

The Experience of having a Sibling with an Autistic Spectrum Disorder

By

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- As the candidate's Supervisor I have approved this dissertation/thesis for submission

Signed:.....

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Abstract

Autistic Spectrum Disorders have shown to be some of the most disruptive and bizarre childhood developmental disorders, affecting all relationships within the family (Glass, 2001). The sibling relationship is possibly one of the most important relationships in childhood development, affecting cognitive and emotional adjustment (Dunn, 2000; Sanders, 2004). While the effects on parents of having a child with an Autistic Spectrum Disorder are well documented, there is very little qualitative research that explores the experience from the sibling's perspective. Using Family Systems Theory as a framework for understanding, the question asked in this study was: "What is the experience of having a sibling with an Autistic Spectrum Disorder?" The study made use of a phenomenological approach, which was useful in exploring the 'lived world' of the participant. Making use of semi structured interviews, a focus group and various projective techniques and one participatory technique, three participants shared their thoughts, feelings and experiences of having a younger sibling with an Autistic Spectrum Disorder. Interpretive analysis guided by the Hermeneutic circle was used to analyze the data. The results showed a complex and protective relationship that also evoked feelings of frustration and embarrassment in the participants. While the relationship was difficult, there was no indication that the participants faced any emotional or adjustment difficulties. Furthermore, the effective coping mechanisms that were utilized by the participants were highlighted. The study also aimed to provide recommendations for care-givers and professionals, as well as future research in this area.

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION.....	1
1.1 AIMS AND OBJECTIVES OF THIS STUDY.....	2
<i>1.1.1 Aims of the Study.....</i>	<i>2</i>
<i>1.1.2 Objectives.....</i>	<i>2</i>
1.2 METHODOLOGICAL APPROACH	3
1.3 DEFINITION OF TERMS.....	3
1.4 OUTLINE OF THE STUDY.....	5
CHAPTER 2: LITERATURE REVIEW	6
2.1. UNDERSTANDING AUTISTIC SPECTRUM DISORDERS.....	6
<i>2.1.1 A Historical Perspective of Pervasive Developmental Disorders and Autism</i>	<i>6</i>
<i>2.1.2 Diagnosis of Autistic Spectrum Disorders.....</i>	<i>8</i>
<i>2.1.3 Etiology.....</i>	<i>10</i>
<i>2.1.4 Treatment of Autistic Spectrum Disorders.....</i>	<i>12</i>
2.2 FAMILIES OF CHILDREN WITH AUTISTIC SPECTRUM DISORDERS.....	13
<i>2.2.1. Family Systems.....</i>	<i>13</i>
<i>2.2.2 Challenges for the family.....</i>	<i>16</i>
<i>2.2.3 The Sibling Relationship.....</i>	<i>18</i>
<i>2.2.4 Siblings and Autistic Spectrum Disorders</i>	<i>20</i>
2.3. CONCLUSION AND RATIONALE	24
CHAPTER 3: RESEARCH AIMS AND METHODOLOGY.....	26
3.1 RESEARCH QUESTION AND AIMS	26
3.2 RESEARCH DESIGN	26
3.3 SAMPLING	28
3.4 DATA COLLECTION	30
<i>3.4.1 The Interviews.....</i>	<i>30</i>
<i>3.4.2 The Focus Group</i>	<i>30</i>

3.4.3 <i>Participatory Techniques</i>	31
3.5 THE RESEARCH PROCESS	33
3.5.1 <i>Informed Consent</i>	33
3.5.2 <i>Interviews</i>	33
3.5.3 <i>Focus group process</i>	33
3.5.4 <i>Ethical Considerations</i>	34
3.6 DATA ANALYSIS	35
3.7 TRUSTWORTHINESS IN QUALITATIVE RESEARCH	37
CHAPTER 4: RESULTS	41
4.1 THE INTERVIEWS	41
4.1.1 <i>Common perceptions of ASD and their sibling</i>	41
4.1.2 <i>Nature of the relationship</i>	43
4.1.3 <i>Perceptions of the family system</i>	46
4.1.4 <i>Social adjustment and coping</i>	48
4.2 THE FOCUS GROUP	50
4.2.1 <i>Common Perceptions of ASD and their sibling</i>	50
4.2.2 <i>Nature of the relationship</i>	52
4.2.3 <i>Perceptions of the family system</i>	54
4.2.4 <i>Social adjustment and coping</i>	56
4.3 CONCLUSION	58
CHAPTER 5: DISCUSSION	59
5.1 COMMON PERCEPTIONS OF ASD AND THEIR SIBLING	59
5.2 THE NATURE OF THE SIBLING RELATIONSHIP WITH AN ASD CHILD	62
5.3 SOCIAL ADJUSTMENT AND COPING	66
5.4 THE FAMILY SYSTEM	67
5.5 THE EXPERIENCE OF HAVING A SIBLING WITH AN ASD	74
CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH AND PRACTICE	77
6.1 CONCLUSIONS ABOUT THE FINDINGS	77

6.2 STRENGTHS AND LIMITATIONS 78

6.3 RECOMMENDATIONS FOR FUTURE RESEARCH AND PRACTICE 80

REFERENCES.....82

APPENDIX A87

APPENDIX B88

APPENDIX C89

APPENDIX D90

CHAPTER 1: INTRODUCTION

Through her previous experience in working with children with Autistic Spectrum Disorders (ASDs) and their families, the researcher noticed that, while ample attention was given to the ASD child in the family – with speech and language therapy, as well as Occupational therapy and private tutors – noticeably less attention was paid to the non-affected sibling. In this sense, it appeared that the non-affected sibling has been somewhat overlooked, fading into the background. A preliminary review of the literature highlighted the importance of the sibling relationship in terms of its influence on adjustment, coping and development in children. Authors such as Merrel (1995), Sanders (2004), Brody (2004) and Dunn (2000) suggest that the sibling relationship is elemental in the social and emotional development of the child. Merrel (1995) in particular, goes so far as to suggest that future adult relationships are often affected by early sibling relationships.

Using Family Systems Theory as a point of departure, one can see how the sibling relationship is affected by a change in the family system. Introducing a child with a disability into the family system impacts heavily on the system, including the marital unit as well as the way in which the parents relate to their children (Sanders, 2004; Yama, 1990). Consequently, the sibling relationship is also impacted upon when one child has a disability. While ASD has become one of the most commonly diagnosed childhood disorders, it is also one of the most complex and disruptive conditions, with often bizarre and complicated characteristics (Glass, 2001). This condition is known to place a large amount of strain, both financially and emotionally, on families. The literature shows that there has been a dramatic rise in the incidence of ASDs and, according to Sicile-Kira (2003), it is now said to be “reaching epidemic proportions in the UK, the US and other countries” (p 9). While there are currently no medical or objective tests to accurately diagnose ASDs, they have become one of the most common developmental disabilities (Glass, 2001; Sicile-Kira, 2003). It was, therefore, important to explore the effects this disorder, in particular, may have on the sibling relationship.

A review of the literature highlighted that a large amount of research has focused on the parental experience of having a child with an ASD, with fewer studies focusing on having a sibling with

an ASD. Previous studies conducted have all been quantitative in nature and tend not to focus solely on siblings of children with ASDs, but focus on siblings of children with disabilities in general. Furthermore, the research that has been conducted on sibling relationships within a family with an ASD child has conflicting findings. Some studies claim that there is a more positive element in the relationship with an ASD child than in normative samples, while others either show no difference between the ASD family and the normative sample, or a negative aspect in the relationship between the sibling and ASD child. Moreover, the quantitative nature of these studies does not allow for the exploration of ambiguity, or complexity that is evident in the sibling relationship and does not offer an in-depth account from the non-affected sibling's perspective. As a result, this study aimed to provide a richer account of what it is like to have a sibling with an ASD.

1.1 Aims and Objectives of this study

The study addressed the following aims and objectives

1.1.1 Aims of the Study.

1. The first aim of the study was to explore the non-affected siblings' understanding and construction of their siblings' disorder.
2. Secondly, the study aimed to investigate how this disorder affected the nature of the sibling relationship between them, from the non-affected sibling's perspective.
3. Furthermore, the researcher was also interested in looking at what coping mechanisms (if any) were employed by the non-affected siblings in dealing with their ASD siblings' condition.
4. Lastly, the study also sought to explore the non-affected sibling's perspective of the family system.

1.1.2 Objectives

In exploring the abovementioned aspects of the experience of having a sibling with an ASD, the researcher hoped to answer the question: “What is the child’s experience of having a sibling with an Autistic Spectrum Disorder?”

Further objectives are as follows:

1. To increase parents’ awareness of their neurotypical child’s experience, thereby providing information about the various stressors faced by the child and guidelines for maximizing the protective factors.
2. To provide professionals with a deeper understanding of the non-affected child’s experience when called upon to assist with the loneliness and adjustment difficulties that siblings of children with an ASD often face.
3. To provide recommendations for future research in this area.

1.2 Methodological Approach

As the study aimed to be exploratory in nature and was interested in the non-affected siblings’ perspective, a qualitative approach and phenomenological perspective were used. The study, thus, made use of individual interviews, a focus group and various participatory and projective techniques with three selected participants to obtain the in-depth information necessary to explore the abovementioned questions and hypothesis. The data was recorded, transcribed and then analyzed using the hermeneutic circle, which allowed for the researcher to remain cognisant of her own preconceived ideas and assumptions regarding this experience. The methodology is described in more detail in chapter three.

1.3 Definition of Terms

Autistic Spectrum Disorders: This is a term used to describe a range of psychological conditions that are characterized by impairments in social interactions and communications, as well as behaviour. The term is used interchangeably with ‘Pervasive Developmental Disorders’ (National Institute of Mental Health [NIMH], 2008).

Pervasive Developmental Disorders: are defined by the American Psychological Association (2000) as a range of disorders usually diagnosed in childhood that are characterized by impairment in three main areas. These areas are: (i) impairment in communication, (ii) impairment in reciprocal relationships and (iii) having stereotyped, or repetitive behaviour. Within this range, the DSM-IV-TR (APA, 2000) describes a variety of conditions that range from severe (such as Autistic Disorder) to the milder forms, such as Asperger's Disorder. The term 'Pervasive Developmental Disorders' or 'Autistic Spectrum Disorders' is, thus, used to refer to the range of conditions from mild to severe that present with the abovementioned impairments.

Autistic Disorder: This is a Pervasive Developmental Disorder where the impairment in reciprocal social relationships is remarkable and continuous, often with marked impairment in the use of non-verbal behaviours such as eye contact and facial expression (APA, 2000). Furthermore, the DSM-IV-TR also describes Autistic disorder as having gross and sustained impairment in communication where there is a delay, or complete lack, of spoken language. Lastly, children with Autistic Disorder often display repetitive, bizarre and/or stereotyped behaviour (APA, 2000).

Autism/Autistic: A term used to refer to Autistic Disorder (Autism), or used to refer to an individual with Autistic Disorder (Autistic)

Asperger's Disorder: Another Pervasive Developmental Disorder similar to Autistic Disorder. In contrast, however, Asperger's Disorder does not show any marked deficits or delays in language acquisition, although the more subtle nuances of social communication may be affected (APA, 2000). Furthermore, in the first three years of life, there are no clinically significant delays in cognitive development, age-appropriate learning skills and adaptive behaviours. In this sense, Asperger's Disorder only presents with impairment in social relationships and communication, and bizarre or stereotyped interests and behaviour (APA, 2000).

Neurotypical: This is a term used by those within the Autism community to describe people with neurological development that is consistent with what is perceived of as 'normal' (National

Autistic Society [NAS], 2008). It is the appropriate way of referring to a 'normal' child who does not have Autism.

Family Systems Theory: This is a theory originally developed by Murray Bowen that, contrary to traditionally psychology that focuses on the individual, focuses instead on a 'system' (Perelli, 2008). The theory understands conflict, difficult relationships and loneliness to name but a few in terms of the family unit that is interconnected and interdependent (Perelli, 2008). In this sense, individuals form part of a family system that works together and produces a result.

1.4 Outline of the study

A brief overview of the following chapters is provided below:

Chapter one has introduced the background and context to the study, illustrating the aims and objectives of the study, as well as the methodology used in answering the research question. It has also clarified some of the terminology used in this study.

Chapter two discusses the relevant literature pertaining to ASDs, family systems theory and the previous research that has been conducted with siblings of children with ASDs.

Chapter three highlights the methodology used for data collection and analysis, dealing also with issues around ethics in research and the reliability and validity of this study.

Chapter four presents the results, which provided a rich and full description of the experience of having a sibling with an ASD, providing insight into the nature of the relationship, the coping mechanisms used and the structure of each of the participants' families.

These results are discussed in more depth in chapter five highlighting any tensions in the data.

The last chapter concludes the study with a discussion around the possible limitations of this study, as well as highlighting the useful insights for both care-givers and professionals and providing recommendations for future research and practice.

CHAPTER 2: LITERATURE REVIEW

The following chapter provides a review of the literature pertaining to Autistic Spectrum Disorders and their effect on the family, and sibling relationship in particular. A broad overview of Autistic Spectrum Disorders, including the diagnosis, etiology and treatment thereof is first provided. Thereafter, the literature review will illustrate how ASD's impact on the family as a whole, and, using Family Systems Theory, show how this impact extends to the sibling relationship.

2.1 Understanding Autistic Spectrum Disorders

2.1.1 A Historical Perspective of Pervasive Developmental Disorders and Autism.

The formal identification of the group of disorders known as Autistic Spectrum began approximately sixty years ago. Since then various authors have contributed to the classification and development of disorders along this continuum. Since its discovery 60 years ago, Autism has remained a fascinating condition, which, until recently, was considered to be a rare condition with paradoxical signs and strange symptoms (Aarons & Gittens, 1999; Wolff, 2004). While there seem to have been many writings about 'insane children' before the 1940's, and even as far back as the 1800's, that describe conditions very similar to Autistic Disorder, it was not until 1943 that Kanner provided the name "Autism" (Aarons & Gittens, 1999; Delfos, 2005; Volkmar & Wiesner, 2004; Wolff, 2004). The term was applied by Kanner to children who exhibited "extreme Autistic aloneness, abnormal speech with echolalia, pronomial reversal, literalness and an inability to use language for communication as well as monotonous repetitive behaviours with an anxiously obsessive desire for the maintenance of sameness" (Wolff, 2004, p. 203). Unfortunately some confusion was caused at the time due to the fact that the term 'Autistic', originally Greek for 'self', had been used by Eugene Bleuler in 1911 to describe withdrawal into fantasy by Schizophrenic patients (Aarons & Gittens, 1999; Delfos, 2005; Ginn, 2007). In following more than 100 affected children, Kanner not only found that the parents of such children also held a degree of aloofness - suggesting a genetic causation - but that there was also

a higher prevalence amongst boys (Wolff, 2004). Through his research he was able to devise a list of classic symptoms for the disorder, which were as follows:

1. An inability to develop relationships
2. Delay in the acquisition of language
3. Non communicative use of spoken language
4. Delayed echolalia
5. Pronominal reversal
6. Repetitive and stereotyped play
7. Maintenance of sameness
8. Good rote memory
9. Normal physical appearance
10. Extreme aloneness, with onset within first 2 years (Delfos, 2005).

During the same time, however, Hans Asperger was writing about “Autistic Psychopathy in childhood” describing a condition similar to Kanner’s ‘Autism’ (Aarons & Gittens, 1999; Frith, 1991). Here, Asperger described children who often had a remarkable ability in Mathematics or Natural Science, but had poor social skills and emotional relationships. Furthermore, he described such children as lacking empathy for others, making idiosyncratic use of language and having stereotypic behaviours (Wolff, 2004). Asperger also felt that parents held similar attributes, but he ascribed the condition as possibly being due to an “extreme variant of male intelligence” (Frith, 1991; Wolff, 2004). Furthermore, during this time of discovery it was also commonly assumed that Autism was as a direct result of poor parenting and that it was closely associated to Schizophrenia as a form of Psychosis (Wolff, 2004). Both these ideas have since been proven false and viewing Autism as a ‘developmental disorder’ illustrates the fallacy in the abovementioned ideas.

Despite his ground breaking work, Kanner had described the condition too narrowly and did not account for children who held some of the symptoms, but did not fit all the criteria exactly. As a result the criteria widened during the 1960’s and 1970’s, which consequently led to an influx of children being diagnosed with Autism and/or Schizophrenia (Wolff, 2004). During the 1980’s

however, Asperger's work was discovered and the notion of 'higher functioning' Autism, with which Asperger's Syndrome is now often equated, was introduced (Wolff, 2004). Furthermore, this discovery led to the advent of the notion of an 'Autistic Spectrum' wherein children who display Autistic features are diagnosed along a continuum of functioning.

2.1.2 Diagnosis of Autistic Spectrum Disorders

While there are currently no medical or objective tests to accurately diagnose Autistic Spectrum Disorders, Autism has become one of the most commonly diagnosed developmental disabilities (Glass, 2001; Sicile-Kira, 2003). According to recent literature, there has been a dramatic rise in the incidence of Autistic Spectrum Disorders (ASD) and, according to Sicile-Kira (2003) it is now said to be "reaching epidemic proportions in the UK, the US and other countries" (p 9). While Autism may have increased with regard to the rate of incidence, it has remained a relatively complicated disorder that is not easily understood.

