised institutions. Now that Dubbie needs to be in Durbanville every day, it makes sense for the Daramola family to move to Durbanville.

So my Human Resource director said that she can assist in there to help my wife to find something in the northern suburbs. Supporting us by [helping to relieve] our situation by finding a job for my wife. That is wonderful support from the job-side of things.

Mrs Daramola enjoyed the same type of support from her employers.

When my husband was away, I told my line manager that my husband is going to travel for quite a long time and I need to travel to Durbanville and back so that will meant that I will arrive late and leave early. So my initial proposal was that I add up the time that I'm missing and fill out a leave form for it. But she was like this is a particular situation and you can do what needs

to be done and just make sure the work is done, so I found that to be quite supportive.

4.4.4. FINANCIAL SUPPORT

The specialised services and accommodation that children with autism need could become of economic concern for most parents. As I am working for a specialised institution for children with autism myself, I am familiar with the economic burden that families face due to the cost of services or interventions for their children. The three families reported that they are enjoying financial support from various sources, which relieves some of their financial strain.

The Botha family has been very fortunate in that regard in that they have received financial support from specific professionals in the form of free professional services. Their occupational therapist, for example, has treated Ethan for free for almost a year as a gift to them.

From the data it seems that their extended families are sensitive to the added expenses that the Bothas, Naidoos and Daramolas have to incur. The Bothas for example had their food contributions waived when the school fees increased. The Daramolas' siblings in Zimbabwe understand that Mr and Mrs Daramola's contributions to the upkeep of their parents have to be reduced due to their "additional cost with Dubbie". The Bothas have reported that they were "pleasantly surprised by wonderful financial support received from family and work colleagues. This includes a work colleague covering a third of Ethan's SNAP cost per month." The Botha family's parents "sold shares and gave up part of his pension" to pay for Ethan's therapy.

4.4.5. EMOTIONAL SUPPORT

It is natural for parents who are raising a child with one of the most severe childhood disorders, and with the most complex developmental patterns (Newsome & Hovanitz, 2006), to require a lot of emotional support to cope with such a challenge. The families who were interviewed received emotional support from various sources and clearly expressed the value of receiving this kind of support. However, through the interviews it became clear that, even though they appreciated the emotional support, their need for physical support appeared to be greater. The Botha family expressed their frustration with family members who are misinterpreting their need for support;

It's a funny thing. For example, my husband's older sister will spend hours reading up on autism and following Ernie Els' tweets and autism speaks. So in her mind she is supporting us emotionally. She feels like she is emotionally engaging in the situation but she has never physically done anything to help us so it almost as if, and it sounds nasty, that she is fooling herself by reading a lot about autism that she is doing something to support us. I think it's a mistake a lot of people make on social networks – they think because they said thinking about you or praying for you, they are supporting you emotionally but they are not physically doing something to help you. If you look at it, they have done sweet nothing to help you. It feels really mean but sometimes it feels rather don't say it.

Even though the Botha family expressed their frustration with people who offer emotional support without realising how much they need physical support, they do also enjoy emotional support from their own siblings who enquire about Ethan's progress. Mrs Botha said: "We've had emotional support from our siblings in the sense that they would ask how things are going."

Mrs Naidoo was much more appreciative of emotional support. It was important for her that her friends and family members were enquiring about Danna’s progress.

She said:

I have the best friends in the world. They were just supporting me emotionally. With every appointment they would phone, asking what happened, what were the results and my cousin wanted to know where we are in the process and what is happening, wanted to know how Danna is doing.

The Daramola family experienced the same type of support from their family. “They are checking in on his progress and how he is doing.”

The three families have expressed feelings of being emotionally supported by friends and family because they were available to listen when they had gone through a difficult day and because they understood their situation. With the advances of technology, emotional support also comes in the form of sms’s and e-mails. Here are some quotes to verify this statement in **Table. 4.6**.

Table 4.6: Quotes verifying emotional support

Family	Quotes verifying emotional support
Botha	<ul style="list-style-type: none"> • “My friends would not be able to look after our son but their support is emotional for us, you know text messaging a friend saying, he is having a terrible day or just chat[ting] to somebody who has an idea. That really helps.” • “I have great colleagues that I can talk to about if my son had a bad day or just my feelings in general.” • “Allowing someone to express their feelings is also a form of support.”
Naidoo	<ul style="list-style-type: none"> • “There is more sympathy and empathy and more understanding and comforting but not support in terms of coming to fetch her.”
Daramola	<ul style="list-style-type: none"> • “The grandparents are in Zimbabwe but they are very available, you can call them and blow off steam, and they are always there to consult.” • “My one friend offers a lot of emotional support. I can call her and tell her I’m not coping with this. And she is just there being really available.”

The Botha family enjoyed the same type of support from professional acquaintances: “Our neurologist has been very available to e-mail her or phone her if something happened, so very approachable” and “our GP even phoned once or twice to hear how it is going.”

The three families were also emotionally supported by friends and family who encouraged them and shared in their joy when their autistic child showed progress. The Daramola family mentioned that it is encouraging when people understand the challenges of the disorder and join in their excitement when their child demonstrates progress. The quotes in the following table support this statement:

Table 4.7: Quotes verifying emotional support from friends and family

Family	Quotes verifying emotional support from friends and family
Naidoo	<ul style="list-style-type: none"> • “When we went to SNAP for the first time, I went out with my friends that day. They took me out and lifted my spirit.”
Daramola	<ul style="list-style-type: none"> • “My one friend has moved to Johannesburg but I can phone her and just talk and she just offers a lot of encouragement.” • “So when Dubbie said a word we could all jump up with excitement because my sister knew what the magnitude is of the problem. Also what a big thing it was for him to say that word. She understands and can walk with us emotionally.”

The Daramola family is part of a church cell group where fellow Christians from their congregation meet at each other’s houses once a week for spiritual growth and support. The Daramola family received emotional support from their cell group:

Even when they are not with us and they hear about autism they relate to us and just offering prayers. For example when my husband was away they wanted to know what my concerns were and I will tell them I am worried about driving the kids back and forth and cope with Dubbie on my own, and things went well while he was away. So it’s good support.