The classic criteria first described by Kanner have evolved over time to allow for a more descriptive set of criteria that take into account variance among different children. In the past a diagnosis of Autistic Disorder was made by counting up a requisite number of points over a set of symptoms. This method, however, was not effective as it did not allow for children who had many of the features characterizing the condition, but not the required number of points for a diagnosis (Aarons & Gittens, 1999). In taking the autistic spectrum into account, Autism is currently recognized as being part of a group of disorders collectively known as 'Pervasive Developmental Disorders' (PDD) (Siegel, 1996). The DSM-IV-TR (APA, 2000) describes PDD as "severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests and activities" (p.69). In this sense, PDD is an umbrella term used to describe associated disorders such as Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (Siegel, 1996). In other words, PDD is often used synonymously with Autistic Spectrum Disorders (ASDs) and is a term that is used to categorize childhood developmental conditions that are similar.

The DSM-IV-TR (APA, 2000) lists the criteria for a diagnosis of Autistic Disorder as follows:

- A. A total of six or more items from items 1, 2 and 3, with at least two from 1 and one each from 2 and 3;
 - 1) Qualitative impairment in social interaction marked by at least two of the following:
 - a) marked impairment in the use of non-verbal behaviours such as eye contact, facial expression, body postures, and gestures to regulate social interaction
 - b) failure to develop peer relationships appropriate to developmental level
 - c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with others
 - d) lack of social or emotional reciprocity
 - 2) Qualitative impairments in communication as manifested by at least one of the following:
 - a) delay in or lack of development in spoken language
 - b) in individuals with adequate speech, marked impairment in ability to initiate and sustain conversation
 - c) stereotyped or repetitive use of language
 - d) lack of varied make-believe play or social imitative play appropriate to developmental level
 - 3) Restricted repetitive and stereotyped patterns of behaviour, interests and activities as manifested by at least one of the following:
 - a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal whether in intensity or focus
 - b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c) stereotyped and repetitive motor mannerisms
 - d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas with onset prior to 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disorder is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

(APA, 2000, p75)

Eaves and Ho (2004) explained that children with ASD appear to develop appropriately in the first year of life, meeting milestones and perhaps making utterances. However, by 30 months they can be identified as having ASD due to their asocial behaviours including lack of eye contact, lack of response to their name, poor motor imitation, lack of shared interest and joint attention (cited in Layne, 2007). Furthermore, a lack of verbal and non verbal communication and an inability to engage in imaginary play are also indicators (Layne, 2007). The difference between Autistic Disorder, in particular, and other PDDs is small. Rett's Disorder, for example, differs only in that the onset of symptoms occurs after a period of normal development and there is a loss of previously acquired skills. Similarly Childhood Disintegrative Disorder is diagnosed only when there has been a significant loss of previously acquired skills (APA, 2000). All of these disorders, however, are eventually marked by social and communicative impairment and stereotypic patterns of behaviour (Sadock & Sadock, 2003).

While the DSM-IV refers to 'Autistic Disorder' in particular, the notion of an 'Autistic Spectrum Disorder' (ASD) appears to be more widely accepted in describing a condition that varies across levels of functioning and will, therefore, be the term used in the remainder of this study.

2.1.3 Etiology

The question often arises as to what the causal or etiological factors of ASD's are. Autism, according to Sadock and Sadock (2003, p 1208), is known as a "developmental behavioural disorder". While Kanner originally thought that the condition was as a result of emotionally unavailable, 'cold' mothers, the validity of this theory has been strongly negated (Sadock & Sadock, 2003; Wolff, 2004). Sadock and Sadock (2003) provide an extensive view into the etiology of the condition, illustrating that theories regarding parental rage or reinforcement of autistic symptoms as causal are unsubstantiated. Studies comparing parents of ASD children with parents of neurotypical children have shown no difference between the two (Sadock & Sadock, 2003). On the other hand, however, there is strong evidence to support the theory that there is a biological and genetic basis for the disorder (Aarons & Gittens, 1999; Sadock & Sadock, 2003).

In this sense, research has suggested that, not only do relatives stand a higher than average chance of having an ASD, but that families usually have a higher percentage of members with speech disorders, learning difficulties and other cognitive difficulties (Aarons & Gittens, 1999; Sadock & Sadock, 2003). Furthermore, there also appears to be a high rate of Mental Retardation amongst children with ASD's showing marked deficits in abstract reasoning, social tasks and verbal performance (Sadock & Sadock, 2003). Research has also shown a correlation between "immunological incompatibility" and ASD's where the lymphocytes of some children react with the maternal antibodies such that tissues are damaged during pregnancy (Sadock & Sadock, 2003).

Other etiological factors, according to Sadock and Sadock (2003), include perinatal factors, where maternal bleeding after the first trimester and meconium in the amniotic fluid have been reported to be associated with ASD children. Neuroanatomical factors show that brain volume is larger in those with an ASD and, consequently, brain enlargement has become a possible biological marker for the disorder (Sadock & Sadock, 2003). Furthermore, as Sadock and Sadock (2003) show, a large number of studies have also shown that one third of patients with an ASD have a higher plasma serotonin concentration illustrating that biochemical factors may also be at play.

Lastly, there is the controversial theory that the Measles, Mumps and Rubella (MMR) vaccination is associated with ASD's. Studies conducted have shown that the increase in prevalence of ASD's started when the MMR vaccine came to be widely used and that the onset of an ASD at 18 months correlates with the administering of the vaccine around the same age (Rimland, 2000). While only traces of mercury are supposedly found in the vaccine, even miniscule amounts of the toxin can do harm in young children whose blood-brain barrier are underdeveloped (Cook, 2005). Since the allegations against the MMR vaccine have been made, a large amount of research has focused on the area (Kmietowicz, 2007), but the verdict remains unclear as to whether there is a plausible causal link between the vaccine and ASD's. As Kmietowicz (2007) writes, many scientists have tried to establish a connection between the vaccination and ASD, but have failed. Essentially, however, the allegations against the MMR

vaccination has led to many parents refusing to have their children vaccinated (Kmietowicz, 2007).

Ultimately, there is no known definite cause of ASD's and, as Sicile-Kira (2003) points out: it is far easier to talk of what does not cause the condition. In other words, "it is known for fact that ASDs cannot be caught through osmosis, dirty doorknobs, or bad parenting. Other than that, nothing can be said for sure" (Sicile-Kira, 2003, p. 27).

2.1.4 Treatment of Autistic Spectrum Disorders.

Sicile-Kira (2003) emphasizes that some children may continue into adulthood without ever being diagnosed with an ASD. This is due to the fact that difficulties amongst individuals on the spectrum vary greatly and may, in some cases, be viewed as slow or delayed development. The fact that difficulties are often ascribed to 'late development' makes early diagnosis and treatment difficult (Sicile-Kira, 2003).

Early detection is of utmost importance as early intervention has shown to affect a better prognosis (Layne, 2007; McVeagh, 2007; Sicile-Kira, 2003). Treatments of ASD's typically range from behavioural techniques, such as Applied Behaviour Analysis (ABA) and Pivotal Response Intervention (PRI), to interventions aimed at improving social interaction, such as Response Development Intervention (RDI). Beginning in the 1960's the intervention strategies for ASD's focused on social learning theory resulting in behavioural techniques based on the principles of learning (Koegel, Koegel, & McNeerney, 2001). Interventions such as ABA tend to focus on ignoring unwanted behaviours and rewarding the correct or required behaviours, thereby creating compliance and reducing disruptive behaviour (Mehl-Madrona, 2006). Such techniques are carried out in a structured manner and often involve the child and therapist sitting at a table. In this sense, PRI is an offshoot of the traditional behavioural approach whereby techniques are used in a natural environment where the child is already interacting and the therapist rewards activities that s/he does well (Mehl-Madrona, 2006). On the other hand, RDI is an unstructured method that makes use of shared interest and enjoyment between the therapist and child through the use of activities and games that the child enjoys. As a result the child

learns to understand and make use of non-verbal social communication. Essentially, all interventions hope for generalized imitation and socially appropriate behaviour (Koegel *et al.*, 2001). Furthermore, while there are interventions such as Vitamin and Nutritional Therapy (Mehl-Madrona, 2006), the abovementioned interventions are the most commonly used.

With the wide range of interventions available, from pharmacotherapy to behaviour analysis, treatment seeking becomes the pivotal role of parents of children with ASD's (Trepagnier, 1999). In fact, it is often the case that when parents hear of a new treatment they are often tempted to try it in the hopes that it may help their child in a way that previous interventions had not (Trepagnier, 1999). As Trepagnier (1999) discusses, aside from the enormous financial costs these interventions incur, there is also the human cost of effort, time and worry. In this sense, interventions often require consistent implementation across contexts and can be both time and energy consuming. Parents often worry whether the intervention is the best method of treatment and wonder whether it is suited to their child (Trepagnier, 1999).

An overview of the diagnosis, etiology and treatment of ASD's has been provided. As the family is the object of enquiry in this study, the literature review will now focus on the impact that an ASD may have on the family.

2.2. Families of Children with Autistic Spectrum Disorders

The focus of this study is the impact of an ASD on the family, and siblings, in particular. A conceptual framework, which is useful in explaining the multiple, complex relationships in families, is Family Systems Theory. A brief overview of this framework is, therefore, provided, after which the specific challenges for the family of an ASD child, and the literature on sibling experiences in particular, are reviewed.

2.2.1 Family Systems

Family Systems Theory recognizes that children are embedded within a multitude of systems that have both a direct and indirect influence on behaviour (Rivers & Stoneman, 2003). In the

past, family therapists such as Haley (1973), Minuchin (1974) and Whittaker (1977) described the family structure in terms of a system (Yura, 1987). In this sense, the arrival of a disabled or special needs child has large implications for the child her/himself, as well as for the system of which s/he is a part. As Yura (1987) highlights, within this family system, there are various subsystems that include the parental subsystem, the marital subsystem, the sibling subsystem and the extra family subsystem (See Figure 1 below).

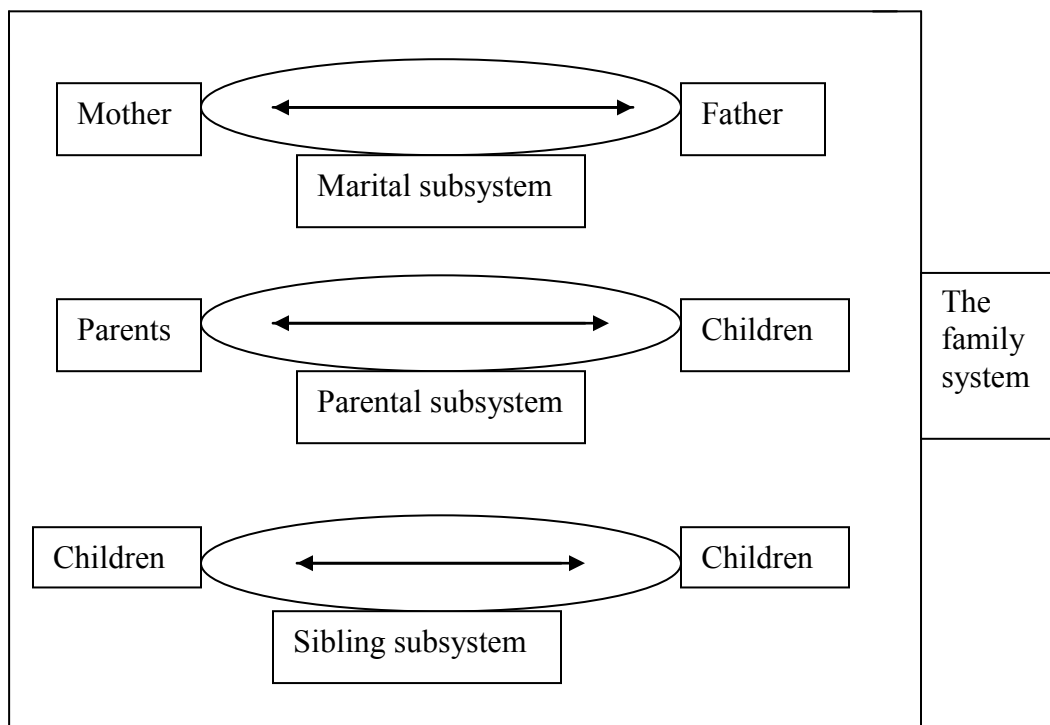


Figure 1: The family subsystems (Sanders, 2004)

Yura (1987) and Sanders (2004) elaborate on this concept, illustrating the reciprocal nature of influence between the subsystems (Figure 2). In this sense, the parental subsystem, which includes all interactions between the parents and the children, may be affected by the parents' initial feelings of anxiety over the diagnosis, as well as sadness and anger discussed in more detail below. Similarly, parents often develop an over-protective attitude toward the child thereby fostering dependence and reinstating the belief that the special needs child is helpless and dependent (Yura, 1987). As Schuntermann (2007) also argues, the perspective in developmental research states that parents are often the transmitters of patterns of thoughts,

behaviours and attitudes and that siblings then tend to resemble their parents (Schuntermann, 2007).

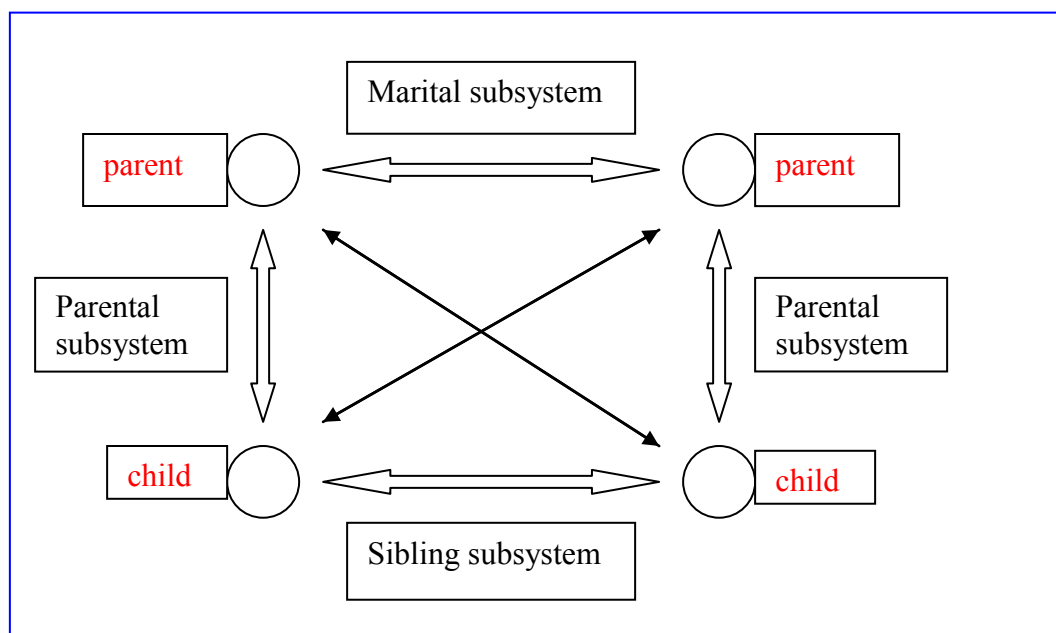


Figure 2: The reciprocal influence between subsystems (Sanders, 2004)

The marital subsystem is also affected where the special needs child is often perceived as a symbol of shared failure and a potential area for discord develops. On the other hand, many marriages are also strengthened by the introduction of a special needs child into the system (Sanders, 2004). In a similar vein the sibling subsystem is affected both positively and negatively depending on the nature of the previous subsystems and their interactions and responses to having a child with special needs (Yura, 1987). So, for example, if the mother interacts in an over-protective manner with the special needs child, it is also likely that the non-affected sibling will feel more responsibility for his/her sibling.

Furthermore, as Sanders (2004) illustrates, it is not only individuals within the system that influence one another, but that relationships may also influence other relationships within that family. For example, a father is influenced by the relationship between mother and child just as the child is influenced by the relationship between the parents. In the same sense, the sibling relationship can be influenced by the marital relationship (Sanders, 2004). Such influential streams may be classified into three groups: first order, where individuals influence one another,

second order, where a relationship influences an individual, and third order, where relationships influence other relationships (Figure 3).

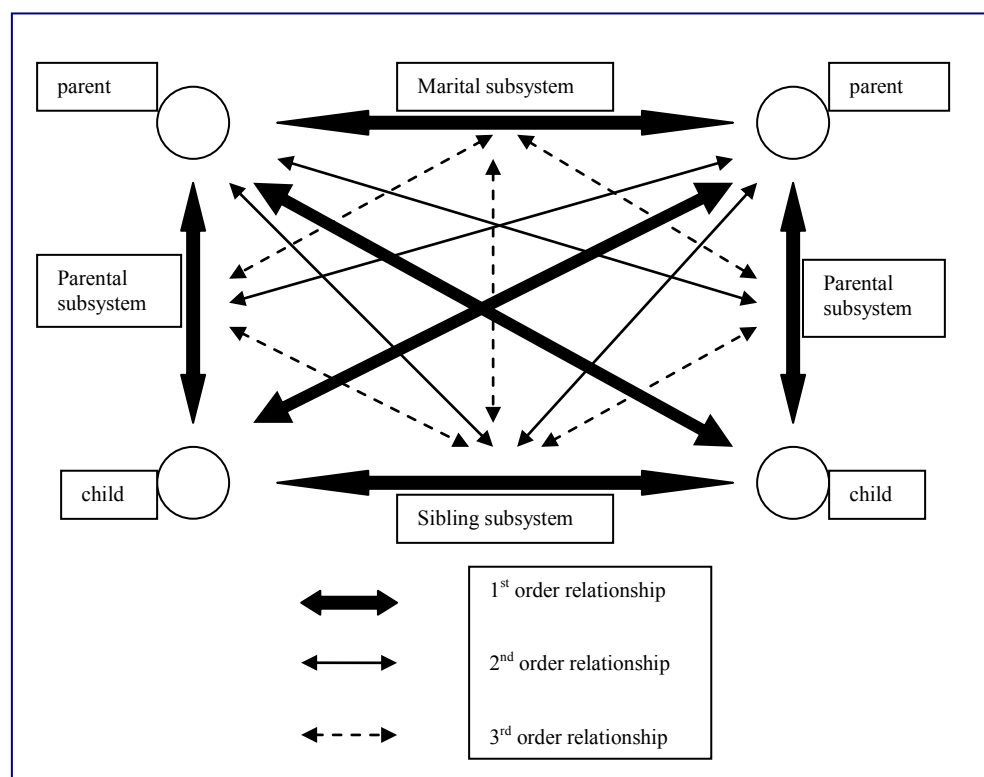


Figure 3. First, second and third order relationships (Sanders, 2004)

In summary, then, the various subsystems and nature of interactions between them are affected both positively and negatively when there is an ASD child in the family. These subsystems, in turn, also have an effect on the functioning of the system as a whole. This understanding of the family as a system predicts, therefore, that family factors, such as parental stress or maternal depression (Rivers & Stoneman, 2003), lack of support, or disability within the family may affect the quality of the sibling relationship.