4.4.6. OTHER SUPPORT – ACCEPTANCE, UNDERSTANDING AND GOING THE EXTRA MILE

The three families felt supported when they experienced their autistic child as involved in attached and devoted relationships with extended family members and friends. The understanding, acceptance and knowledge about the child's disability of immediate family and close friends are experienced by the parents as a source of support. Autism is characterised by low social functioning, impairment in communication, and aggressive and self-destructive behaviour (Altiere & Von Kluge, 2009).

These characteristics and people's general lack of understanding of the disorder make it difficult for other people to relate to and to engage with autistic children. During the interviews it became clear that parents felt supported when their extended family look beyond their child's socially odd behaviour and make an effort to engage with the child and build a relationship. This seemed to be the case for the Botha family, where the grandparents have developed close relationships with Ethan. The grandmother would read to him and play with him, something that her daughter is grateful for as "she spends ages reading him the same stories over and over again and relates to him". So, too, the granddad, "spends time with him and always made an effort to do the things that Ethan likes".

This type of support was not just provided by family members. Professionals working with their autistic children were also providing support that extended beyond the professional relationship, as the following excerpt shows:

They aren't just tutors, they love him and they are becoming part of the family. I can see that she has attached to him and he has built a relationship, I mean that is special.

The Bothas and the Daramolas both had negative experiences when their autistic child was phased into a mainstream environment. The Botha, Daramola and Naidoo families' stories reflected how parents tend to gravitate towards professionals persons, institutions and friends that have a better understanding of the disorder and who accept the child's deficits. All three families The autistic children involved in this study attended SNAP Education programme. SNAP is a unique, child-specific, one-on-one integrated programme for children with autism. The staff are specialised in Autistic Spectrum Disorders and understand the condition and the challenges that the families' are facing. The Botha family said:

If SNAP wasn't there, I don't know what we would have done, because no one else will take him. SNAP's the only place that still believes there is still hope for our son. If you got hope you've got a lot.

The Daramola family described SNAP as "being so different", and said: "They support us just by appreciating his condition." In the mainstream environment, the Daramola family used to be called in with great concern about Dubbie's challenging behaviour. As part of Dubbie's condition he would, for example, bang his head against the cupboard or bite the other children in his class. The teachers involved in the mainstream environment, experienced Dubbie's behaviour as highly disruptive and had no plan for addressing his behaviour. Mrs Daramola explained how different it was the moment they took their child to an institution that understood the disorder and accepted her child's deficits:

When Dubbie was biting the other children at SNAP, it was so different. They haven't tried to down play what happened and they told us that they had called the other parents but they emphasised that they have seen this before and you just need to fill out a form so we can track it and see what is triggering it. So to observe him at home and fill the form in and we will also fill

the form in at the centre and the purpose is to find out what is causing the behaviour and stop it from happening again. It was so supportive. They were looking for an answer for his behaviour and not trying to kick him out of the class.

The Naidoo family also spoke about how supportive it was to find a therapist who understood the condition and who accepted Danna and knew how to address her difficulties. Mrs Naidoo said:

Her physiotherapist was amazing. She loved Danna. She had this gift with all these kids that got all the problems. Danna had silly fear. The way she broke it down and helped Danna to get over her fears, which for me was amazing.

Probably as a result of the alienation that they have experienced due to their exclusion by people who were unaccepting of their child's challenges, these three families reported that they naturally gravitate towards friends who show acceptance and understanding of their child's challenges. The Botha family explained:

My friends are primarily mothers who also have autistic children or children with challenges. I think you just gravitate towards the people who are in a similar situation to you, who understand what it is like living with these challenges.

Even though the Naidoo and Daramola families did not socialise with people whose children are in the same situation as their autistic children only, they did mention that they felt more supported by friends and family who understood, accepted and tolerated their child's deficits. Statements to support this are quoted in **Table 4.8**.

Table 4.8: Quotes verifying other support

Family	Quotes verifying other support
Botha	<ul style="list-style-type: none"> • “Well if your friends who also have autistic children come and visit we don’t mind what their kids destroy and what our kids destroy. When they stim, no one gets bothered by it.” • “When our son goes on and on about the same thing they will really patiently answer his questions.” • It’s really just putting up with each other’s difficulties.” • “My son got a fascination with our friend’s lawn mower so they will let him walk around their lawn pushing the lawn mower up and down. I really appreciate people just cutting us some slag.” • “Most of our friends are understanding about our child’s particular needs and accept him the way he is.” • “They usually accommodate him in their homes without too much fuss and even specially put out the toys they know he likes to play with.”
Naidoo	<ul style="list-style-type: none"> • “My friends are so accepting and when they see her stimming, they don’t talk to her differently.” • “If Danna stims, my mother will know that Danna is getting anxious.”
Daramola	<ul style="list-style-type: none"> • “Our church is really supportive. So in our cell group everybody knows about Dubbie’s condition so we go there to their houses and they are very accommodating because most of them have [an] empty nest so they [are] used to having all their glass ornaments there open on the shelf. So they are very tolerant.”

The parents pay a lot for the specialised services and accommodations that their children with autism need. Even so, the Botha, Naidoo and Daramola families were willing to pay for professional services that have their child’s best interest at heart and are willing to go the extra mile for their child. According to Mrs Botha, the tutors who are working with Ethan:

...don’t just see it as a job, they want to see your child make progress. They would go out of their way to adapt things for him. I know that they do a lot of extra work outside of their sessions with him to help him develop.

This is an experience that the Daramola family also shared. The fact that all three families had such positive experiences with teachers and tutors, made them interact

with these professional persons as they would with good friends or family. This is reflected in Mrs Naidoo's comments about Danna's teacher and her programme manager:

I would always tell my friends that Dana's program manager is coming around for an observation at our house and I say to them, you know she is the manager of the southern suburbs. But it is not a business thing that she is doing, its actual emotions involved and she is genuinely caring about our family.

The three families have reported that it is not the acceptance only of the deficits on the part of those rendering professional services and friends that make them feel supported, but also their focus on the positive progress the children make. As the Daramolas' child, Dubbie, was in a mainstream class before being placed at SNAP, the parents kept on comparing the two schools and how different the teachers' responses were:

When we walk in at SNAP, for example to drop Dubbie off, his teacher just wants to tell my husband all the good things that Dubbie is doing. I think his reflex reaction after the mainstream teacher was probably that he just [wanted] to run away from any teacher. The mainstream teacher just wanted to talk about all the bad things Dubbie did. With SNAP it is very different they are focusing on all the positives.