2.2.2 Challenges for the family

Right from the start, the experience of realizing that there is a child with an ASD in the family is a difficult one. Diagnosis is seldom reached quickly, suggesting a period of uncertainty and concern. Once diagnosis is achieved, however, the sense of relief felt is often accompanied by

anxiety and sadness (Trepagnier, 1999). The very term “Autistic Spectrum Disorder” tends to make parents rethink their child’s potential future and create a sense of fear of what lies ahead (Hodge, 2005). As Hodge (2005) also states, the fact that the label does not classify a particular set of behaviours, but encompasses a broad range of possibilities and eccentricities, means that parents often feel insecure and unsure about how their child will be in the future.

Siegel (1996) agrees that there are many aspects of coping with the diagnosis that are very similar to the stages of grief that are experienced when a loved one dies. The difference is only that the ‘death’ that the parent experiences is actually the death of an idealized child (Siegel, 1996). Furthermore, the experience in coping with a diagnosis of Autism may actually carry with it a unique burden, namely that the child is impaired in social reciprocity. In this sense, parents are often deprived of a reciprocal relationship with their child where love, needs and affection are expressed (Siegel, 1996). Moreover, the impact on the marital relationship is high where it is very possible that husband and wife lose one another, as well as their own identities, in the struggle to meet the extraordinary demands of raising a child with an ASD (Siegel, 1996). The damaging effects on marital relationships may range from divorce, where one spouse completely separates themselves from the family, to arguments on who gets up with the child on sleepless nights (Glass, 2001). The first dynamic contributing to this disruption is very often the fear that discipline or restriction will be experienced by the ASD child as rejection. This fear, as Siegel (1996) elaborates, stems from the child’s aloofness and the fear that any form of rejection will exacerbate this. As a result, the child is often allowed to destroy all sorts of household items in the form of ‘play’, behave in ways that are disruptive and chaotic and, quite simply, do what s/he wants to. Consequently, family functioning often depends on how the family meets the many challenges and stressors faced in raising a child with an ASD (Glass, 2001; Siegel, 1996).

The stressors faced by families differ across contexts and families often face very different challenges (Glass, 2001). The behaviours and idiosyncrasies of ASD children differ markedly. As a whole, however, the behaviors and characteristics associated with ASDs may appear to be quite bizarre and are typically quite disruptive to family life (Glass, 2001). For instance, some associated characteristics may include lack of eye contact, self-injurious behaviours, hyperactivity and impulsivity (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004), as

well as sleep and eating disturbances, obsessions and compulsions, and the keeping of non-functional routines that may disrupt family functioning. Studies by Bristol and Schopler (1983), Holroyd and McArthur (1976), Wolfe (1989), and Sanders and Morgan (1997) report that parenting stress is significantly higher in parents of ASD children when compared to parents of children who have Down Syndrome, Mental Retardation, or are normally developing (cited in Glass, 2001). Parents, however, are not the only ones affected by the diagnosis and challenges faced by raising an Autistic child in the family. The symptoms of the disorder, as Glass (2001) states, do not occur in a vacuum and, as a result, the family as a whole is likely to be affected. Therefore, not only is the marital relationship affected by having a child with an ASD in the family, but so too is the relationship between parents and children, as well as the sibling relationship itself.

2.2.3 The Sibling Relationship

In taking the family system into account and for the purposes of this study, the sibling subsystem in particular will be highlighted. Until recently, studies of the family system have not focused on the importance of the sibling relationship (Kaminsky & Dewey, 2001; Sanders, 2004), but research is illustrating that the sibling relationship is one of the most pivotal and impacting relationships studied (Sanders, 2004). In this sense, researchers are beginning to find that the emotional ties in the sibling relationship are second only to the ties between children and parents (Rivers & Stoneman, 2003). Dunn (1988) has gone so far as to describe the sibling relationship as “distinctive in its emotional power and intimacy, its qualities of competitiveness, ambivalence and of emotional understanding” (cited in Sanders, 2004, p.1). Siblings affect one another from earliest childhood throughout life in a variety of ways: learning from them, envying them, dominating or being dominated by them, hating them and loving them, to name but a few (Merrel, 1995). As Merrel (1995) discusses, the nature of intimate relationships in later life are often greatly influenced by early interactions with siblings and, as a result, more research into the sibling relationship is required.

It is only since the beginning of the 1980’s that there has been a growing interest in research exploring the aspects of the sibling relationship that contribute to cognitive, social and emotional

adjustment (Brody, 2004). In this sense, the sibling relationship has been found to be an influence in the development of cognitive abilities, empathy, pro-social and antisocial behaviours (Deater-Deckard, Dunn, & Lussier, 2002). Factors such as differential treatment by parents, being the older or younger sibling, providing care-giving and the extent of responsibility of the child are all proposed to have an effect on the adjustment of siblings (Brody, 2004). For example, as Brody (2004) suggests, an older sibling who assumes a teaching or care-giving role often develops greater cognitive competence. When this care giving role becomes excessive, however, it may impact negatively on his cognitive or social adjustment. Furthermore, parental behaviour often becomes a symbol used in indicating the extent to which the child is loved or rejected by the parents. This belief by the child that s/he is receiving less warmth and attention than her/his sibling has also been associated with poor emotional and behavioural adjustment (Brody, 2004). As Schuntermann (2007) suggests, children are vigilant about the ways in which their sibling receives affection and discipline. As a result, the relationship between siblings is likely to be compromised when children formulate negative attributions to the differential treatment by parents. Moreover, maternal differential treatment has, in fact, been associated with more conflict and hostility in the sibling relationship (Schuntermann, 2007). The perceived legitimacy of the differential treatment determines whether adjustment is affected negatively or not. In this sense, children who perceive this treatment as unjust or unfair tend to experience lower levels of self worth or other negative reactions (Brody, 2004).

In order to understand the nature and effect of the sibling relationship fully, it is necessary to take cognizance of the above discussion on family systems and subsystems. In this sense, the sibling relationship, and experience thereof, is largely influenced by the interaction between the various subsystems (Sanders, 2004). In applying this to the field of ASDs, one can see how the parent – ASD child relationship may have an influence on the non-affected sibling, as discussed above in terms of differential treatment. In this sense, the subsystems, and system as a whole, are affected when there is a child with a disability such as ASD. This affects not only the cohesion and functioning of the family as a whole, but the nature and degree of relationships within that system. The overall quality of the sibling relationship contributes to the psychological well-being of children, rendering the experiences within that sub system very important (Ross & Cuskelly, 2006). As a result, as Ross and Cuskelly elaborate, it is essential that we increase our

understanding of the impact that a possible disturbance within that sub system has on children. Taking the above into consideration and realizing the importance of the sibling relationship in child development, it seems evident that adjustment of siblings of a child with a disorder should also be investigated (Verté, 2003).

2.2.4 Siblings and Autistic Spectrum Disorders

It has been assumed that siblings of children with a disorder are more susceptible to emotional, social and behavioural maladjustment than siblings of normally developing children (Verté, 2003). Research in this area, however, has shown contradictory results and, as Verté (2003) states, one can place the influence of a child with a disorder on a continuum from very positive outcomes to very negative outcomes. Morgan (1988) has illustrated that due to the complexity, unpredictability and variability of ASD symptoms, siblings of children with ASD are more likely to show different patterns of positive and negative outcomes than siblings of children with other disorders, and this may account for the contradictory findings in recent studies. Some studies claim that there is a more positive element in the relationship with an ASD child than in normative samples, while others either show no difference between the ASD family and the normative sample, or a negative aspect in the relationship between the sibling and ASD child (Glasberg, 2000; Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003).

Typically, one would expect research to show that siblings of children with ASD's are often disturbed by their sibling's behaviour and that the quality of the relationship is negatively affected by having a sibling with an ASD. This is understandable when one takes into consideration the constellation of presenting symptoms that range from an inability to play imaginatively and lack of communication skills, to the more disruptive behaviours and tantrums that are often present in children with ASD's. Stoneman (2001) emphasizes that many studies have highlighted the fact that children with ASD and their siblings spend less time interacting together than neurotypical siblings or siblings of children with Down's syndrome (Stoneman, 2001).

A study conducted by Ross and Cuskelly (2006) in Australia investigated the type of difficulties reported by siblings of children with ASD. Twenty-five normally developing siblings of children with an ASD were asked to respond to questionnaires exploring their knowledge of their siblings' condition and the types of problems they experienced with their siblings. The coping strategies that the participants used in response to those problems were also explored. The study concluded that aggression was the most common stressor within the sibling relationship, where over eighty percent of participants identified aggression from their ASD sibling as a problem (Ross & Cuskelly, 2006). This is consistent with Bagenholm and Gillberg (1991) who found that a significant number of siblings of children with ASD reported adjustment problems due to aggression from their siblings. This quantitative study using questionnaires found that siblings of children with ASD expressed more negative perspectives of their sibling, reported more problems with their siblings, such as breaking things or disturbing them, felt lonelier and played less with their sibling than the comparison siblings of children with Mental Retardation or neurotypical children (Bagenholm & Gillberg, 1991). The study by Ross and Cuskelly (2006) also found that anger was the most common reaction to the aggression displayed.

In looking at the types of coping mechanisms employed, Ross and Cuckelly (2006) concluded that emotional regulation and wishful thinking were the common coping strategies employed. Furthermore, peer relationships and friendships are also viewed as protective factors that enhance self esteem and coping skills (Schuntermann, 2007). In fact, Schuntermann (2007) claims that negative sibling relationships have been associated with more positive social relationships.

Moreover, research shows that siblings of children with ASD's also have to cope with changes in family roles, feelings of guilt and shame, the differential treatment by parents, as well as the increases in parental stress (Morgan, 1988; Pilowsky *et al.*, 2004). Rivers and Stoneman (2003) conducted a quantitative study in the United States of America to investigate whether certain family factors influence the quality of the sibling relationship when the child has ASD. Both parent and child reports were used with 50 participants and the results suggested that marital stress compromised the quality of the sibling relationship (Rivers & Stoneman, 2003). Another study highlighted other difficulties faced by siblings of children with a disorder: using a

Structural Equation Model with 252 children and parents, Williams *et al.* (2002) examined the psychosocial variables that affect the health and development of siblings of children with a chronic illness or disability. The study concluded that other difficulties faced by siblings of children with a disorder also include long term care-giving burdens, strains on financial and emotional resources, and interaction and communication problems within the household (Williams *et al.*, 2002).

However, as the study by Williams *et al.* (2002) also shows, the sibling's knowledge and understanding of the disorder may also impact positively on his/her experience of the relationship. As a result, an important factor in determining the impact of having a sibling with an ASD on a child may in fact be the child's knowledge and understanding of the disorder (Ross & Cuskelly, 2006). In fact, Howlin (1988) also noted that the extent and openness of communication by parents about ASD to the neurotypical child appeared to be a significant factor in the sibling's adjustment and that this was, in fact, a critical factor in establishing well-being (cited in Ross & Cuskelly, 2006).

Research conducted by Hastings (2003) in the United Kingdom aimed to explore what factors, if any, would influence sibling adjustment in a family with an ASD child. In particular, it was surmised that aspects such as same sex match, age difference and whether the child with an ASD resides at home or not would have an impact on adjustment. Using rating scales and questionnaires with 22 mothers of normally developing siblings of children with an ASD Hastings (2003) found that such factors, with a few exceptions, did not have a large influence. The study also focused on whether maternal stress and difficult behaviour from the sibling with an ASD would negatively affect the siblings adjustment (Hastings, 2003). It was found that, while siblings of children with an ASD scored significantly poorer on the adjustment scale than the normative samples, maternal well-being and difficult behaviour from the ASD sibling did not contribute to adjustment difficulties. This is of interest in that the study illustrates that maternal stress and difficult behaviour cannot be seen as risk factors for the non-affected sibling (Hastings, 2003). Generally, the majority of research indicating a negative effect on the non-affected sibling shows that behaviour difficulties, depression and loneliness are often higher in

siblings of children with ASD's than in those with normally developing siblings (Pilowsky *et al.*, 2004).

At the same time, however, there is a wealth of research indicating a positive effect on siblings of children with disabilities. Some studies suggest the exact opposite where siblings of children with ASD's have good self concepts and are well adjusted when compared to siblings of children with other disorders (Pilowsky *et al.*, 2004). A study by Kaminsky and Dewey (2001) investigated sibling relationships of children with ASD compared to children with Down's syndrome and siblings of normally developing children. The study focused on 90 siblings between the ages of eight and eighteen. Self report scales were given to the child participants assessing their perception of the support received from parents and peers, as well as assessing their levels of loneliness and social dissatisfaction. Rating scales and checklists were administered to parents to obtain information about their child's behaviour, their child's adaptive level and the demographics of their family structure. The results of this study highlighted the fact that, while the sibling relationships in families with an ASD child were characterized by less intimacy and nurturance than the comparison groups, both siblings of ASD children and children with Down's Syndrome reported greater admiration for their sibling and less quarrelling and competition between them as compared to the sibling relationship between neurotypical children (Kaminsky & Dewey, 2001). In a later study, Kaminsky & Dewey (2002) again found no significant difference in the levels of externalizing and internalizing behaviours between children with siblings with ASD, Down's Syndrome, or normally developing siblings. Overall, the three groups of participants were all found to be well adjusted (Kaminsky & Dewey, 2002).

Furthermore, the study by Pilowsky *et al.* (2004) compared social-emotional adjustment, behaviour problems, social skills and sibling relationships among 30 siblings of children with an ASD, 28 siblings of children with Mental Retardation and 30 siblings of children with a developmental language disorder. Using questionnaires and rating scales with the both the participants and their care-givers, the study found that most siblings of children with ASD did not differ significantly from the comparison groups and are well functioning and adjusted despite the genetic, social and familial stresses they face (Pilowsky *et al.*, 2004). Further research suggests that siblings have fun playing together and feel a strong loyalty toward their sibling (Wilson, Blacher, & Baker, 1989). Generally, as Stoneman (2001) claims, the assumption that

siblings of children with a disorder experience a relationship that is less warm and positive is refuted as the majority of studies have shown an opposite pattern.

On the whole, there appears to be some debate as to whether the development of the non-affected child and the sibling relationship are impacted upon negatively or positively by having a sibling with an ASD. The majority of studies have focused on quantitative comparisons between siblings of children with ASD's and siblings of normally developing children. Reports from clinicians working in this area propose that siblings may have concerns that go unnoticed by the standardized instruments used in most quantitative research (Glasberg, 2000). Furthermore, as Kaminsky and Dewey (2001) state, there has been very little research investigating the "non-disabled siblings' perspectives" on the relationship with their sibling (p. 400) – all of which suggests that there is room for more qualitative research in the area of a sibling relationship.

2.3 Conclusion and Rationale

The review of the literature has highlighted that ASD's are one of the most complex disorders of childhood with varying levels of functioning and a diverse range of impairments and eccentricities. Family Systems Theory highlights how the family system functions in a complex and multilayered manner, illustrating how one member of the family not only affects the other members, but the relationships within that family as well. Having a child with an ASD in the family has a large impact on the family as a whole, as well as the relationships within that system. Research has illustrated the many challenges that families face in having a child with a disability. Parents often face struggles regarding the best method of treatment, the financial costs that the specialist treatments incur, as well as the anxiety and disappointment of having a child with a disability. Not only is the marital subsystem affected, but all subsequent interactions within the family system are affected in one way or another. Research has shown that the sibling relationship is also impacted upon, where siblings of children with ASD's are often affected cognitively and emotionally.

The nature of the impact on the relationship varies across studies. Some studies illustrate that having a sibling with a disorder will impact negatively on the child, increasing negative feelings

toward the sibling, while others indicate a positive effect on the sibling relationship; where feelings of loyalty, affection and warmth are higher in siblings of children with ASD's than those with normally developing siblings.

Essentially, while the impact of parenting a child with an ASD is well documented, there is considerably less research that focuses on the area of the sibling experience and relationship with an ASD child. Within the clinical literature, there is also a growing interest in children's subjective responses to their sibling's illness or disability that moves beyond merely looking at developmental issues such as social, emotional and cognitive adjustment (Dunn, 2000).

In the main, the majority of research conducted has used a quantitative approach and does not provide a more in-depth understanding of the non-affected sibling's experience. This may also account for the range of contradicting findings, where in fact what is being tapped into is a more relationship with an ASD child. In this sense, some studies may be highlighting the positive aspects of this relationship, while others are bringing the negative aspects to the fore. As a result, a study that investigates the non-affected sibling's lived experience and perspectives would prove useful in gaining a deeper understanding of the complexity and nature of the relationship between an ASD child and his/her sibling. Such a study may assist in integrating the negative and positive aspects highlighted by previous studies. Furthermore, the majority of studies have been conducted in countries such as the United Kingdom, Australia and the United States of America, with few (if any) studies being from a South African perspective. A qualitative study will, therefore, enable an understanding of the ambiguous and complex interaction of factors affecting the sibling relationship and highlight the issues and concerns that may arise across various family settings. Moreover, this study will also take into account factors that are unique and different about the South African context in which this study is based.

CHAPTER 3: RESEARCH AIMS AND METHODOLOGY

3.1 Research Question and Aims

Making use of a phenomenological approach, which seeks to understand the lived experience of a particular phenomenon, the key question that the research aimed to investigate was “What is the child’s experience of having a sibling with an Autistic Spectrum Disorder?”

More specifically, the research aimed to investigate:

- The common attitudes that children hold about ASD and their sibling
- The nature of the sibling relationship in a family with an ASD child
- The experiences that children with an ASD sibling have in terms of social adjustment and coping
- The experiences that children with an ASD sibling have of the family system

Some presuppositions about the findings are as follows:

- That, as suggested by the literature, the experience of having a sibling with an ASD is a lonely and difficult one
- The non-affected sibling may feel left out, or rejected, by all the attention afforded to the ASD sibling by therapists and other professionals
- The experience will be more negative when the ASD sibling is lower functioning
- The non-affected sibling will show signs of social and emotional adjustment difficulties, as suggested by the literature

3.2 Research Design

A qualitative research design was chosen for this study in order to gain a deeper understanding of the participants’ experiences and behaviours. As indicated in the previous chapter, much of the research in this area has been quantitative in nature and has, therefore, been unable to capture the rich complexity of the participants’ lived experience. Qualitative research is primarily interested

in describing and understanding human behaviour rather than explaining it (Babbie & Mouton, 2005). It is a broad methodological approach to studying social action and includes a collection of methods and techniques of data collection and analysis that share the same principles. These principles include: conducting research in the natural setting, an emphasis on the insider view, thick and rich descriptions of situations and events, and the use of the researcher as the principle instrument in the research process (Babbie & Mouton, 2005). Within the qualitative framework, the phenomenological perspective has a particular focus on the life world of the subject (Kvale, 1996). As Kvale (1996) explains, this perspective emphasizes the experience of subjects from the subjects' own perspective and, thereby, describing and understanding the world as the subjects see it. As Starks and Brown-Trinidad (2007) describe, it is through the close investigation of the individual's experience that analysts capture the meaning and any common features of the experience. Essentially, the phenomenological perspective carries with it the assumption that the only important reality is what people perceive it to be (Kvale, 1996). Furthermore, the researcher acts solely as a witness to the individual's experience, remaining honest and vigilant about her own perspective and thoughts, bracketing her assumptions to attend to the participants' accounts with an open mind (Starks & Brown-Trinidad, 2007). As Starks and Brown-Trinidad (2007) elaborate, the process of 'bracketing' requires only that the researcher recognizes, but not abandon, her own perspectives and assumptions. This requires the researcher to adopt a particularly self-reflexive position. Due to the fact that the study aimed to investigate the particular lived experience of a particular phenomenon, namely, the non-affected sibling's experience of having a sibling with an ASD, the phenomenological methodology was found to be most useful.

A hermeneutic approach to analysis was adopted as this is highly suited to answering "what" and "how" questions about human issues in order to understand the participants' experience. Hermeneutics is, essentially, a method of understanding the world of the participants and to interpret their meanings and practices through immersion in the data (Hutchinson, 1991). It is, however, impossible to separate the researcher from her past experience and preconceived ideas about events and phenomena. Hermeneutics also recognizes that it is difficult to separate understanding from a particular frame of reference circumscribed by a cultural and historical timeframe and its methodology, therefore, encourages recognition of this influence on

interpretation. This means that the prejudices that a researcher brings to a study are influential on the process of research and should be reflected upon (Whitehead, 2004). In this sense, hermeneutics does not try to eliminate the researcher's presuppositions in order to reach 'objectivity', but rather asserts that pre-judgments have a special importance in the process of interpretation (Dowling, 2004). The method is typically characterized by a Hermeneutic Circle as the method of analysis, whereby the researcher continually moves back and forth between the parts and the whole of the text (Kvale, 1996). Starting with a vague understanding of the whole, the various parts are interpreted, clarified and related to the totality such that an understanding that is clear and concise is reached (Kvale, 1996). Throughout this process, the researcher is aware of her preconceptions in order for the text to reveal its uniqueness against her own fore-meanings (Dowling, 2004).

The Hermeneutic understanding suits the phenomenological approach as it acknowledges the researcher's presuppositions about the participants' lived experience and recognizes where this presupposition is supported or contradicted by the data.

3.3 Sampling

Due to the in-depth nature of this approach the study aimed to work with rich and meaningful data. As a result, a smaller sample was necessary. Only three participants were used as the study was exploratory in nature and required a more in-depth exploration of the issues associated with having a sibling with an ASD. The research, therefore, made use of purposive, convenience sampling to select the three participants. Purposive sampling is sampling based on careful selection of cases that are typical of the phenomenon being studied (Terre-Blanche, Durrheim, & Kelly, 2006). Convenience sampling (Kerlinger, 1986) makes use of a sample that is easily accessible to the researcher. In this case, the three participants were selected from a population group easily accessible to the researcher due to previous interaction at a school for children with Autistic Spectrum Disorders. These participants were selected according to the following criteria: The participants were to be between seven and eleven years of age and to be the older sibling of a child that had been formally diagnosed by a professional as having an Autistic Spectrum Disorder. Furthermore, the participants had to be residing with both parents that were

still married. These criteria were set such that large age differences, birth order, or parental divorce, did not become factors that influenced the results. Moreover, participants were chosen if they were aware of the aims of the research and were willing to participate.

The three participants chosen for this study were as follows:

Adam* is an eleven year old boy with a younger brother diagnosed with an Autistic Spectrum Disorder in the lower range of functioning. His sibling makes very limited use of verbal communication, but uses some degree of sign language to express his needs. He is unable to play imaginatively with others and often makes use of stereotypic and repetitive behaviours. Furthermore, he has some obsessions and compulsions. Adam's parents are married. Adam's mother is a housewife who is actively involved in the community and support groups for parents with Children who have ASD, while his father is a successful businessman.

Kim* is a seven year old with a younger brother diagnosed with an Autistic Spectrum disorder in the higher functioning range. While it is sometimes difficult to understand his pronunciation of words, her sibling does make use of verbal communication to express himself spontaneously and appropriately. He is able to play with others, but does make use of some stereotypic and repetitive behaviour and has some obsessions and compulsions. Kim's parents are married and both are successful at work.

Paul* is an eleven year old with a younger brother diagnosed with an Autistic Spectrum Disorder in the average range of functioning. His sibling is able to use verbal communication to express himself, but does not always understand social communication or norms. He makes use of some repetitive and stereotypic behaviour. Paul's parents are married and, while his mother works from home, both are successful at work.

Ethical issues such as informed consent and confidentiality, will be discussed in more detail in the proceeding sections.

* Names changed to protect anonymity

3.4 Data Collection

Three forms of data collection were used in obtaining in-depth information about the participants' experiences. These are outlined below.

3.4.1 The Interviews

This study made use of individual semi-structured interviews with each participant in order to gain a deeper understanding of the participants' perspectives on having a sibling with an ASD. Interviews are particularly suited for investigating people's understanding of the subjective experiences and meanings in their lives (Kvale, 1996), and are one of the most frequently used methods of data collection within the qualitative approach (Babbie & Mouton, 2005). A rough interview guide was drawn up to elicit information pertaining to the participants' understanding of Autistic Spectrum Disorders, their feelings towards, and interactions with their sibling, their perceptions of their parents and their social functioning (Appendix A). This guide ensured that similar thematic areas were explored with each participant, but allowed room for particular issues to be probed as they arose uniquely in each situation. Audio recordings were made of the interviews, which were then transcribed.

3.4.2 The Focus Group

Focus group research is amongst the most commonly used methods of social science research (Stewart & Shamdasini, 1998). It involves a group discussion around a topic that is the focus of the conversation and aims to stimulate an in-depth exploration of the specific topic (Stewart & Shamdasini, 1998). Although focus groups generally consist of eight to twelve participants, this study made use of a focus group with three participants. The focus group was used in order to create an environment that was potentially less threatening than the individual interview and to encourage a shared, open and natural discussion on the experiences of each of the participants. Sometimes conversation allows for new information or perspectives to emerge, and focus groups allow for shared development of ideas as well as variety in perspectives. The group took place at

one of the participant's home and was three hours in duration. The group aimed to focus conversation around topics such as the family environment, the sibling relationship, the difficulties faced within the relationship and the participant's perceptions of how other people perceive their ASD sibling. A semi-structured guide was also used for the focus group (Appendix B). An audio recording of the focus group was made and transcribed.

3.4.3 Participatory and Projective Techniques

Due to the fact that children communicate well through non-verbal media (O'Kane, 2000), the study also made use of participatory and projective techniques to elicit more sensitive information surrounding the sibling relationship. Working out a response to the various techniques also assists in accessing the participants' cognitions around a certain topic. During the focus group the participants were, therefore, requested to make use of drawings, as well as to complete a sentence completion exercise and a ranking exercise. These techniques (Theis & Grady, 1991) were used to supplement the information gained in the focus group. The drawings were, therefore, used to elicit material about the child's internal world regarding perceptions of self and family. The sentence completion exercise was used as a projective measure aimed at highlighting some of the child's unconscious wishes, fears and feelings. In the ranking exercise, the participants were requested, as a group, to create a list of difficult situations with their sibling and to rank these situations according to the level of discomfort or difficulty these cause in their daily living. This activity was aimed at creating rapport between the participants in doing a task together and to facilitate a more in depth discussion around their personal experiences of having a sibling with an ASD. (Example of the sentence completion exercise is attached in Appendix C)

Projective measures, such as a drawing of a person (DAP) and drawings of the family – Kinetic Family Drawings (KFD), are considered to be indicators of the child's perception of him/herself and/or family (Burns & Kaufman, 1970), and have become one of the most widely used assessment tools (Yama, 1990). Despite this popularity, experimental studies have also brought the validity of these measures into question and, as Yama (1990) states, many are quick to assume that measures such as the Draw-A-Person have little to contribute in a practical sense to diagnosis. Recently, support is given to the validity and reliability in using more global aspects

of the drawings, rather than focusing on specific areas and making subtle differential diagnoses (Groth-Marnat & Roberts, 1998). As a result, aspects such as overall artistic quality, bizarreness, and trends of emotional indicators rather than specific aspects such as direction of stroke, may be useful in assisting the assessment of factors such as adjustment (Yama, 1990). Essentially, projective measures have proven useful in assessing personality when used in conjunction with other methods of assessment.

This study made use of projective measures, not as formal measures of adjustment, pathology or personality, but to create a less threatening platform from which discussion could be generated. The drawings were more generally interpreted, taking broader patterns and themes into account, rather than specific indications of pathology, or adjustment difficulties. Ogdon (1979) provides a list of indicators associated with specific drawing patterns. For example, a large head and square shoulders are suggestive, according to Ogdon (1979) of intellectual preoccupation and assertiveness, or aggressiveness. The researcher made use of Ogdon's (1979) suggestions to guide the interpretation of the drawings. In this sense, only aspects that repeatedly emerged as recurring themes in the drawings were taken as possible suggestions and no absolute conclusions were drawn from the material.

The sentence completion test was first used as an educational assessment tool in the nineteenth century and, according to Barton, Morley, Bloxham, Kitson and Platts (2005) has now developed a long tradition of use in clinical psychology as a projective assessment measure. The method requires respondents to continue incomplete sentences using the first words, or ideas that come to mind such that unique responses are generated by each individual (Barton *et al.*, 2005). The method is expected to reveal spontaneous and unexpected truths about personality, or psychopathology. Barton *et al.* (2005) also state that these methods have lost their contemporary popularity as obtaining adequate reliability and validity for the claims made by the test is difficult. This study did not make use of a previously designed form of the sentence completion test, but the researcher designed a simple 18 item exercise with incomplete sentences proposed to elicit information about the participants' current internal feelings and emotions. The exercise was administered toward the end of the focus group and the answers were interpreted only in terms of obtaining information that may otherwise have been difficult for the participants to state. In this

sense, the answers to the exercise were coded and analyzed in the same manner as the interviews and focus group.

The focus group discussions and discussions around the exercises were recorded and transcribed. This was then analyzed as described below.

3.5 The Research Process

3.5.1 Informed Consent

Due to the fact that the participants were minors, each participant's primary caregiver was issued with a letter requesting permission to work with their child, stating the aims of the research, as well as what would be required of each participant in the study (Appendix D). The recording process of the interviews and focus group was highlighted, as well as the method in which the data would be stored and worked with. The caregivers were asked to sign the letter before the data collection process could begin. Furthermore, a letter was also issued to each participant explaining the research process and they were asked to sign assent before continuing with the collection phase.

3.5.2 Interviews

The interviews were conducted with each child individually. The children were given an opportunity to assent to the research process before the data collection commenced. The researcher chose to interview the participants at their respective homes in order to reduce any threatening feelings and to make the child feel more comfortable. The interviews were conducted according to the interview schedule (Appendix A) and recorded for later transcription.

3.5.3 Focus group process

The focus group was conducted at the home of one of the participants after all interviews had been conducted with the individual participants. The group was conducted over three hours with

a short half hour break. The participants were first asked to draw a picture of their family and then discuss the picture with the group. Thereafter, the participants were asked to describe some situations with their ASD sibling in which they felt very uncomfortable. This was also used as a point for further discussion. The participants were then asked to work together in ranking the situations from most uncomfortable to least uncomfortable. After a short break, the participants were asked to complete the sentences provided. As the final activity, each participant was asked to draw a picture of a person. The group was then asked to provide feedback of their experiences and discuss any feelings that may have surfaced during the focus group. The researcher also informed the participants and their caregivers that follow up sessions could be provided if required.

3.5.4 Ethical Considerations

When dealing with children in research, particular attention needs to be paid to the issue of ethics. In fact, it is of utmost importance that the basic principles informing ethics, such as confidentiality, beneficence and non-maleficence, be strictly adhered to (Wassenaar, 2006). The most important aspect of ethically sound research is informed consent, which allows the researcher to respect people and their autonomous decisions (Emmanuel, Wendler, & Grady, 2000). Therefore, before commencing data collection, the researcher obtained informed consent from the relevant legal guardians, as well as signed assent from the child participants. In obtaining informed consent, the research methods were made explicit such that both legal guardians and participants understood the process and what was expected of them. Furthermore, the participants were made aware of their right to withdraw from the study at any point without any negative effects if they wished to do so. As the participants were minors, their parents' needed to consent to their participation, but the children were also given the opportunity to assent to their participation. This means the research was explained to children and they agreed to participate and understood that they could withdraw at any stage without any negative consequences. The children were encouraged to discuss any concerns they had with the researcher.

Confidentiality is another important aspect to ethics in research (Wassenaar, 2006) and, in this sense, the participants were ensured that no identifying data would be recorded or used in the research. The issue of confidentiality was clearly explained at the outset, ensuring that the participants fully understood that the sessions would remain private. The researcher stored all transcribed data on her computer under encryption and password protection. Audio recordings will be stored under lock and key for two years and over-written once transcribed and research verified. All electronic data will be deleted through the use of a word shredder.

The issue of beneficence and non-maleficence was also taken into consideration. In this sense, the risks need to be identified and minimized using procedures that are consistent with sound research design (Emmanuel *et al.*, 2000). The potential risk in this study was that participants were required to relate some potentially difficult or painful experiences. The researcher, a trainee psychologist with prior experience of working with children with an ASD, was particularly aware of this fact and conducted all interviews and focus groups in a sensitive and non-threatening manner, ensuring that participants were treated with utmost respect and empathy. The interviews and focus group aimed to be a cathartic experience, which was gentle and non-threatening. A debriefing session was also arranged where the participants were allowed to discuss any difficult experiences. Secondly, potential benefits need to be highlighted and enhanced (Emmanuel *et al.*, 2000). The potential benefit was that the process may have provided the participants with a space that allowed them to discuss and make sense of their experiences.

3.6 Data Analysis

According to Kvale (1996), interviews can be interpreted within the hermeneutic frame through an analysis of the conversation co-created by the subject, interviewer and others in the individual's construction of meaning. The Hermeneutic Circle was the start of the analysis process where the researcher immersed herself in the data and clarified any points where necessary. By remaining aware of the whole 'picture' that the participant provided, the researcher also began to interpret and clarify the parts, thereby engaging in the Hermeneutic Circle as described by Kvale (1996). In essence, the analysis started with a vague and anticipated understanding of the whole and then moved on to interpreting the separate parts. Out of these

separate interpretations the meaning of the whole was reviewed. This process was accomplished by immersion in the data and identification of the various themes and patterns that emerged.