This view of positive reinforcement by professionals talking to parents about their autistic child is shared by the Naidoo couple:

There were no negatives – oh at this age she should have been doing this. You know, she never focussed on all the issues. She focussed on the positives. She said she was doing well and making progress. She was really amazing.

4.4.7. INFORMATION AS SUPPORT AND GUIDANCE

Not knowing what is wrong with one's child can be disempowering and can be troubling for couples. Schall's (2000) findings indicated that, when families received a diagnosis of autism, it was both horrible and empowering. On the one hand, participants in his study felt a sense of despair at the pervasive nature of the disorder. On the other hand, they finally had a name of a disorder that they could research. Once they were told that it was autism, they could find out what to do about it. This was the situation for the three families who participated in my study, too. With knowledge of the diagnosis of autism, the families had to learn to adjust to the child's ritualistic behaviours and get assistance and education in correctly interpreting and adapting the child's behaviour. The three families reported that they went from one professional to the next trying to find answers and information to deal with the challenges that they were experiencing. They only felt supported once they were provided with useful information. The Naidoo's described the relief they experienced after their first consultation at SNAP:

She answered a lot of questions, so much information in that one session alone. She spoke to me and she supported me with thing[s] to do with Danna at home. She supported me emotionally because she was giving me information and skills to help my child.

The Daramola family also experienced access to information at specialised institutions for autistic children as a valuable source of support:

When you got questions you can walk up to any one, the teacher, program manager or the director and everyone is willing to offer you information and advice. So we find that the support that we are getting from them is very real.

Receiving a diagnosis of autism can be extremely overwhelming to parents and the three families reported that they felt supported when they were provided with a plan of action to address their child's difficulties. As stated by Mr Naidoo:

We needed someone to say, I know you are in a difficult situation, but don't worry, we put a plan together for you. Whether that plan is going to work or not. Just to hear the fact that you put a plan together, that is important.

Though professional people themselves, the Daramola parents were struggling with what their plan of action should be. Under such circumstances, being guided by Danna's programme manager and the tutor was greatly appreciated by Mrs Naidoo:

She just showed me the way. The tutors held up the directions and the program[me] manager just walked me through it. That's a fact, I'll never forget that. Really that was phenomenal. Always I'd come to her ... asking her what must I do here, I have hit a brick wall. Because I couldn't see, it was my child. Emotionally you are so overwhelmed you are blinded. You need someone that is looking in from above. Who is more exposed and who got more knowledge than I got. Who knows far more and say[s] look, let me take you by the hand and show you where [you] need to go.

The information that these professionals gave provided the three families with hope and reassurance. According to Mr Naidoo, they were given reassurance and hope that things would get better. "You know what, don't stress, you will work through this one step at a time. This was really reassuring to hear."

During the interviews it became evident that information did not come from professional services only, but also from friends and colleagues who also had children on the spectrum. Mr Naidoo said:

I think some technical support that I got was from my colleague and his wife. They also got a child that [has] special needs and he works with me. So we

would exchange notes and compare it. Did you do this? Have you tried that? Why didn't you try that? Read this? He gave us a lot of fresh ideas which is good. His support was mainly exchanging ideas and information. You know like I'm giving him this to eat or he is going to that school, why don't you try this? He told us about the High 5 social group. We got the details and that's where we send Danna.

For the Daramola family, a great source of valuable information was their church group:

When they hear something about autism they are, like, oh we heard this and thought it might be useful for you to look into it. We appreciate that.

4.4.8. LACK OF SUPPORT

The purpose of this study was to gain a deeper understanding of the support that families in South Africa are receiving whilst raising a child with autism. Even though the focus was on the support that they received a very strong theme that came to the fore was the lack of support from different sources. Throughout the interviews, the three families reported that they have had to face some uncomfortable and disappointing situations in connection with individuals and institutions that did not know what autism is or cared about what they were going through as a family.

Grey's (2002) qualitative findings demonstrate that social support is an integral part of the coping milieu in families with a child with autism. However, positive and negative coping mechanisms mirror each other. For example, the family gains support through interaction with family members and friends. On the other hand, they may withdraw from, or lack the time for, important social support activities. Thus, families with a child with autism may gradually lose their friends because of their limited availability. Realistically, social support is clearly important for families with a child with autism, although it may be difficult to find the time for social interaction.

The three families in the current study reported that they were engaging less in social and recreational activities with family and friends than before their children were diagnosed. The theme that surfaced was not necessarily the stressful nature of the disorder, as the literature states, but rather that they wanted to avoid people who lacked knowledge and understanding of the disorder. The three families explained this statement with the by means of the examples quoted in **Table 4.9**.

Table 4.9: Quotes verifying lack of support

Family	Quotes verifying lack to support
Botha	<ul style="list-style-type: none"> • “I would say our non-autistic friends distanced themselves from us. I would say the distancing also came from us but they are much less involved in our lives than they used to be. Possibly things like they would invite us to a braai and then they would do that at night. Nothing malicious, just the lack of understanding [of] our situation in terms of how restricting our son’s disability is. He has to have certain routines otherwise he doesn’t sleep properly.” • “They will never spend time with him. It’s like they don’t know how to relate to him.” • “It’s not malicious; it is just that it has never occurred to them that they have the responsibility to help us.” • “Our experience with a school for disabled children was really bad. They didn’t get what autism was about. We got the impression that Ethan is more of a liability – something they didn’t want there.”
Naidoo	<ul style="list-style-type: none"> • “We got no support from our family. They didn’t know any better, also because developmental delays and spectrum traits are not popular. If you are not educated about that, or even if it is popular and you are not educated, you wouldn’t understand. People will keep on asking what’s stimming, what’s this, why is she doing that?” • “I also think people don’t know how to handle someone like Danna. You know even I got very good friends that I work with and if they invite us to a braai at their house. They know Danna is special needs but they don’t know what to do with her.” • “Even our family, they don’t even talk to her. They don’t know how to interact. Exactly, because they don’t know what the issue is, how to deal with it, what is the real issue? Will she understand me if I speak to her like a normal kid?” • “It’s nothing that’s so obvious that you will just pick up by looking at her. It’s something that is a bit more subtle, so they don’t

	<p>really know how to play the game. So Danna will go there, they will talk normally with her but not really interact that much with her because they don't know."</p> <ul style="list-style-type: none"> • "Because she looks so normal. I think people think that when you are special needs or autistic you need to look, down's. Or she must walk funny. You know something like that. How someone looks normal, you won't say there is something wrong. I mean lots of people say that you won't even see there is something wrong with her if you don't spen[d] time with her or mention it once in a while."
Daramola	<ul style="list-style-type: none"> • "But all our other siblings, I mean I don't think they really [know] what it means to be autistic." • "My sister now understand[s] and ... sort of walks with us. But before her visit to us she really didn't know and I'm sure our other siblings have no idea what it really means. They know he doesn't speak but they don't know the extent to what autism is affecting a child."