Specific themes and categories that were evident in the data were highlighted and NVivo software was useful in this regard. Terre-Blanch, Durrheim and Kelly (2006) suggest that there are five steps involved in the process of interpretive analysis that are common to most qualitative analytic traditions such as thematic analysis and grounded theory. These steps are described as follows.

The first step is familiarization and immersion in the data, which involves immersing oneself in the data by reading and re-reading the text. In so doing, the researcher becomes aware of the organizing principles that naturally underlie the material and is able to move to the second step of inducing themes. Such themes are more than mere summaries of the data, but highlight patterns of thought or behaviour. The third step happens simultaneously, whereby the researcher begins to code the emerging themes to mark them as being instances of, or relevant to, the chosen themes. Here NVivo software was used to organize the coded material and any relevant information. (Examples of the codes and themes used are presented below). The themes are then explored more closely in the fourth step of elaboration to capture the finer nuances in the text. Themes at this point may be subsumed into each other, or elaborated and broken down further. The researcher remains close to the data continually moving between themes and rereading data to make sure the correct meaning is maintained. During this stage the researcher also seeks for what may not be being said. The process of coding and elaboration is circular in nature as more information surfaces during the elaboration phase. Lastly, the researcher provides an account of what was found, interpreting the themes and insights as they pertain to the original question (Terre-Blanche *et al.*, 2006). As a result, the process of analysis moves the researcher from seeing an important moment through encoding it and to interpreting it (Boyatzis, 1998). The researcher attempts to tell the story of the data, including that which has not been said. In this sense, the researcher attempted to stand back and see the patterns emerging across participants' information and seek the differences between, and within, their accounts.

A breakdown of themes and codes that emerged from the data is as follows:

<u>A: Common perceptions of Autism</u> <ol style="list-style-type: none"> 1. Doesn't understand/speak 2. Stressed out/screaming 3. Difficult behaviour 	<u>B: Nature of relationship</u> <ol style="list-style-type: none"> 1. Embarrassing 2. Protective/Responsible 3. Shared activities 4. Negative Emotions
<u>C: Perceptions of Family System</u> <ol style="list-style-type: none"> 1. Mom's role and feelings 2. Dad's role and feelings 3. Emotional effect on child 4. Family activities 5. Difficult outings 	<u>D: Social Adjustment and Coping</u> <ol style="list-style-type: none"> 1. Friends and sports 2. Professional help

An example of the coding process:

“Well Tim is quite a bit of a responsibility and I have to take care of him a lot and its ok, but sometimes it gets a bit stressed out. It's ok, though, because my mom is usually there as well.” (Adam)

<i>Well Tim is quite a bit of a responsibility and I have to take care of him a lot</i>	B2
<i>it gets a bit stressed out</i>	A2
<i>because my mom is usually there as well</i>	C1

3.7 Trustworthiness in Qualitative Research

In order to ensure the validity and reliability in qualitative methods, a number of specific criteria must be satisfied. Assessing the reliability and validity of research is, therefore, an important step in conducting good quality research. Traditionally the concept of ‘validity’ and ‘reliability’ have been rooted in the positivist approach and quantitative paradigm (Golafshani, 2003). As Golafshani (2003) explains, due to the fact that the qualitative paradigm makes use of a more naturalistic approach to understanding human phenomena, the concepts of reliability and validity can be redefined as that of ‘trustworthiness’ and ‘dependability’ to suit this more naturalistic approach. Essentially, reliability and validity are concepts that aid in assessing the quality of a

study. In this sense, as Healy and Perry (2000) believe, “the quality of a study in each paradigm should be judged by its own paradigm’s terms” (cited in Golafshani, 2003, p. 601). Traditionally, reliability refers to the extent to which a study can be replicated and repeated with consistent and accurate results over time, and validity refers to whether the research truly measures what it intended to measure. Both constructs are a way of assessing the quality of a study (Golafshani, 2003).

Qualitative researchers argue that factors such as trustworthiness, confirmability, dependability, applicability, neutrality and consistency are more relevant constructs for assessing the quality of a qualitative study (Golafshani, 2003). Essentially, if a study has high dependability then it will yield consistent results over time when a similar methodology is used. Similarly, if a study is trustworthy, then we can have confidence in its findings (Golafshani, 2003). As a result, as Johnston (1997) asserts, if the trustworthiness of a study can be maximized and tested it will lead to a more credible result, which in turn leads to generalisability that, according to Stenbacka (2001), is the cornerstone of good quality research (cited in Golafshani, 2003). It follows, then, that in order to increase the quality of a study, one needs to increase the trustworthiness of the study (Golafshani, 2003).

The first method used in increasing the trustworthiness of a study is the use of triangulation. Mathison (1988) argues that triangulation has become an important factor in qualitative research to control bias and to ensure valid suggestions as traditional scientific techniques of ensuring such qualities are incompatible with qualitative methodology (cited in Golafshani, 2003). In this sense, triangulation refers to the use of multiple methods of data collections and analysis to eliminate bias and maximize the truthfulness of the results.

This study aimed to maximize trustworthiness by utilizing several different methods of collecting data. Not only were the participants individually interviewed, they were also asked to participate in a focus group using both interview methods, as well as participatory and projective techniques such as drawings, sentence completion exercise and the ranking exercise. With regards to the data analysis process, while only one method was used, the research was co-supervised by two supervisors providing a richness of perspectives and reducing possible bias.

While triangulation is often used to increase the trustworthiness of a study, good quality research also requires that a number of other specific criteria are met. In this sense, not only does one need to increase the trustworthiness of a study, but criteria such as credibility, dependability, confirmability and reflexivity (William, 2006) also need to be satisfied in order to render the research valuable. William (2006) describes credibility as being related to the internal validity of the data and interpretation. In this study this issue was addressed by the researcher by attempting to remain true to the data by recognizing her own assumptions and ‘bracketing’ them out. With regard to this process, Boyatzis (1998) warns against three major obstacles to using interpretive analysis effectively. The first is the idea of projection whereby the researcher reads into, or attributes to the participant something that is her own emotion, attitude or value. In this sense, the stronger the researcher’s theory, the more likely she is to project her own conceptualizations onto the data. As a result, developing an explicit code, establishing consistency of judgment and using several people to encode the information are helpful ways in overcoming this obstacle. The second obstacle often faced occurs within sampling where the raw information may already be contaminated by factors that the researcher was not aware of. Lastly, mood and style may also become obstacles. In this sense, the researcher may feel frustrated with the data, fatigued or confused, thereby decreasing her ability to conduct analysis effectively. As a result, tolerance to ambiguity and simple perseverance are essential (Boyatzis, 1998).

To minimize the abovementioned obstacles, the researcher ensured that coded themes were reviewed by supervisors in order to minimize projection. The sampling procedure aimed at reducing variables such as age differences, birth order and differences in family contexts. Lastly, the analysis phase was carried over a period of time to reduce fatigue and over stimulation. The use of co-supervision increased the confirmability of the study by ensuring the accuracy of the analysis and interpretation, and allowing for minimal bias by providing alternative perspectives.

Throughout this process, the researcher attempted to remain aware of her own prejudices and pre-assumptions, as Whitehead (2004) suggests, and did not attempt to abandon them. She kept a record of her thoughts after interviews and during the analysis process using NVivo software. Any divergent patterns and alternate themes that provided rival explanations were noted and

attention was given to findings that both supported and did not support the original ideas. Throughout this process, there was an emphasis on the individual's account of the experience, as suggested by Dowling (2004) and special attention was paid to the uniqueness of this account. In this manner the criterion of reflexivity was satisfied

Lastly, the issue of dependability refers to whether or not consistent results will be obtained should the study be replicated using similar methodology (William, 2006). To increase dependability of this study, an audit trail was provided through clearly outlining the research methods, as well as data collection and analysis processes, to the reader in a step-by-step manner such that this study could be easily replicated. Pitfalls and weaknesses in the research are openly discussed detailing why certain results were obtained as opposed to others.

CHAPTER 4: RESULTS

The data from the individual interviews with each participant and from the focus group was transcribed and analyzed as described above. NVivo Software was used to organize the coded material. The resultant themes and codes that emerged from the data will be presented, after which a discussion of the results will follow. The individual interviews will be discussed first, with a discussion of the focus group and the various participatory and projective techniques thereafter.

4.1 *The interviews*

Each interview was transcribed and analyzed. The emerging themes are presented below in their various categories and codes.

4.1.1 Common perceptions of ASD and their sibling

All the children interviewed revealed common perceptions about ASD and their siblings. This highlighted both the participants' formal understanding of Autistic Spectrum Disorders as well as information pertaining to the lived experience of, and attitudes toward, the disorder and their siblings.

- *“Cant speak or understand”*

Through the individual interviews it became apparent that all three participants held perceptions about their sibling and the disorder that were common. Although the family context, as well as the level of functioning of each ASD sibling, was different for each participant, all three participants spoke of the fact that their sibling couldn't understand or speak properly. As Adam described:

“Well he can’t speak properly and it’s hard for him to understand lots of things and he can’t figure out things so easily. He won’t be able to read, but he’s learning so he probably will, except he can’t understand.”

In Adam’s case, he felt that the most prominent feature of his brother’s ASD was the fact that he was unable to use verbal language to communicate. He felt that, while his sibling used very limited sign language, he was unable to speak at all. As a result, Adam feels that he is unable to argue or fight with his brother the way other siblings might. On the other hand, both Kim and Paul’s siblings are able to use verbal communication. However, they also felt that their siblings were unable to communicate or speak properly. Kim’s brother struggles to use language appropriately to communicate his needs so she often finds it difficult to understand what he is wanting. Similarly, while Paul’s brother is able to speak, Paul still feels that he is unable to do so properly and feels this is a defining feature of ASD.

The participants also felt that their siblings were unable to understand certain things properly. Adam felt that his brother was unable to understand him properly when he spoke to him. He also felt that, even though his sibling was learning to read and use sign language, his brother was still unable to understand precisely what he was signing, or reading. Kim also felt that her brother wasn’t able to understand the rules and norms in her household, particularly where wearing her clothes was concerned. Paul felt that, while his brother enjoyed going to the cinema with him, he wouldn’t understand very much of what was happening in the movie.

- *“Gets stressed out or screams”*

Another common perception that the participants held about their ASD sibling was that their sibling often got ‘stressed out’ easily and would scream a lot. All the participants stated in some way during the interviews that they found it difficult when their sibling would get ‘stressed’ for some reason. When stressed out, they would scream or have a tantrum. Adam felt this behaviour made it very difficult for the family to go to new places as his brother would feel scared and then start screaming. Similarly, Paul also felt irritated and angry at the times when his brother would get ‘stressed out’ and then begin breaking his stuff. Kim on the other hand stated that her brother

often screams and that this would bother her. When asked how she felt being the older sibling, for example, Kim stated:

“Horrible. Because um... he always comes into my bedroom and he always wants mommy or daddy to do it. Like he says he wants water and we’ll go get it if mommy is getting dressed, but he screams and gets stressed and wants them to do it. We can’t take care of him, only mommy or daddy can.”

In a sense, Kim not only feels frustrated by the screaming, but also feels frustrated by the fact that she is unable to alleviate her brother’s distress. This quote illustrates some of her feelings of powerlessness where helping her brother is concerned.

- *Difficult behaviours*

Although the participants did not all necessarily agree on the different types of difficult behaviour that their siblings displayed, it was clear that difficult and frustrating behaviours in their various forms were common to the ASD sibling. Kim stated that her brother often hurt her when they were playing and that he frequently wanted to wear her clothes and stay in her bedroom instead of his own. She also spoke about certain toys that he wanted and would feel upset if he didn’t have them. Paul also mentioned some difficult behaviour:

“You know he gets stressed out, breaks my things, breaks the shower door, steals my toys, books and stuff.”

He also finds it difficult when his brother strips in public places, or runs away and gets lost. Adam described how his brother often makes strange noises, takes objects and hides them, or switches off the television while he is watching it.

4.1.2 Nature of the relationship

In the course of the interviews the participants discussed their relationship with their sibling. The themes below highlight the non-affected sibling's perspective on his/her relationship with the ASD sibling.

- *“Embarrassing” – other people’s perceptions of their sibling*

When interviewing the participants, certain aspects of the sibling relationship were highlighted. In particular, none of the participants overtly described feeling embarrassed about having a sibling with an ASD. When asked about their friends’ perceptions of their siblings and how they felt about it, Paul and Adam both alluded to the fact that their brothers did not attend the same school, which made it easier for them. They did not feel embarrassed about having a sibling with an ASD as the sibling did not attend the same school. While they had to explain their siblings’ behaviour to their friends if they came over to the house, they felt their friends understood there was something ‘wrong’ and not to laugh at, or tease their brothers. In fact, Adam stated that he felt ‘normal’ about it and, in a similar way, Paul did not describe any feelings of embarrassment over his sibling in front of his school friends. Kim did not feel embarrassed in front of her school friends either. She felt that her friends saw her brother as being ‘cute’, something with which she didn’t agree as she knew they only saw one aspect of him. On the other hand, she did later report feeling embarrassed in public by his behaviour and his need to wear her clothes. Similarly, both Adam and Paul later stated that they felt embarrassed only when their sibling behaved strangely, like stripping his clothes off, or screaming in public, for example. As Adam stated when asked during his interview if he felt embarrassed by having a brother with an ASD:

“Not really. Only when we are out and he suddenly starts screaming.”

- *“Protective and responsible”*

When Adam was asked what it was like for him being the older sibling, he answered:

“Well Tim is quite a bit of a responsibility and I have to take care of him a lot and its ok, but sometimes it gets a bit stressed out...”

In this sense, the most prominent feature of the sibling relationship that emerged from the interviews was the fact that all the participants felt protective or responsible for their sibling in some way or another. Remarkably, all the participants felt that their most scary memory of their sibling was when something bad had happened to them. For example, Adam felt most scared when his brother fell into the springs on the trampoline, Paul stated he feels most scared when his brother gets lost, and Kim felt most scared when her brother had to go for an ear operation. In all three cases an element of feeling protective over their sibling emerged. In this sense, Adam stated that he needed to protect his brother, as did Paul, stating that he needed to watch out for his brother and help him when he got into trouble. As a result, it was clear from the interviews that the participants all felt responsible for their siblings. Not only did Adam feel he needed to protect his brother, but also help him when he needed things, such as finding the television remote, changing the channel, or looking out for him when they go to the local coffee shop. Kim also stated that she needed to help her brother in a variety of ways, from looking for grasshoppers, to taking him to the toilet before bed time. Paul agreed that the important part of being a sibling was taking care of his brother and helping him out of trouble and felt that it would be very difficult if his brother were the older of the two.

- *Shared activities*

The interviews also yielded information pertaining to the types of activities that the participants did with their siblings. It was interesting to note that, while each participant claimed to enjoy spending time with their siblings, the range of activities engaged in was limited. In this sense, Adam, was only able to play on the trampoline with his brother until his brother stopped enjoying that. Now they only play ball together. Kim felt the same about her brother, stating:

“The only thing he likes to do is play in the garden and jump on the trampoline.”

Similarly, Paul felt that his brother only really enjoyed ‘hide and seek’ and he would only ‘sometimes’ play with him.

- *Negative emotions*

Although the participants interacted with their siblings and felt largely protective towards them, some feelings of anger and irritability toward their siblings also surfaced during the interviews. For example, when Kim described the things she needed to do when helping her brother she stated:

“Um...I try look for his grasshoppers, that’s what he wants all the time. Or he wants an insect or a spider or something. But, what he wants the most is my bedroom because he wants all my girl stuff and it’s irritating.”

In the example above, Kim was describing her frustration when her brother wanted to take her things. In the same way, Paul also described feeling irritated and angry when his brother takes and breaks his things. Aside from feeling frustrated and angry, Adam also stated that he felt sad that he was unable to communicate and interact with his brother in certain ways. In general, the difficult behaviour displayed by their siblings often left the participants feeling irritated and angry.

4.1.3 Perceptions of the family system

The research also aimed to explore the participants’ perceptions of the family system and the various roles in it. These roles, as well as the emotional effect that various roles and relationships had on the participants, are highlighted below. As illustrated above, each participant felt that they were responsible in some way for the sibling, needing to take care of, or help them where necessary. Their role as an older sibling, as such, was therefore to be protective of their younger sibling as described above.

- *“Mom’s role and feelings”*

In some way or another, the participants expressed that their mothers felt the most stressed and angry about, or toward, their sibling. They felt their mothers were negatively affected by this stress in that they would often become irritated, frequently shouting at the participants’ sibling or the participants themselves. As a result, the participants were also often emotionally affected.

This was highlighted when Paul responded to a question about whether his mother's moods affected him by stating:

“Yes, she gets irritated and shouts and gets in a very bad mood and it irritates me too.”

Kim also stated that she felt scared when her mother was angry a lot. Their perceptions of their mothers' roles were very similar. Adam felt that his mother was very busy with his brother, having to take him to speech and language therapy, as well as his other therapies. Kim, however, perceived her mother's role to be that of disciplinarian. In this sense, Kim stated that she would go talk to her mother if her brother was bothering her and that her mother would be the parent to give hidings and get angry. Similarly, Paul perceived his mother as the disciplinarian in that she shouts and gets angry, but also ascribed to her the role of having to explain the disorder to visitors and friends.

- *“Dad's role and feelings”*

With regards to the participants' perceptions of their fathers' feelings and roles in the family, both Adam and Kim stated that their fathers were not as stressed as their mothers and did not get as angry. Paul, however, stated that his father felt just as irritated at times and that it was 'hard on everyone'. The roles ascribed to their fathers differed slightly across the participants interviews. Adam described how his father did the work to pay for aspects such as school fees and therapists and, while he wasn't directly involved with his brother, actually did do a lot for him. When asked how he thought his dad felt, Adam stated:

“My dad doesn't usually do much with Tim, but in the long term he actually does quite a lot even though I don't usually see it. He doesn't get stressed with him as much though.”

He also perceived his father as the parent with whom he could go out and have fun with as his mother would stay home and be with his brother. While Kim felt that her father was sometimes too busy to spend time with the family, she also perceived him as the 'fun' parent who played

with the children more often than her mother and who wasn't as strict as her mother. Paul, on the other hand, did not view his father's role to be very different from his mother's. In this sense, he felt that his father was just as affected, and sometimes irritable, as his mother.

- *Emotional effect on child*

With regards to the participants perceptions of their parents and the roles ascribed to them, all three participants seemed to be emotionally affected by their parents' reactions. In this sense, Adam stated that he would feel sad and worried about his mother when she felt stressed, and Kim also felt scared when her mother became angry. Paul agreed that his parents' mood would affect him and he would also feel irritated and in a 'bad mood'. Although the participants seem to be affected by their parents' responses, they still enjoy spending time with their family.

While Paul particularly enjoyed going on holiday with this family, Kim and Adam stated that they went to the beach together. Adam, however, added that it was difficult going on family outings with his brother as his sibling did not enjoy new places and would go out with his dad instead or have to get a babysitter for his sibling if he was to go out with both parents. When Kim was asked if her brother could accompany the family on outings to parties and the church she stated:

“Yes, he does and has fun but not always behaving himself.”

In this sense, one can see how the ASD sibling's behaviour affects the family's experience of outings, often making them impossible (as in Adam's case where his brother cannot go to new places), or difficult when their sibling's do not behave.

4.1.4 Social adjustment and coping

Information about the participants' level of interaction with the social environment outside of their home environment also emerged from the interviews. Information about the activities they engaged in and any coping resources used were also highlighted.

- *Sports and friends*

It was apparent that all three participants were very busy at school with extramural activities and sport and also felt they had many friends. Kim, the youngest of the participants, enjoyed the physical activities at school, such as dodge ball and ‘fire engines’, and felt that they were fun. Paul and Adam are both very involved with sporting activities such as hockey, cricket and tennis at school and both stated that they enjoyed school for the sporting activities. All participants felt they had a lot of friends at school. When asked what they thought was the most important aspect about having friends Adam and Kim felt that it was about not being lonely and having people to help you. Paul, on the other hand, alluded to the fact that friends were the people that he was most comfortable around as they were the ones who understood about his sibling, and stated:

“Um, well my friends are the ones who know the most about Sam.”

Interestingly, both Adam and Paul stated that they would go to their friend’s houses more often than having their friends over to their own houses. Adam stated that this had to do with the fact that it was easier for his mother as she was very busy taking his sibling to his therapies during the week. Kim, however, felt differently stating that her friends came over to her house more often, because her friends’ parents were busier than her own.

- *Professional help*

With regards to professional help, all three participants were given opportunities to speak to a psychologist when they became very frustrated. While Adam felt that it helped him deal with his feelings, Kim and Paul seemed more indifferent to the process. In this sense, Kim felt that she was able to get help, but that the problems still remained the same and Paul felt that it didn’t make too much difference. In fact, when asked about whether he enjoyed speaking to the psychologist he responded:

“Um... It was ok; it didn’t faze me all that much.”

Furthermore, all three participants understood that their sibling required extra help and that more professionals were enlisted in helping them. It did not appear to affect any of the participants negatively.

4.2 *The focus group*

The focus group highlighted very similar themes as discussed above. It was observed, however, that the participatory and projective techniques allowed the participants to talk more freely about their experiences and appeared to discuss some of the above themes in more detail.

4.2.1 *Common Perceptions of ASD and their sibling*

While the participants did not elaborate on the fact that their siblings were unable to use language appropriately, they did highlight the difficulties faced when their siblings' became stressed out and started screaming. For example:

Researcher: *Now we are going to discuss what we have drawn and why. So for example, I drew my family, my dad, my mom, and me. I don't have any brothers or sisters.*

Kim: *I think it's better with no brothers and sisters. Mine screams at me.*

Researcher: *That's hard...*

Kim: *yes, he screams at me and hits me, so you are lucky with no brothers*

Paul: *Mine also screams and fights*

Researcher: *sounds like it is not easy having a brother*

Adam: *No, it isn't easy at all*

Adam elaborated on this topic, stating that his brother's affect often influenced his mother, resulting in her becoming stressed out as well. Furthermore, the participants also elaborated on the difficult behaviours that are part of their siblings' ASD. All three participants discussed how their siblings would scream and/or cry when not getting what they want. Paul mentioned that his brother would get very upset if he didn't get his peanut butter sandwich, while Kim spoke about

her brother screaming when he didn't get a book or toy he wanted. Adam mentioned, again, that his brother often burst into tears for no reason.

Other difficult behaviours faced by the participants included behaviour during meal times. In this sense, Kim and Adam explained that their brothers were unable to eat unless their mothers were present and Kim mentioned that her sibling would play with his food instead of eating it. Adam also elaborated that his sibling didn't like certain foods.

Kim: *My brother doesn't eat when my mom isn't there*

Adam: *Same!*

Paul: *He just doesn't like to eat his vegetables*

Kim: *My brother loves vegetables, he plays with them*

Adam: *Mine hates vegetables*

Kim: *He plays with his food not eating it*

In discussing these difficult behaviours, the participants again spoke about the fact that their sibling often took their things. Both informal discussion and the sentence completion exercise highlighted that this frustrated the participants, especially Adam, who described how his brother would hide the objects taken. Furthermore, both Kim and Paul described incidents when their sibling got lost, and the sentence completion exercise highlighted the fact that the participants were emotionally affected by these behaviours.

For example:

It is scary when... *Tim runs away and we can't find him*

It is scary when... *he gets lost*

(Adam and Paul)

Moreover, Paul felt that this was a frequent occurrence and made outings difficult. He described how his brother had cycled a long way across town to be found in the city, as well as an incident where it had taken the family two hours to find him in a shopping centre. Kim agreed, stating that even though her brother was very young, he would easily disappear and use elevators if he wasn't watched carefully.

4.2.2 Nature of the relationship

While the themes emerging from the interviews also emerged in the focus group, the theme of feeling embarrassed was elaborated on in both informal discussion and the sentence completion exercise. Adam described how his brother would just start screaming in public and that people would stare at him. Paul also elaborated on the fact that his brother would often take all his clothes off in public and stated:

“It’s very embarrassing for me when my brother doesn’t care and just pulls down his pants in a public place. Even at the beach, he just doesn’t care.”

Kim spoke about how her brother would insist on swimming in her girl’s costume instead of a boy’s Speedo, making her feel very embarrassed. The participants voiced their discomfort in these situations during the focus group:

Researcher: So it feels like people don’t really understand so they start staring and then you get embarrassed.

Paul: He just strips

Adam: People think it’s your fault when he screams and that’s why they look

Kim: He goes and swims in my costume, a girls costume and then everybody stares

Researcher: Sounds like your brothers do things that are different and then people look at you funny

Paul: Yes, that’s when I pretend I don’t know him.

The focus group, in this sense, yielded more information than the interviews about how embarrassed the participants often felt. In particular, the participants admitted to feeling ‘different’ because they had siblings with an ASD and this also emerged in the sentence completion exercise. Furthermore, Adam stated that he was often teased at school by his peers who called him names and Paul agreed that, even though the condition was explained to people,

they often didn't understand. All three of the participants agreed that their experiences with their siblings were very different to their peers' experiences, resulting in feelings of being 'different'. Kim also elaborated more on the fact that her friends did not see her sibling in a realistic light and often referred to him as being 'cute', thereby not fully realizing the difficulties she often faced.

There was very little discussion about the participants' role as being responsible or protective during the focus group, and more discussion around the difficult behaviours that the participants and their families had to deal with. In particular, both informal discussion and the sentence completion exercise highlighted that Kim struggled with the fact that her brother often shouted at her and hit her, making the relationship very difficult. This was highlighted in the sentence completion exercise where, for example, Kim completed the sentences in the following ways:

My brother/sister... *sometimes hits me*

I think about... *when Rob doesn't hurt me*

I really don't like it when... *he hurts me*

As a result, she often felt scared and angry. The sentence completion exercise also illustrated that Paul and Adam felt scared and frustrated when their siblings got lost. Discussion showed that this aspect of their siblings' ASD made family outings and shared activities very difficult. Adam described how his brother was afraid of new places, but that the family could go to a nearby coffee shop as there was a television there for him to watch. The other two participants agreed, stating that having a television nearby always aided as a helpful distraction for their sibling at outings. All the participants indicated on the sentence completion exercise that family activities evoked positive emotions in them, while the discussion showed that such activities were often difficult. Other difficult situations and behaviours faced by the participants emerged more clearly during the ranking exercise.

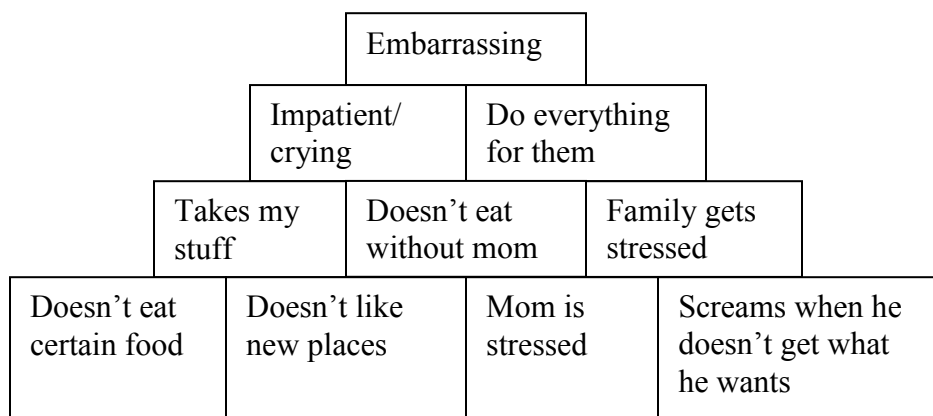
- *The ranking exercise*

In the ranking exercise the participants were asked to name a few situations with, or behaviours of their siblings that were difficult to deal with. The participants ranked their siblings' frustrating

behaviours and their experiences in order from ‘most difficult to tolerate’ to ‘easily tolerated’ in a pyramid shape. As a result, the participants agreed that the most difficult aspect of having a sibling with an ASD was that it was embarrassing in public. There was no debate around this point as all three the participants felt strongly about this. The participants also stated that the next difficult aspect to tolerate was their siblings’ impatience and bursting into tears and the fact that they, or their parents, had to do everything for their sibling. The third most difficult aspects included the fact that their siblings often took their things, had difficult meal times and that their behaviour often stressed the family out. Lastly, the participants placed the fact that their siblings didn’t eat certain foods, didn’t like going to new places, upset mom and screamed when not getting what he wants as the more easily tolerated aspects of the relationship.

- *Output of the Ranking Exercise:*

The item placed on the top of the pyramid was the most difficult to tolerate, while the items towards the bottom were more easily tolerated.



The participants found the activity quite hard because they all had differing experiences of their sibling. In a sense, the experiences were similar, but the different participants experienced the behaviours in different ways, making it difficult to agree on the different levels of the pyramid.

4.2.3 Perceptions of the family system

Both the informal discussion during the focus group and the sentence completion exercise yielded further information about the participants' perceptions of their parents' role in the family. Interestingly, not much mention was made of their fathers, but comments and discussion centered mainly on their mothers' roles. In particular, all three the participants stated again that they thought their mothers were very busy, often not having time to do things such as collecting them from school. Mention was also made about how the participants perceived their mothers as often feeling very stressed and shouting at them or blaming them for no particular reason. For example, when discussing what to draw in their Kinetic Family Drawings, the participants stated:

Adam: *I don't know what to make my mom do.*

Researcher: *What does she normally do?*

Kim: *Work*

Adam: *Yell at me and scream at me*

Kim: *yes, screams*

And later, Adam also stated about his mother that:

"When he gets stressed my mom has to sort him out and then she screams at me."

Lastly, the participants also elaborated on the perceived roles of their mothers. In particular mention was made again that their mothers often did most of the explaining of their siblings' condition to family and friends.

- *Kinetic Family Drawings*

The Kinetic Family Drawings also yielded rich information about the participant's perceptions of the family system and their role in it. The suggestions for emotional indicators provided by Ogdon (1979) were used as a guide in finding recurring themes and patterns that emerged from the drawings. The interpretations were used as a general understanding and not as specific indicator of pathology or adjustment difficulties.

Paul's drawing showed his family swimming in the sea. This could indicate feeling a bit 'out at sea' with all the difficulties the family face, or could also be indicative of an activity that the family enjoys together. Due to the fact that the family was engaged in a similar activity, the drawing suggested family cohesiveness. The drawing also suggested that Paul felt closer to his father than to his mother and that his brother and mother were more involved. Furthermore, the drawing suggested that Paul felt a fair amount of external pressure exerted on the family.

Kim's drawing showed her family, including grandparents, swimming in, or lying next to the swimming pool. As with Paul's drawing, this suggested family cohesiveness. As her grandparents were drawn somewhat larger than any of the other family members and occupied the foremost space on the page, one can surmise that her grandparents are the most significant people to her. The drawing also suggested that she perceives her mother to be fairly isolated, in that she was drawn to one side, while she felt more 'involved' with her father drawn swimming with the children.

Adam's drawing showed the family members doing separate activities, such as fishing, eating ice-cream or watching television, each in separate areas of the page. As opposed to the other two drawings, this may suggest that he feels his family is quite divided. As his father was drawn fishing and his mother more actively involved with Adam himself, it could suggest that Adam perceives his father to be more passive than his active mother. Furthermore, the drawing also suggests that Adam perceives some pressure from his mother.

4.2.4 Social adjustment and coping

In terms of social adjustment and coping, the interviews and sentence completion exercise highlighted the fact that the participants were very busy socially and involved with sports. For example, as Kim completed her sentence:

During the week...I have lots of things planned.

The sentence completion exercise also revealed that the participants most enjoyed outings and going away from home. Kim, for example, spends her holidays at her grandparents' home and finds she is very busy during the week. On the other hand, Adam and Paul often enjoy going overseas with their parents. All the participants indicated in both the informal discussion and the sentence completion exercise that they were happiest when the family was able to do things together, or when things were running smoothly. For example:

I am excited when... *we go to places*

(Paul)

I am excited when... *I am going overseas or to a party*

When it is holidays... *we go to the beach or Mbona with Tim*

(Adam)

No further elaboration about the participants' social activities or coping skills was elicited during the focus group.

- *Draw-a-Person Drawings*

The Draw a Person activity yielded rich information about the participants' self perceptions. These drawings were also interpreted using Ogdon (1979). Again, the themes emerging from the drawings were not used as a diagnostic tool, but rather to obtain information that may lend to a deeper understanding of the participants' internal world. The common themes and suggestions from all the drawings are presented here.

Possible feelings of aggression, anger and expansiveness were suggested in all drawings, indicating some acting out tendencies as well. The drawings were also suggestive of some impulsivity and temperamental outbursts. In all of the drawings indicators of anxiety and tension were present, suggestive of emotional adjustment difficulties, possible depression and rigidity. Another common element in all the drawings was possible feelings of inferiority and inadequacy that perhaps lead to interpersonal conflict and psychological inefficacy. All drawings also indicated a strong need for autonomy.

4.3 Conclusion

The results show that the participants had very similar perceptions about ASD and how the disorder affects their sibling. As a result of the difficult behaviour associated with ASD, the nature of the relationship was affected in some way where the participants felt embarrassed in public, have feelings of frustration, anxiety and anger, and often find it difficult to engage with their siblings. They all took a protective role in the family towards their sibling, and all three participants felt some degree of responsibility for their siblings. All three participants, however, seem to cope very well by keeping active and busy with friends and extra mural activities.

CHAPTER 5: DISCUSSION

This study aimed to investigate the experience of having a sibling with an ASD. In particular, the study explored various aspects of that experience. The following is a discussion of each of the explored aspects, concluding in a discussion of the overall experience of having a sibling with an ASD.

5.1 Common perceptions of ASD and their sibling

The first aspect that this study aimed to investigate was the common attitudes, if any, that the participants held about Autistic Spectrum Disorders and their sibling. The literature illustrates that the core features of ASD include impairment in communication, impairment in social relationships and idiosyncratic, repetitive or stereotyped behaviour or interests (APA, 2000). The results on this were clear. All participants felt that impairment in both expressive and receptive communication was present with their siblings. Although the participants all had siblings that were diagnosed with different levels of functioning, all three felt this was a prominent feature of their sibling's ASD. In fact, when asked what she understood about her brother's disorder, Kim responded:

“Um... That sometimes he doesn't want things that he wants and sometimes when he says he wants to bath then he actually means he wants to shower. And sometimes when he says it he means something else. He can't speak properly.”

From this quotation one can see that, while Kim's sibling was able to make use of verbal language in what seems to be an appropriate manner, she still highlighted his inability to communicate effectively as a key feature of his ASD. As a result, she seemed to have as much difficulty, if not more, than the other two participants with lower functioning siblings.