4.4.9. THE ROLE OF CULTURE IN SUPPORT

It would seem from the data that cultural influences affect how autism is dealt with and how it is perceived. During the interviews, the Naidoo couple shared interesting information about their culture and how that was playing a role in their support structure. I have been working in this Indian, Moslem family's home for a few years, and my observation was that their culture involved regular family get-togethers. My assumptions were that these family get-togethers would play a pivotal role in the support structure of a family who was raising a child with autism. My understanding was that better family support would be available in such close-knit families – that, for example, the cousin who was present at the family event would play with Danna and help her to improve her social skills and the grandparents and siblings would support the parents emotionally. However, what I assumed was possible and what the Naidoo's experienced did not support my assumptions. During my interview with the Naidoo family, I realised that I entertained a misperception of their culture. In their culture parents set high standards and have high academic expectations of

their children, therefore having an autistic child challenged their expectations. Because of this, they, as parents, did not seek out family support because they did not want anyone to know of Danna's condition even though people noticed and suspected that something was wrong with her. The statements that are quoted explain this:

You must understand one thing with the Indian mentality. It's the way they are brought up. They are very conservative and rigid. These things won't happen to Indian people. When you are in a bunch of Indian people they will ask where Danna is. Is she in Herschel's or in what private school is she? Because it needs to be one of the top three schools.

In their culture there is respect for privacy; thus no-one would broach the issue of Danna with them if they would go there for a function or a visit. The result was that:

...they would see there is something wrong but you know because of the culture thing, they don't approach you. And we never allowed them and we never spoke about it. When I did tell my mother it came out that they thought there were something wrong but they didn't come to us.

Because of their respect for cultural attitudes they were denying themselves a valuable source of support. They also expressed their great relief they experienced once they had told the family, because they no longer had to hide her deficits. According to Mrs Naidoo, the burden was lifted once they told the grandparents.

We could go to his mother's house after that, calm, not stressing. Because every time we went to his mother's house it was like, you know, you take Danna inside the room if anything happens while we were there. It was a lot of planning and that type of thing. Plotting before we had to go to any place. We still do that, the two of us sometime. But it's a lot calmer after we told them.

4.4.10. NOT ALL PROFESSIONAL PERSONS ARE SUPPORTIVE

Though these families were very impressed with the support they have received from some professional persons, notably those who worked with the child at the school, they also spoke of the lack of support other professional people showed. With Autism Spectrum Disorder on the rise, the parents feel that there is an increasing need for specialised training for teachers, therapists, occupational therapists, physiotherapists, psychologists and doctors in dealing with this complex disorder. Such professionals are the first people with whom the parent of a child with autism has contact, therefore they need to be able to diagnose the symptoms early and to present practical and effective interventions and advice. The three families did not only experience lack of support from friends and family because of their lack of knowledge and understanding of the disorder, but also from professional persons who were consulted who did not have experience in autism or who did not offer useful recommendations. Mrs Naidoo expressed her disappointment in the lack of support from Danna's paediatrician. She said, "I got along with our paediatrician, but she was clueless with Danna. She had no idea." Mr Naidoo confirmed this by saying:

She was good but she didn't have experience with autism. You can take any mainstream child to her but with Danna you need to be long in the game to understand that.

The three families also reported that they were disappointed with the lack of support that they received from psychologists and neurologists. Mr Naidoo said that one will be given the black and white facts, for example "Danna is 13 months behind in this developmental area", but the parents feel that that is the type of information they already have about their child, because they spend every day with the child. What

they want to gain from professionals is guidance, useful recommendations and reassurance. Mr Naidoo said:

...the only thing that a human would want to hear is, you need reassurance. I think it was the lack of reassurance and useful recommendations that disappointed us. We needed to hear, don't stress, we got a plan for you.

The Botha and Daramola families expressed their disappointment with the support that they receive from the state. Mrs Botha felt that the "lack of state support is shocking". What the families were most concerned about was the lack of public schools available for autistic children. A number of the Bothas' friends have had to leave the country to seek better support for their autistic child. They have found that the state provides free schooling, offers transport for children with special needs and offer free interventions like speech training, physiotherapy, etc. in countries like the USA.

The Daramolas expressed their disappointment with the support they hoped to receive from their medical aid. Children with autism need specialised services to treat their condition. Most of these specialised services are not covered by the medical aid. Mr Daramola said:

I consider professional support as something that the medical aid is supposed to cover a big part [of]. The medical aid is just one part of it. There is the medical council that need[s] to decide this is either claimable or not. But [what] if none of them really understand the whole thing themselves? The other thing is if you look internationally to more developed countries they actually know the latest things. I assume that statistic[s] show that it happens to all sorts of people. But if you look for instance to the USA they certainly have much more acceptance that this is an increasing problem and therefore they are providing more support.

4.5. CONCLUSION

In this chapter, I have presented the data from the research and discussed the eight categories that emerged in this study. In Chapter 5, I report on the eight categories, the strengths and limitations of the study and my recommendations.

CHAPTER 5. DISCUSSION OF THE FINDINGS

5.1. INTRODUCTION

This chapter is focused on answering the research questions, and discussing and interpreting the themes that emerged in the study. This is followed by a review of the strengths and limitations of this study and recommendations are made for possible future studies. I conclude with my reflections on the process. The study explored the support structures available to families from different cultural groups in South Africa who are raising a child with autism. The following research questions were posed to gain insight into the families' support structures:

- What are the support structures available to parents raising a child with autism within their cultural group?
- How do they access the support?

The eight themes that emerged during the data analysis phase of the study offered rich insight into the support that families from different cultural groups in South Africa are enjoying whilst raising a child with autism. The eight categories, namely spousal support, sibling support, physical support, financial support, emotional support, other support (acceptance, understanding and going the extra mile), information as support and guidance, and lack of support, are discussed in the sections that follow.

5.1.1. SPOUSAL SUPPORT

The parents described their respective partners as each other's primary support structure and were unanimous in their view that having such a strong marriage facilitated their success in coping. This finding is supported by research conducted

by Ekas, *et al.* (2010) who identified social support as a critical factor that reduces the negative psychological effects of raising a child with autism. One of the ways in which the spouses in the three families supported one another involved sharing responsibility for children and home. The spouses in all three families share the child rearing responsibilities and alternate between the responsibilities of looking after the children and household responsibilities.

In some cases the challenges of raising a child with autism took parents away from the traditional roles as parents. Mrs Daramola, for example, explained that her husband supported her by stepping out of the traditional role of a Shona father by which it is determined that it is the mother's sole responsibility to raise and look after the children.

The three families reported that they supported each other by enabling their spouses to have some free time. They believe that it is because they give each other personal time, that they are able to cope.

They felt supported because they were part of a couple and as such were not alone in the situation. This finding was supported by research done by Lindblad, *et al.* (2007), who explained togetherness as a concept that stands for a sense of belonging to a group, security and trust in someone else and of not being alone when facing difficulties in life.

5.1.2. SIBLING SUPPORT

What the data showed is that the neuro-typical siblings played an important role in the family support structure through their involvement with their autistic sibling. The support that siblings offer is two-fold. Firstly, by playing together, siblings teach their

autistic siblings to interact appropriately with other people and to relate to them. Secondly, having a neuro-typical sibling playing with the autistic child and keeping him busy provides parents with freedom to have some time to themselves to do what needs to be done.

These siblings also serve as role models and initiators of new things that can be tried. Children with autism generally resist transition and change, because sameness provides security, order and predictability (Mash & Wolfe, 2005; Koudstaal, 2005). This trait prevents children with autism from trying out new things, which can be very restrictive with regard to normal family routine and outings. Through play, the siblings not only model appropriate behaviour but they also convince the autistic sibling to try new things and thereby broaden their worlds.

5.1.3. PHYSICAL SUPPORT

Through the interviews it became clear that the three families valued physical support as they found that it gave relief from the stressors of raising a child with autism. Contrary to what existing research (Lee & Gardner, 2010; Lindblad, *et al.*, 2007), has shown about the supportive role of grandparents, only one of the families participating in this investigation had enjoyed that support. However, the lack of support in the case of the other two families was the result of a cultural understanding of the grandparents' role in the family, rather than an inability to help. Even though the grandparents are not unavailable for providing emotional support, it is not common in these cultures for them to be physically involved as part of the support structure of their children's families. In both the Daramola and the Naidoo family's case their own parents live far away, which also contributed to the grandparents' limited involvement in the families' physical support network.

In the absence of, or in addition to grandparent or extended family support, the families also enjoyed physical support from professional services that were often extended beyond what was paid for. So, for example, Ethan's tutor and Danna's teacher transported the children to schools on days when their parents were unable to do this.

All the adults spoke about their need to sometimes have a break from their responsibilities and to have someone to look after their children. However, this requires a very specific person with ability to deal with the autistic child's challenges and it also requires a very specific person for the autistic child to warm up to. All three families knew individuals whom they trusted who could step in when they needed time away from their responsibilities. Such individuals included the Bothas' parents, a teacher or the professional support environment.

In all three families, the parents were full-time employees. Due to their challenging circumstances, all could tell of situations in which they had to renegotiate work schedules due to their personal challenges. The families all expressed how they were physically supported by their employers, who understood their circumstances and allowed practical alterations to their job descriptions to accommodate their physical needs. For example, when Ethan needed to see a specialist, his father's employer would give him time off from work to take the child to the specialist.

5.1.4. FINANCIAL SUPPORT

The specialised services and accommodation that children with autism need would become an economic concern for most parents. The Bothas and Daramolas reported that they were enjoying financial support from various sources, which relieved some of their financial strain. These sources included free therapy sessions from

professionals, financial contributions towards therapy from grandparents, a contribution from a colleague and a reduction in family responsibilities towards taking care of grandparents.

5.1.5. EMOTIONAL SUPPORT

The data showed that all three families received emotional support from various sources. It became clear during the interviews however, that their need for physical support was greater. The Botha family expressed their frustration with family members who misinterpreted their need for support. They explained that some members of their family felt that they were supporting them emotionally by reading up on autism and by joining autism sites on social networks, but without the family's physical support, they did not feel supported.

Emotional support was available from friends and family who would listen to them on a difficult day and show understanding of their situation. With the advances of technology, emotional support also came in the form of the sms and e-mail services. This statement is supported by the research undertaken by Lindblad, Holritz-Rasmussen and Sandman (2007) who explained that emotional support also entails being provided a room for sorrow. This involves the awareness of being enabled to share experiences of heavy feelings, which are too burdensome to carry alone.

The data showed that the three families experienced emotional support from professionals, friends and family who encouraged them and shared in their joy when their autistic child showed progress.

One family also received spiritual support from their church group. The Daramola family mentioned that they were receiving emotional and spiritual support in the form

of prayers being offered for them by members of their cell group. This is similar to findings reported in the Phelps, Hodgeson, McCammon and Lamson (2009) study which found that spirituality is experienced as a means of ensuring strength and support during the care giving process.

5.1.6. OTHER SUPPORT – ACCEPTANCE, UNDERSTANDING AND GOING THE EXTRA MILE

Understanding, acceptance and knowledge of the child's disability on the part of the immediate family and close friend are experienced by the parents as a source of support. The three families felt supported when they experienced their autistic child as involved in attached and devoted relationships with members of the extended family and friends. This finding was supported in research by Lindblad *et al.* (2007) in which the meanings of informal support appeared to be related to appreciation of the child by other persons by whom problems arising from the child's disability were acknowledged and not considered an obstacle to the relationship with the child.

The presentation of low social functioning, impaired communication and self-destructive behaviour (Altiere & Von Kluge, 2009) in children with autism and lack of understanding about the disorder among people make it difficult for other people to relate and to engage with autistic children. During the interviews it became clear that parents felt supported when their extended family looked beyond their child's socially odd behaviour and made an effort to engage with the child and build a relationship. This type of support was not just provided by family members, but also by professionals working with their autistic children.