An interesting point that emerged is that all three participants felt that their siblings became easily 'stressed out'. While impairment in affect regulation is not mentioned as a core feature of ASD in the literature, it would appear that the participants felt that their siblings were not able to

regulate their affect effectively. Furthermore, it is common for children with an ASD to find it difficult to tolerate change in routine and to modulate their affect when such changes occur. This may also be related to the above criteria of impairment in communication where understanding of the environment, and its unpredictability, is limited in children with ASD resulting in feelings of anxiety and stress. Essentially, however, it would appear that the siblings of children with ASD perceive this anxiety as a prominent feature of their siblings' disorder.

In discussing the various social activities that the participants took part in with their siblings, it was clear that the range of activities were limited. In all three cases the participants described certain activities, such as jumping on a trampoline or looking for grasshoppers, as the only activities their siblings enjoyed. As a result, the sibling pairs did not engage much. It was also clear from the limited amount of interaction between the two, that the ASD siblings were unable to engage in more imaginative or age appropriate games with their neurotypical siblings. This is consistent with the second characteristic of ASD as described by the DSM-IV-TR, where individuals with ASD have difficulty in forming and maintaining reciprocal social relationships.

Studies suggesting a negative influence on the sibling relationship with an ASD child show that children spent less time interacting with their ASD sibling and felt lonelier than the comparison children with siblings who were normally developing, with Down's syndrome or with Mental Retardation (Bagenholm & Gillberg, 1991; Stoneman, 2001). When looking at both the common perceptions that children hold about their ASD sibling, and the fact that the literature shows impairment in reciprocal social relationships as being a core feature of ASD, this reported limited interaction becomes understandable.

Whether this limited interaction necessarily implies a negative influence on the sibling relationship is debatable. Literature in this area suggests that the child's understanding of the disorder and difficulties faced by their sibling will impact positively on the relationship and reduce negative consequences (Williams *et al.*, 2002). This implies that understanding that the sibling with an ASD will have impairment in social communication and relationship building will lead to an absence in negative feelings regarding the lack of, or limited interaction, between the two. Adam, however, clearly stated:

“Sometimes I feel quite sad, because I can’t exactly talk to him or interact with him in certain ways and I feel quite sad about that. Sometimes a little angry. I still play with him and it’s quite nice when I do that.”

In this sense, Adam’s experience is negatively influenced by the fact that he is unable to interact with his brother the way other children do. As a result, the nature of the relationship is affected by this aspect, despite having a good working understanding of ASD. The nature of the relationship will be discussed in more detail in the following sections.

A variety of difficult behaviours were also described by the participants as features of their siblings’ presentation. While the range of behaviours varied between the participants’ accounts, there were striking similarities. It would appear that the participants’ accounts are closely correlated to the third characteristic of ASD as described in the DSM-IV-TR as ‘repetitive, stereotyped or idiosyncratic behavior’. In particular, Adam noted that:

“Well he keeps making funny noises, like he’s a dog and it’s really irritating. Or like say I’m watching the TV programme, he just turns it off and leaves the room again and he just does the same thing all the time. He takes stuff too, and then hides it so you can’t find it”

The ranking exercise provided more in depth information about the difficult behaviours that the participants often faced. Their inability to agree completely upon the level of difficulty ascribed to the chosen behaviours indicates the degree of variability in symptoms and presentation between different children with ASD. As illustrated in the literature, studies into the nature of the sibling relationship have contradictory and varying results. Morgan (1988) has explained that due to the complexity, unpredictability and variability of ASD symptoms, siblings of children with ASD are likely to show different patterns of positive and negative outcomes than siblings of children with other disorders. The accounts from the participants in this study serve to confirm the variety of difficulties that children with ASD siblings face.

However, the accounts from participants in this study do have some level of similarity between them. While there was some disagreement as to the level of difficulty ascribed to the behaviours of their siblings, there was agreement about the types of difficulties and behaviours faced. Both Paul and Adam, for example mentioned incidents of their brothers getting lost. All three participants related difficulties around meal-times and all three participants had trouble with their sibling taking and breaking, or hiding, their belongings. Again, these difficult behaviours can be ascribed to the three DSM-IV-TR (2000) criteria of ASD where the child shows impairment in social communication and understanding of the environment. As a result of not understanding, or not being able to interpret social cues, the child is unable to behave within the boundaries of what is socially acceptable. The study by Bagenholm and Gillberg (1991) also found that participants reported more problems with their ASD siblings, such as breaking things or disturbing them, than comparison siblings of children with Mental Retardation and children with normal development. The difficult behaviours displayed by their siblings evoked negative emotions from the three participants in this study and affected the nature of the relationship between them.

5.2 The Nature of the Sibling Relationship with an ASD Child

“Sometimes it feels... *different to have a different brother*”

(Kim)

The sentence completion exercise revealed the sentiments of the participants. Further discussion around this topic elaborated on the fact that the participants were aware of the fact that their experiences with their siblings were simply different from their peers' experiences, making them feel different too. Largely, this had to do with the disruptive, difficult and often bizarre behaviours their siblings display, which, as discussed, can be attributed to the ASD child's inability to understand social norms. The results show that the participants carry an element of embarrassment regarding their sibling, especially in public areas. Interestingly, they did not freely discuss this feeling in the individual interviews, but allowed it to emerge in the less threatening and more accepting environment of the focus group. The literature shows very little information or previous studies on feelings of embarrassment by siblings of children with disabilities. The fact that the participants only tentatively mentioned such feelings in the

interviews suggests some feelings of guilt about being embarrassed. Only when surrounded by others who have similar feelings and experiences, did they feel safe enough to admit to these feelings. None the less, the bizarre behaviour, such as stripping clothes or wearing girls' clothes, became an influencing factor in the nature of the relationship.

“He just does anything like strips in the middle of a public beach.”

(Paul)

Such difficult behaviour can also be seen to give rise to the negative feelings that the participants gave voice to. Such negative feelings may allude to the fact that the non-affected sibling feels that his sibling's behaviour reflects on his identity and, in being able to interpret social cues, recognizes that such difficult behaviours are not the social norm. Feelings of irritation, anger and sadness were reported as a result of their belongings being taken and/or broken, their sibling being unable to regulate affect, and difficulties at meal times, to name a few. A number of studies have been conducted to explore what factors, if any, affect siblings of children with disabilities such as ASD. In particular, the study by Hastings (2003) suggested that, while siblings of children with an ASD scored significantly poorer on the adjustment scale than the comparative samples, maternal well-being and difficult behaviour from the ASD sibling did not contribute to adjustment difficulties. While sibling adjustment was not directly under investigation in this study, the participants' accounts suggested that aspects such as their siblings' difficult and disruptive behaviour did negatively impact on their relationship with their siblings. Not only did it result in feelings of frustration and anger toward their siblings, but also in embarrassment in public areas and an inability to engage and interact in age-appropriate ways. It is important, however, not to overlook the fact that siblings of normally developing children are also faced with negative feelings of anger, frustration and embarrassment. In this sense, normally developing children and siblings also often take one another's belongings, behave inappropriately and embarrass one another. While such feelings may be 'normal' in sibling relationships, it is important to note that the participants in this study gave voice to these feelings in relation to their ASD sibling and it is, therefore, a factor that impacts on the experience of having a sibling with an ASD.

In this sense, negative emotions appeared to be entwined within the sibling relationship. Studies, such as that conducted by Pilowsky *et al.* (2004) illustrate this point in showing that siblings of children with ASD report good relationships with their siblings, but hold more negative views than comparison groups, where the participants did not directly report having bad relationships with their siblings, but did give voice to a variety of negative emotions regarding their interaction with their siblings. Kim, in particular, gave voice to feelings of anxiety regarding her brother's aggression. This is consistent with the study by Ross and Cuskelly (2006) that concluded that aggression was the most common stressor within the sibling relationship with an ASD child. Furthermore, the finding that anger was the most common reaction to this aggression (Ross & Cuskelly, 2006) is also highlighted by the experience of the participants in this study.

Interestingly, Kim showed more evidence of anxiety and negative feelings about her brother and reported more aggressive behaviour from him than the other two participants. Both Paul and Adam's siblings fall within the lower range of functioning, whereas Kim's brother is higher functioning. As a result, her sibling engages in more social games and interacts more with her when compared to Paul and Adam's siblings. While research shows that siblings of children with ASD report more negative emotions and report more aggressive behaviors from their siblings than comparison groups (Bagenholm & Gillberg, 1991; Ross & Cuskelly, 2006; Stoneman, 2001), there is very little research to show the relationship between the reported negative emotions and the ASD sibling's level of functioning. In other words, it is interesting that the participant with a higher functioning sibling would report more negative feelings toward her sibling and more aggressive behaviour from him than those with lower functioning siblings.

This may correlate with the study by Kaminsky and Dewey (2001) that found that siblings of children with disabilities reported less quarrelling and competition than siblings of normally developing children, but also reported less intimacy and nurturance. In this sense, it appears there is a relationship between the degree of interaction between the siblings and the degree of competition and/or conflict. As Adam, for example, stated when asked what he liked best about his brother:

"Well he is like quiet, or he doesn't have the ability to argue, so we don't argue. And we don't fight like normal brothers."

Kim, on the other hand, has a very different experience with her brother. She reported playing with him and often arguing and fighting, illustrating that her levels of anxiety and frustration may be related to the fact that she has a more intimate relationship with her sibling. One may also postulate that this relationship may have to do with the suggestion by Williams *et al.* (2002) that the child's understanding of the sibling's disorder reduces negative consequences. One can suppose that Kim is less aware of her sibling's disorder due to the fact that he is able to do most things with her, such as play, use verbal communication and shows less idiosyncratic or stereotyped behaviour and interests than the other two participants' siblings. As a result, both Paul and Adam face daily reminders of their brothers' difficulties by their inability to communicate, their use of repetitive and stereotyped behaviour and inability to play imaginatively with them. It could follow that Paul and Adam are, therefore, more aware of their siblings' ASD than Kim is, and are less likely to be negatively affected by their siblings' disruptive, aggressive and difficult behaviour, therefore supporting the abovementioned suggestion by Williams *et al.* (2002). While Kim reports a more interactive relationship with her brother, this relationship contains more anxiety and frustration whereas Paul and Adam report less involvement, but also less anxiety.

Furthermore, one could surmise that the difference between participant accounts may also have been influenced by gender expectations. In this sense, the two boys may not feel the same degree of anxiety regarding their siblings' aggressive behaviour as it may be seen as more appropriate for them to defend themselves in some way. On the other hand, Kim may find it difficult to hit her brother back and, therefore, feels defenseless. Moreover, Adam and Paul's brothers may well use their clothes, but this has not caused embarrassment as brothers often borrow one another's clothes. Conversely, the social construction of gender norms does not deem it appropriate for boys to wear girl's clothing, as in Kim's case. Again, the ASD sibling has no understanding of such norms and, thus, is unable to behave within such boundaries whereas Kim – the non-affected sibling – is acutely aware that these norms are not being adhered to. Moreover, Kim is four years younger than the other two participants, which may also introduce the element of

developmental level, where Kim's level of maturity affects her capacity to understand what is happening between herself and her ASD sibling. As a result, aspects such as gender differences and developmental level may indeed have an effect on the sibling relationship as Hastings (2003) suggests.

5.3 Social Adjustment and Coping

The results showed that the participants often felt disappointed, frustrated or angry with their sibling and the situations created or disallowed by their siblings' ASD. This study also aimed to highlight what coping mechanisms (if any) the participants made use of. It was clear from all the participants' accounts that they were very busy with extra mural activities and had lots of friends at school. The literature indicates that positive peer relationships are associated with an increased sense of self-worth and increased coping skills, thereby diminishing psychosocial risk and vulnerability (Schuntermann, 2007). In this sense, the participants' involvement with friends and sporting activities could be seen as a protective factor. In fact, Schuntermann (2007) suggests that negative sibling relationships have been associated with more positive friendships, and this is perhaps due to the fact that the child seeks stimulation and companionship elsewhere when not receiving such warmth from the sibling relationship. As a result, siblings of children with ASD are likely to seek companionship and stimulation from their peers due to the fact that their sibling is unable to engage in an age appropriate and reciprocal manner.

As the literature shows, the majority of research indicating a negative effect on the non-affected sibling shows that depression and loneliness are often higher in siblings of children with ASD's than in those with normally developing siblings (Pilowsky *et al.*, 2004). This is understandable when taking into account the fact that the sibling relationship lacks intimacy and nurturance. One can postulate that the participants in this study are effectively coping with such feelings of loneliness by expanding their friendships, and involvement in sporting and extra mural activities. However, it is necessary to note that the participants in this study have access to resources and finances that enable their involvement in sports and other activities, whereas families with limited resources may not have access to these luxuries.

In fact, it is interesting to note that the participants spend very little time at home and are often away at friends' houses, or engaged in sports after school. Kim, in particular, stated that she spent a lot of time with her grandparents, which was also illustrated by her Kinetic Family Drawing. Schuntermann (2007) also suggests that siblings may erect a façade in order to avoid expressing anger and emotional needs in their determination to be 'normal' Furthermore, they may also surrender any opportunities to request parental support and companionship as they may feel that parents are too preoccupied with the disabled sibling (Schuntermann, 2007). In this sense, it may be that the participants engage in such an extensive range of activities and are away from home as often as they do not wish to 'intrude' upon their 'busy' parents. None the less, should this indeed be the case, it could still be agreed that their busy schedules are functioning as an effective coping mechanism against possible feelings of depression and loneliness.

Interestingly, the projective techniques such as the Draw-A-Person exercise, suggested that the participants are all struggling with similar feelings of anxiety and tension. Another common thread found in the drawings was the indication of possible feelings of inadequacy and psychological inefficacy. These drawings may support the hypothesis that siblings of children with ASD have more emotional and adjustment difficulties (Hastings, 2003; Pilowsky *et al.*, 2004; Rivers & Stoneman, 2003). All drawings, however, also indicated a strong need for autonomy, which may also account for the position of 'responsibility' that the participants had ascribed to themselves, as well as their involvement in activities outside of the home environment. Interestingly, while all the participants had been to see an educational psychologist to help deal with frustrating feelings, it did not make a large impression. Paul in particular felt quite 'un-fazed' and believed that she was unable to make the situation at home better. In this sense, it would appear that the participants experience more support, and cope better, with their situation at home through having busy schedules and large friendship groups than from getting professional assistance. It is important to note that this is the subjective experience of the participants and not a comment on the usefulness of psychologists and other professionals.

5.4 *The Family System*

“...if Rob hasn’t eaten his dinner and screams, my dad says ‘ok, you can have some ice cream’, my mom gets angry.”

“...It makes me scared when they angry, mom is angry a lot.” (Kim)

The research also aimed to understand how the participants perceived their various family systems. It was interesting to note that all three participants alluded to the fact that their mothers were far more involved with their siblings than their fathers were. In this sense, their mothers were given responsibility of taking their siblings to the various therapies that they attend, explaining to friends and others about the condition, and tending to their siblings when they get “stressed out”. All three the participants also constructed their mothers as the person in the family that gets most upset or angry with the situation. Their fathers, on the other hand, were constructed as peripheral figures, with whom they could play and go on outings with.

The study by Hastings (2003) found that, while siblings of children with ASD scored significantly lower on adjustment scales than normative samples, factors such as maternal stress did not contribute to these difficulties. As a result, it was concluded that maternal stress and the siblings’ difficult behaviour could not, and cannot, be seen as risk factors for adjustment of the non-affected sibling (Hastings, 2003). Again, while this study did not measure participants’ levels of adjustment difficulties, the experience of the participants is certainly negatively affected by maternal stress, as evidenced by the above quote. Both Paul and Adam felt similarly regarding their mothers’ stress and stated:

“She gets irritated and shouts and gets in a very bad mood and it irritates me too.”

(Paul)

“Mom gets stressed quite a lot. She doesn’t really show it but sometimes she does. She gets irritated a lot with him, but she can be calm with him. Sometimes she seems a bit sad.”

Researcher: How do you feel about that?

“A bit sad and worried I guess.”

(Adam)

When one takes cognisance of Family Systems Theory, it becomes evident how maternal stress affects the non-affected sibling. As a result of the family functioning as a system, Yura (1987) suggests that the parental subsystem is bound to be affected and influenced by the parents' feelings and anxiety over the ASD sibling. In this sense, all interactions between the parents' and the children will be influenced by emotions, attitudes and beliefs held about the ASD child. Similarly, the sibling subsystem will also be affected by the parental subsystem. Consequently, if the parent behaves in an over-protective manner toward the ASD child, it is likely to reinforce the belief that the special needs child is helpless and that the non-affected sibling will feel more responsibility.

Taking this theory into account, one can further surmise that the negative feelings that the participants feel toward their siblings may also be influenced and reinforced by factors such as maternal stress. In other words, it may be that the participants feel negatively towards their siblings due to the fact that they often witness their mothers feeling 'stressed' and angry. The witnessing of these emotions in their parents, as can be seen through the above quotes, certainly causes discomfort and tension in the participants, perhaps resulting in negative feelings toward the perceived cause of their parents' stress – the ASD sibling. Furthermore, if the developmental perspective is correct in asserting that parents often transmit behaviours and beliefs, and that siblings resemble their parents (Schuntermann, 2007), then it makes sense that the participants will, to some degree, demonstrate feelings of stress and anger as evidenced by their mothers. This influence on the sibling subsystem within the family is illustrated below in figure 4.