The data reflected how parents tend to gravitate towards professionals, institutions and friends that have a better understanding of the disorder and who accept the child's deficits. The autistic children of all three families in this study attended a

specialised institution for children with autism where the condition and the challenges that the families are facing are understood. The families reported that the support that they were receiving from these specialised institutions was different because these children were appreciated and their condition was accepted.

Probably as a result of the alienation that they experience due to their exclusion by people who are unaccepting of their child's challenges, these three families reported that they naturally gravitate towards friends that show acceptance and understanding of their child's challenges. Research by Lindblad et al. (2007) also found that mothers' abilities to share concerns about their children with a mother who had children with autism was a valuable form of informal support.

The three families expressed how supported they felt when the professional people involved with services that they were paying for had the child's best interest in mind and if they were willing to go the extra mile for their child. According to these families, the tutors who were working with their children did not just see their work as a job; they wanted to see the child make progress and they would go out of their way to adapt things for them. The data indicate that it is not just the acceptance of the deficits perceived with regard to professional services and friends that helped them to feel supported but also their focus on the positive progress the children were making.

5.1.7. INFORMATION AS SUPPORT AND GUIDANCE

Receiving a diagnosis of autism was an extremely overwhelming experience for the three families because they felt a sense of despair due to the pervasive nature of the disorder. On the other hand, they finally had a name for the disorder that could guide their research, something that is supported by Schall's (2000) study. The three

families conveyed that, following the diagnosis of autism, they had to learn to adjust to their child's ritualistic behaviours and be assisted and educated in correctly interpreting and adapting the child's behaviour. They viewed the access to information at specialised institutions for autistic children as a valuable source of support. They felt most supported when they were provided with a plan of action to address their child's difficulties. The information that they obtained from institutions and professionals, provided the families with hope and reassurance. During the interviews it became evident that information did not come from professional services only, but also from friends and colleagues who also had children on the spectrum.

5.1.8. LACK OF SUPPORT

Even though the focus was on the support that the parents received, a very strong theme that came through was the lack of support from different sources. Throughout the interviews, the three families reported that they had to deal with some uncomfortable and disappointing situations with individuals and institutions that do not know what autism is or care about what they were facing as a family. This theme is supported in a study that was conducted by Altieri and Von Kluge (2009), who found that many parents complain about the lack of support groups, their financial struggles, inadequate research and unhelpful and unqualified schools, doctors and clinicians.

Contrary to what Gray's (2002) research has shown about families that gradually lose their friends because of the stressful nature of the disorder and parents' curtailed availability for socialising, the families in this study reported that they were engaging less in social and recreational activities with family and friends because

they wanted to avoid people who lack knowledge and understanding of the disorder. They have conveyed the information that some of their friends and families did not understand what it meant to be living with autism and did not know how to relate to their autistic children. They also did not realise how restrictive their children's disability was and would invite them to social events, for example an evening braai, without realising that their children had to follow particular routines, otherwise they just could not sleep properly. The autism spectrum traits are not common and when people are not educated about the disorder, they do not understand and do not know the extent to which autism affects a child.

It would seem from the data that cultural influences affect how autism is dealt with and how it is perceived. In the Indian culture, parents set high standards have academic expectations of their children, therefore having an autistic child challenged their expectations. This being so, parents did not seek out family support because they did not want anyone to know of their child's condition, even though people noticed and suspected that something was wrong with her. In their culture there is respect for privacy; thus no-one broached the issue with them when they met or visited family. Because of their cultural attitudes, they were denying themselves a valuable source of support.

The three families not only experienced a lack of support from friends and family because of their lack of knowledge and understanding of the disorder, but also from professionals who did not have experience in autism or who did not give them useful recommendations. The three families reported how they were disappointed by paediatricians, psychologists and neurologists who either had no experience in the

field of autism or who only pointed out the deficits of the child. What they needed from professionals was guidance, useful recommendations and reassurance.

The Botha and Daramola family also expressed their disappointment regarding the lack of support from the state. With the prevalence of autism on the rise, it is a cause of concern that very few public schools are available for autistic children. This forces people to seek help from private organisations that are extremely expensive because of the one-on-one nature of the interventions. The Bothas mentioned that some of their close friends had had no choice but to leave the country to look for more support for their child. The three families were grateful that they were able to afford to pay for the support they were receiving from private institutions, but they were all concerned about other families that might not be in the same financial position. During the interviews it also became clear that information about the support that the state can offer is not readily available to parents. Parents who are raising a child with autism and who receive a net income of less than R 270 000 per year can apply for the Care Dependency Grant from SASSA (South Africa Social Security Agency).

5.2. STRENGTHS AND LIMITATIONS OF THE STUDY

One of the strengths of this study was that the specific families who were raising a child with autism were given the opportunity to let others hear their stories. The data collected through this study provided valuable insight into the support that families are enjoying whilst raising a child with autism. Secondly, family, friends and professionals could be made aware of such families' needs for support through this study.

A limitation to this study is that a small sample limited to Cape Town was used, which might not provide a good enough representation of the experiences of other families that are raising a child with autism. Another limitation concerned the cultural groups of the families. This study only gained information from families from three different cultural groups, namely White, African and Indian families. Considering the cultural richness of South Africa, valuable information could have been obtained if more families from different cultural groups were included in this study.

The autistic children of the three families were enrolled at an intervention centre that specialises in working with children with autism. The experiences of these families may have been different if their children had received no intervention and support from the institution that they are attending.

Time constraints governed the completion of this thesis. If more time had been available, the researcher would have liked to observe social interaction with family and friends and conduct follow-up interviews with the three families.

5.3. RECOMMENDATIONS

This study was delimited to three families and thus the results are unique to their experiences of raising Ethan, Danna and Dubbie. In the study I have argued that a considerable part of these parents' support structures comprised support that they received from the intervention centre that their child is attending. The focus of centres focused on early intervention is very much on the needs of the children, sometimes leading to the family's needs being overlooked. Support groups could be initiated for families who would like to make use of this kind of support. This will also provide opportunities to meet parents who are experiencing similar challenges.

Intervention centres and the state need to create more awareness around autism including awareness around the disabilities and the challenges that a family experiences whilst raising a child with autism. Intervention centres can have open days that provide the opportunity for friends and family to visit the centre to be educated on the disorder and to gain understanding of what it means to live with autism. There is scope for further investigation in this field. As such, the following recommendations are made for further research.

5.4. RECOMMENDATIONS FOR FURTHER RESEARCH

- Further research could be undertaken to explore the support structures of families who are raising a child with autism during the adolescent developmental phase. This developmental phase brings many new challenges to the foreground that parents have to face and for which new support structures will have to be put in place.
- The experience and support structures of single-parent families, or families with some degree of marital stress who are raising a child with autism could also be investigated.
- Research could also be undertaken to explore the experiences of families whose children are not receiving any form of intervention.
- Further research could be undertaken on the socio-economic and cultural differences in families' support.
- There is a desperate need for funding from the state to support the children and the families affected by autism. Financial support from the state will enable

families to access the necessary services that are available to address their children's specific needs. There is also a need for government mainstream schools to become more inclusive to meet the needs of autistic children.

5.5. REFLECTION

Having worked in the field of autism for six years, this study was very meaningful for me. As programme manager of an early intervention centre specialised in working with autism, part of my duties have been to provide support to families affected by autism. During the interviews I realised that all three the families felt that they were deprived of necessary support from friends and families when these individuals did not understand the struggles they were facing due to autism. However, I have also realised that the three families have experienced considerable support from other families who are facing the same challenges. Providing opportunities for these families to meet or starting support groups could be very valuable for families. With this newly acquired information I have been enabled to adjust my approach to how I am supporting families who are raising a child with autism.

Having been a part of SNAP for many years prior to doing this research, I may have developed an insider view of the problem, and this might have worked to my advantage as a researcher. The families may have been more open and willing to share their personal stories with me as we have developed a trusting relationship over the years. However, because I am part of the intervention centre that their child is attending, they may have been hesitant to disclose negative information about the centre. Even so, the data collected was information rich and seemed to be an accurate reflection of the views of the participants.

During this research process, I gained valuable insight into the families' experiences. Some parents started to cry during the interviews. This was of great concern to me, because it led to the realisation that, even though these families were linked to a specialised intervention centre, parents currently are not supported sufficiently. Also of concern was their disappointment with the lack of support from role players such as the state, professional services, friends and families, usually as a result of a lack of understanding and knowledge about the disorder. It appeared that families enjoyed the opportunity to tell their stories within a psychologically safe environment.

5.6. CONCLUSION

Though there has been a tremendous increase in the prevalence of ASD and the amount of research conducted on this topic, little is known about the support structures of families from different cultural backgrounds in a South African context, or the support that is available to these families. Despite the good support that the three families who participated in this study enjoyed from different sources, they were still dealing with a variety of challenges. Often families deal with these difficulties by withdrawing from social activities and trying to deal with the challenges on their own. However, if support is not provided, a build-up of worries, the pressure of responsibilities, the tiredness due to dealing with the demands of the disorder, and feelings of disappointment may result in stress-related problems and depression at a later stage, and in some case become at risk for marital problems.

Awareness of ASD is another important aspect that needs to be addressed. A better understanding of the condition and the challenges that accompany it might have several positive outcomes for the support that families are receiving from their friends and families.

The manner in which the families participated in this study have adapted to tremendously challenging circumstances is astonishing. The stories told were unique and profound. In the midst of a devastating condition, these families found courage, perseverance and hope. Their optimism and strength is profound and they deserve society's admiration.

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APPENDIX A. ETHICAL CLEARANCE



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Approval Notice New Application

31-May-2012
HOFFMAN, Elaine

Protocol #: DESC2/2012

Title: Raising a child with autism: Exploring family support structures

Dear Miss Elaine HOFFMAN,

The **New Application** received on **13-Feb-2012**, was reviewed by staff members of the REC office on **23-Feb-2012** and was approved. Please note the following information about your approved research protocol:

Protocol Approval Period: **26-Apr-2012 -25-Apr-2013**

Standard provisions

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.

You may commence with your research with strict adherence to the abovementioned provisions and stipulations.

Please remember to use your **protocol number (DESC2/2012)** on any documents or correspondence with the REC concerning your research protocol.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) number REC-050411-032.

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant parties. For approvals from the Western Cape Education Department, contact Dr AT Wyngaard (awyngaar@pgwc.gov.za, Tel: 0214769272, Fax: 0865902282, <http://wced.wcape.gov.za>).

Institutional permission from academic institutions for students, staff & alumni. This institutional permission should be obtained before submitting an application for ethics clearance to the REC.

Please note that informed consent from participants can only be obtained after ethics approval has been granted. It is your responsibility as researcher to keep signed informed consent forms for inspection for the duration of the research.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 0218089183.

Included Documents:

DESC applications / checklist

Sincerely,

Sidney Engelbrecht
REC Coordinator
Research Ethics Committee: Human Research (Humanities)

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.
2. Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.
3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.
4. Continuing Review. The REC must review and approve all REC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur**. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.
5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.
6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouch within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the REC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.
7. Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC
8. Reports to Sponsor. When you submit the required reports to your sponsor, you **must** provide a copy of that report to the REC. You may submit the report at the time of continuing REC review.
9. Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.
10. Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.
11. On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

APPENDIX B. LETTER OF PERMISSION FROM SNAP



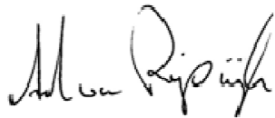
REG. NO. 2010/003266/08 • SNAP EDUCATION (ASSOCIATION INC UNDER SECTION 21) • PBO NO. 930035281

To whom it may concern

This serves to confirm that we at SNAP Education are fully informed of the research that Elaine Hoffman is going to be carrying out this year, and that she has our permission to do so.

We understand that Elaine needs access to our list of families on the program to be able to choose the research participants carefully. Elaine will approach the parents for consent regarding participation in her research.

Yours sincerely



Annalies van Rijswijk
PROGRAM DIRECTOR

Directors: A van Rijswijk (Managing Director),
CGM Vikos, M Bezuidenhout, N Visser

9 De Dam St, Vierlanden, Durbanville, 7550 • PO Box 1323, Durbanville, 7551
Tel/Fax: +27 (0)21 975 7224 • Info@snap.org.za • www.snap.org.za

APPENDIX C. CONSENT FORM



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Raising a child with Autism: Exploring family support structures

You are asked to participate in a research study conducted by **Elaine Hoffman**, a M Ed Psychology student from the **Department of Educational Psychology** at Stellenbosch University. I selected you as a possible participant in this study because of your suitability, which is that you are raising a child who meets the criteria in the Diagnostic and Statistical Manual of mental disorder (4th Ed, Text revision) for Autism or Pervasive Developmental Disorder Not otherwise specified. I am studying the support structure that parents have available to them, and the ways in which they access such structures.

1. PURPOSE OF THE STUDY

The purpose of this study is to gain a deeper understanding of the support that families from different cultural groups in South Africa are receiving whilst raising a child with autism. It is also to understand how they access the support.

2. PROCEDURES

Data will be collected through semi-structured interviews, observations and written reflections.

If you agree to participate in this study, we would ask you to do the following things:

- Both parents will have to be available and willing to be interviewed for an hour.
- You will be asked to invite me to one of your family events where I will observe your family for an hour.
- Both parents will be asked to keep a reflective journal.
- You might be asked to be willing to be interviewed again should I need to clarify something.

3. POTENTIAL RISKS AND DISCOMFORTS

This research aims to contribute to the general well-being of people. As such great care will be taken by me that your rights will not be abused for the purpose of gaining information and knowledge.

Should the interviewer feel it necessary, she will refer the participant to a counselling psychologist to provide support. The following counselling psychologist has experience in the

field of Autism and can be contacted: Carlyn Coetzee (carlynlightfoot@gmail.com, 082 556 8246).

4. PAYMENT FOR PARTICIPATION AND POTENTIAL BENEFITS TO SUBJECTS AND/OR SOCIETY

There will be no financial benefits for participation. However the findings of this study may help you as well as other parents who are dealing with the same challenges and could contribute to research that can be used to implement new policies to assist children with autism and their families. There are no costs for participating in the study other than the time you spend in the interview, doing my observation and on completing the written reflection.

5. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by using pseudonyms for you. Your names will not be known. Confidentiality will be maintained by means of keeping all records of your participation (the interview recording, field notes, written reflection and the signed consent form) locked away at all times, I will destroy all audio recordings after the research is completed.

6. PARTICIPATION AND WITHDRAWAL

Your participation in this study is voluntary. If you agree to be in this study, you still have the right to withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

7. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact me or my supervisor. My contact details are:

- Elaine Hoffman
Student number: 14028735
Cell phone: 083 204 2250
Email: elaine.hoffman@gmail.com

I am accountable to Prof. Doria Daniëls, my supervisor at Stellenbosch University.

- Her contact details are:
Telephone: (021) 808 2324
Fax: (021) 808 2021
Email: Doria@sun.ac.za

8. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by **Elaine Hoffman** in **English** and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Subject/Participant

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____
He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in English.

Signature of Investigator

Date

APPENDIX D. Semi-structured interview guide



DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

SEMI-STRUCTURED INTERVIEW GUIDE

Raising a child with autism: Exploring family support structures

The interview guide provides topics or subjects areas within which the interviewer is free to explore, probe and ask questions that will elucidate and illuminate that particular subject. Thus, the interviewer remains free to build a conversation within a particular subject area, to word questions spontaneously, and to establish a conversational style that but with the focus on a particular subject that has been predetermined (Patton, 2002).

Part 1: Personal Data

1. Name of the Participants (or code name) _____

2. Name of their child diagnosed with Autism (or code name) _____
3. Age _____
4. Age being diagnosed _____
5. Gender (boy/girl) _____
6. Do you have more children _____
7. Gender: Boys _____ Girls _____
8. Age _____
9. Do you have any extended family members or friends living with your family _____

10. Your family's cultural orientation _____
11. Professional background:
Mother: _____
Father: _____

Part 2: Support Structure – General

- I know that you are raising _____. Describe to me in one sentence, what is it like raising him/her?
- Positive answer – are there any days when it's not so easy raising _____?
- Challenging – in challenging times I can understand that you need more support from others.
- Today I would like to talk about the support that parents enjoy while raising _____? Can you tell me more about the support that you as parents are enjoying whilst raising _____?
- PROBE – Why is that? What do they do? Can you give an example? How does that make you feel?

Part 3: Support Structure – Professional Services

- What role does professional service play in your support network?
- How do they support you? Can you give an example?
- Are there any gaps? How would you like to be supported?

This is wonderful to know. I was wondering, what happens outside the support of professional services. I would like to start with your family.

Part 4: Support Structure – Partner and Siblings

- In your family you are a married couple. How do you support each other? Maybe we can start with you (mother/father) – how does your partner support you? What does he do? Can you give an example? How does that make you feel?
- Do you feel like you are receiving enough support? How can you feel more supported?
- Thank you for sharing that with me. It looks like you are a great support to each other. You have mentioned that you also have another child, _____? How would you describe his/her role in your support structure at home?

You have shared very interesting information with me about how professionals support you and how you as a family support each other with the challenges of raising _____.

Part 5: Support Structure – Extended Family

- I would now like to proceed to support that you are receiving from extended family members. When I talk about extended family members I talk about grandparents, aunts, uncles and cousins.
- Can you tell me about the role that your extended family play in your support structure?
- PROBE - How often do you meet? What do they do? How does that contribute to the support that you are receiving from them? How involved are they?
- In what way can you rely on them for help if you have a serious problem? What type of support would you like to receive from them?

Part 6: Support Structure – Friends, neighbours, cleaning lady, nannies etc.

- Do you have any friends that contribute to the support that you are receiving? How do they support you? Can you give me an example? How often do you meet? What do you do together?
- Why / why not? Have you asked them for support?
- How much can you rely on them for help if you have a serious problem?
- Who would you phone in a crisis?
- We have spoken about professionals, your family, extended family and friends that all contribute to your support structure. Is there anyone else that you feel is supporting you that we haven't spoken about? (neighbours, nannies, cleaning ladies etc.)
- Is there anything that I haven't asked that you would still like to talk about?

Thank you for the valuable information that you have shared with me. I have learned a lot from you and appreciate the time that you put aside to participate in my study.

APPENDIX E. REFLECTIVE JOURNAL



DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

REFLECTIVE JOURNAL

Raising a child with autism: Exploring family support structures

NAME (OR CODE NAME): _____

In this journal, I would like you to reflect on the support that you are receiving from Professionals, your partner, extended family, friends, community etc. whilst raising your child with autism. (You can type in this block and it will expand as you type)