Another issue arises regarding the degree of attention, affection and discipline that is afforded to the ASD sibling. The participants all perceived their mothers as being more involved with their siblings. As a result, there may be some degree of perceived differential treatment. Schuntermann (2007) suggests that maternal differential treatment is associated with more conflict and hostility in the sibling relationship. Whether this has been illustrated by the experience of the participants in this study can be debated. Negative emotions towards, and

about, their siblings could be seen to be influenced by this perceived differential treatment. It has also been suggested that the belief by the child that s/he is receiving less warmth and attention than her/his sibling has also been associated with poor emotional and behavioural adjustment (Brody, 2004). However, the participants did not give voice to any concerns regarding the amount of attention that their mothers pay to their siblings. It would appear that the participants' experiences in this study support the proposition made by Brody (2004). He suggested that the perceived legitimacy of the differential treatment will determine whether the child experiences lower levels of self worth or other negative reactions. In this sense, the participants all understood clearly that the level of involvement between their mothers and their sibling was necessary as their sibling required more guidance and assistance than they did.

When looking at the diagram presented by Sanders (2004) to illustrate the reciprocal influences in subsystems as discussed in the literature review (figure 3), the change from ordinary reciprocal influence can be shown. The following diagram illustrates the types of relationships within the participants' families with the introduction of an ASD child, and how the sibling subsystem has been affected.

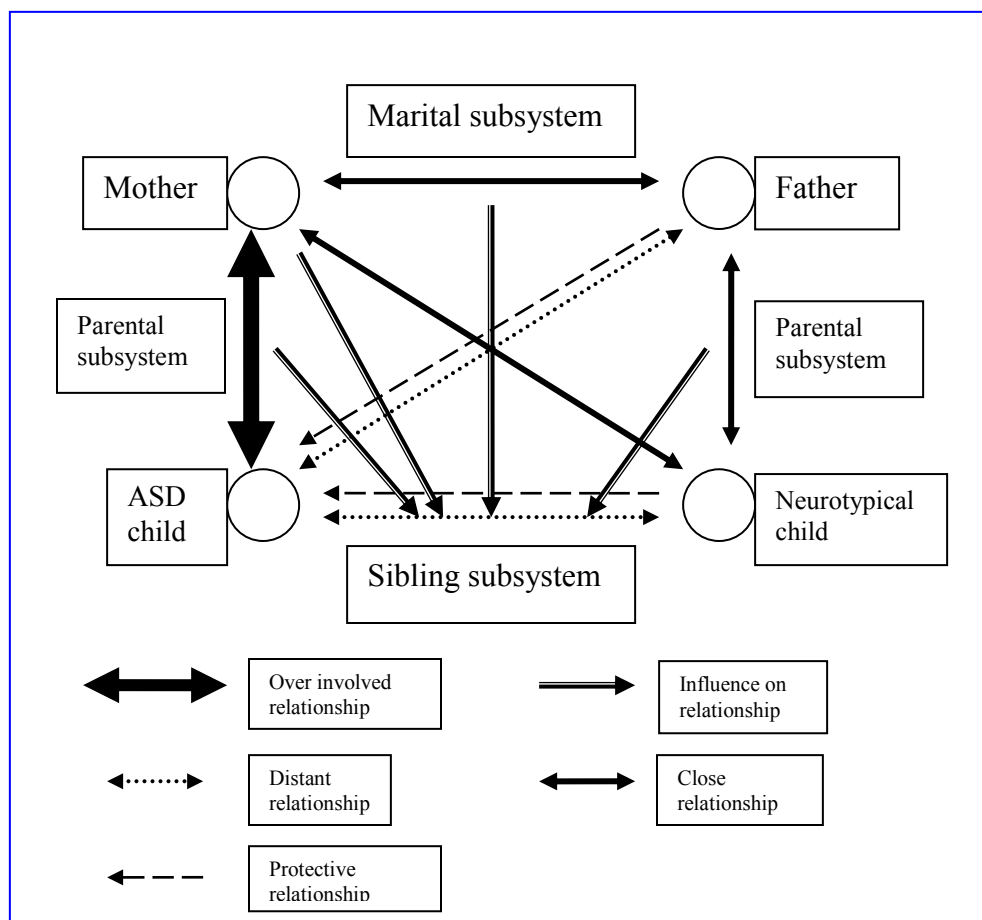


Figure 4: Relationships and effect on sibling subsystem adapted from Sanders (2004).

The above diagram illustrates that not only do the relationships between their mothers and their ASD siblings influence the nature of the sibling relationship, but so does the relationship between the participants and their fathers. In this sense, the relationship with their fathers can be seen as a protective factor mediating any negative feelings the participants may have about the differential treatment received by their mothers. Furthermore, the marital relationship will also influence the relationship between the participants and their siblings and the fact that all participants came from intact families could also be seen as a mediating factor reducing possible negative feelings and adjustment difficulties.

Furthermore, the above diagram can also be modified to illustrate the positions that the family members take in a family with an ASD child and how the relationships within that family are negotiated through the child with an ASD.

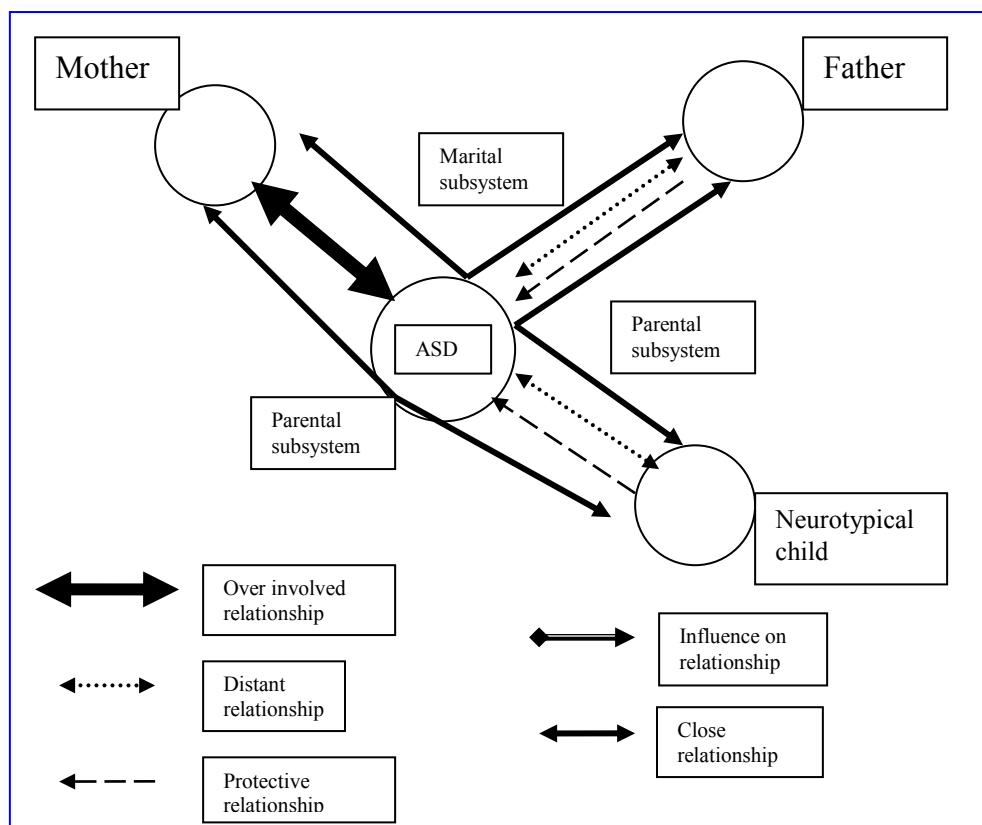


Figure 5: illustrating how all relationships are negotiated through/affected by the ASD child

In terms of providing assistance to their siblings, the participants all saw their own roles in the family as that of ‘protector’ of their sibling. All three participants alluded to the fact that they often held themselves responsible for helping their sibling when the need arose, and also felt particularly anxious when their siblings’ well-being was affected. Family Systems theory as discussed above may also account for this perception where the over-protection showed towards the ASD sibling by their mothers reinforces the belief that their sibling is helpless. As a result, the participants have taken their ‘roles’ in relationship to their sibling from the manner in which their parents interact with their sibling.

Taking a position of responsibility may also be associated with higher levels of competence and feelings of autonomy (Brody, 2004). However, should this role result in excessive care-giving burdens, the child’s cognitive and social adjustment may also be negatively affected. The experiences of the participants in this study do not appear to include excessive levels of

responsibility, but this may also have to do with the resources available to each family in terms of coping with, and treating, the ASD child.

Many quantitative studies have shown that difficulties faced by siblings of children with a disorder include long term care-giving burdens, strains on financial and emotional resources, and interaction and communication problems within the household (Williams *et al.*, 2002). This may not be the case in this study due to the fact that all three families were financially stable and had access to various resources such as au pairs, speech and language therapists and occupational therapists. All three families also made use of private tutors for the ASD sibling and were financially able to provide a range of sporting and extra mural equipment to the participants. As a result, it is apparent that the abovementioned difficulties may not be the experience of the participants in this study, as negative experiences are lessened and coping skills increased by added resources and finances.

Despite the fact that all three the participants' families were financially stable, the Kinetic Family Drawings draw attention to aspects where the participants do not feel as stable. Here it was interesting to note that two of the participants drew themselves and family members in a body of water – in the sea, or in the pool. While the families were cohesive in the picture, one might speculate that these participants perceive their family, in some sense, as 'drowning' or 'being out at sea'. Projective measures often bring to light unconscious feelings and beliefs, and it may be that these participants feel a little overwhelmed by what is occurring in their family. The third participant drew each family member doing something different. The drawing did not feel, or look united and may illustrate how isolated and divided he feels from his family. In this sense, when Adam was asked if they were able to do things as a family often he stated:

“No, he gets very scared of new places and people. So its better when he is taken care of by a babysitter.”

One can imagine that finding a babysitter for an ASD child is not an easy task and, as such, the family does not frequently go on outings. On the whole, while the participants stated that they

really enjoyed doing things as a family, it was clear that this did not always happen easily due to their ASD sibling's inappropriate behaviour. As Paul wrote in his incomplete sentences exercise:

I love...it when my family goes out and nothing goes wrong

5.5 Conclusion: The Experience of Having a Sibling with an ASD

The literature shows that ASD is a challenging, disruptive and often bizarre condition that affects everyone involved in the family. The participants in this study gave voice to experiences that demonstrate the challenging nature of this disorder and what it is like having a sibling with this condition. On the whole, the participants experienced the disorder in their siblings in line with the diagnostic features described by the DSM-IV-TR. These diagnostic criteria had not been used by their parents to explain the disorder to the participants, so their understanding was not influenced in this way. The participants had simply experienced each of the core criteria as a daily part of their sibling's ASD. As a result, the impairment in both receptive and expressive communication, impairment in forming and maintaining reciprocal relationships, and the difficult behaviours that are often stereotyped and idiosyncratic were the basis for the participants' conceptualization of how ASD affected their siblings. A fourth related characteristic was also introduced by the participants' perception of ASD and their sibling, namely that their sibling is unable to understand and interpret social cues and, therefore, does not behave within the confines of social norms. The experience of these areas of impairment also appeared to affect the relationship between the participants and their siblings.

The experience of having a sibling with an ASD is, it appears, a difficult one. The participants gave voice to feelings of frustration, anger, anxiety and embarrassment regarding their siblings' difficult and disruptive behaviour. It is interesting to note that the participants with lower functioning siblings did not have more negative views regarding their sibling. In this sense, more anxiety and frustration was experienced by the participant with a higher functioning sibling, where she also experienced more conflict and competition between them. On the other hand, the participants with lower functioning siblings, while experiencing less interaction with their siblings, appeared to experience less conflict and, consequently, less anxiety. It also appears that

gender and developmental level may be a mediating factor in the experience of having a sibling with an ASD. In this sense, it appears that developmental maturity may positively affect the child's capacity to understand and integrate the frustrating experiences and feelings that are generated by having a sibling with an ASD.

As a result of their siblings' inappropriate behaviour, the participants also gave voice to feelings of embarrassment. Due to the fact that during the interviews the participants were not quick to admit that their siblings sometimes embarrassed them, one could suppose that this embarrassment is somewhat complicated and, perhaps, entwined with feelings of guilt. The difficult feelings associated with the embarrassment may also account for why the participants found this to be the aspect of their relationship with their sibling that is most difficult to tolerate.

Furthermore, difficult and disruptive behaviour, as well as their siblings' inability to play imaginatively, have left the participants with less nurturance and companionship than is normally found in a sibling relationship. As a result, it would seem that the participants have very busy schedules possibly to provide them with the companionship that is missing from their home environment. Furthermore, it appears that the participants experience their mothers as being very busy with their siblings, and one wonders whether the participants also feel, to some extent, that their mothers are too busy for them. In this sense, there may be a tension between their need for more care and affection at home and need for autonomy (as evidenced in the Draw-A-Person exercise).

The feelings of anger and frustration experienced by all three participants, it seems, is exacerbated by their perception of maternal stress and frustration, where the participants were all affected by their parents' stress in situations involving their siblings. Furthermore, while all the participants valued family time, the time spent with the family was often disrupted and difficult due to their siblings' inability to go to new places, or behave appropriately in public.

Having a younger sibling with ASD also appears to evoke feelings of protection and responsibility, as seen by the common construction of their own roles in the family as being 'responsible' and 'protective' over their siblings. The participants construction of their role at

home as being the ‘responsible’ one and protective over their sibling, may also factor into their need for autonomy and wish to be seen as efficient and competent. Moreover, the guilt over feeling embarrassed may also be as a result of feeling protective over, and responsible for, their siblings.

Essentially, it seems that the experience of having a sibling with an ASD is fraught with emotion and feelings that are entwined and complicated. Stressors faced include parental (particularly maternal) stress, coping with a relationship that does not follow social rules and norms, perceived differential treatment by parents and a loss of sibling companionship. These stressors, it would seem, are in constant interplay with a variety of mediating factors. In this sense, a clear understanding of the disorder tends to mediate the frustration and embarrassment felt over the difficult behaviour displayed by their siblings. Similarly, understanding of their siblings’ needs mediates the loss felt over the perceived differential treatment by their mothers. Furthermore, accessing affirmation through busy schedules and friends also appears to be a successful coping mechanism used in mediating any feelings of loneliness and depression. The relationship between the participants and their siblings is a complex one. On the one hand the experience is special and loyal – mediated in this sample by many protective factors, but on the other hand there is the loss of family cohesiveness and outings, loss of parental attention and, most of all, the loss of sibling companionship. As Adam poignantly showed in his sentence completion exercise:

I think about... *having a brother that isn't Autistic*

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH AND PRACTICE

This study aimed to provide an in-depth account of the experience of having a sibling with an ASD. A phenomenological approach was used where the researcher used the hermeneutic circle to guide the method of analysis. In concluding, it is first necessary to highlight the findings. The limitations to this study will then be discussed, and any recommendations for future research in this area will be provided.

6.1 Conclusions about the findings

The first important finding was that, while the sibling relationship was difficult, it was not as lonely as expected. The researcher presupposed that the experience of having a sibling would be difficult and often lonely. On the one hand, the data from this study confirmed this expectation, where the experience as related by all three participants was, reportedly, entwined with negative and difficult feelings. Tolerating the difficult behaviours displayed by their siblings resulted in high levels of frustration and irritation. In this sense, the researcher's assumption that the experience would be a difficult one was confirmed. On the other hand, the experience did not prove to be as lonely as the researcher had expected. The participants were busier with social activities than expected and, therefore, did not seem to be as affected by the differential treatment their siblings received. The researcher presupposed that the participants would feel rejected, neglected, or 'left out' of the attention afforded to their siblings through the number of therapies they attend and the amount of people, such as tutors, that assist their siblings. Conversely, the participants did not give voice to any feelings of rejection, and were in fact so busy with their own lives that there was little time spent at home to witness the differential treatment. As a result, it would seem that the protective or mediating factors that were present for this sample were effective in protecting against feelings of loneliness and depression.

Another important finding was that the experience was more difficult when the ASD sibling was higher functioning. The original preconception held by the researcher was that the experience would be more negative and difficult when the sibling was lower functioning and, for example,

unable to communicate and displaying a range of stereotyped, or idiosyncratic behaviours. As highlighted in the discussion chapter, the results in this study contradicted this expectation in that Kim, with a higher functioning sibling than the other two participants, showed more anxiety and negative emotions regarding her relationship with her brother. The researcher had expected the participants' experience to be more negative when faced with a wider range of difficult behaviours, routines and disruptions. The study showed that understanding what ASD is and how it affects their sibling influences whether the experience is more positive or negative. It also illustrated that the more intimate the relationship between the siblings is, the harder it becomes for the non-affected sibling to tolerate the disruptive, bizarre and difficult behaviour of their ASD sibling. Moreover, the study confirmed that aspects such as developmental level and gender may influence the experience of having a sibling with an ASD.

Significantly, the study also showed that the participants were coping well with ASD in their homes and lives. The literature points, more often than not, to adjustment difficulties, loneliness and depression in siblings of children with ASD. The researcher held the preconception that the participants would show difficulties in the areas of school, friendships or social adjustment. This study contradicted that assumption, illustrating that the participants were socially autonomous and made use of busy schedules to cope with the difficult situation at home.

On the whole, the participants were found to be friendly, well adjusted and coping with having a sibling with an ASD. While their relationship with the sibling is often difficult and frustrating, they have learnt to use their environments as a protective factor against the different experience of having a sibling with an ASD.

6.2 Strengths and Limitations

The choice of a phenomenological approach was suitable as it allowed the researcher to gain the in-depth information desired. As this approach is interested in the 'lived world' of the participant, it was appropriate when exploring the *experience* of having an ASD sibling. This approach, however, has its limits in that no collateral information could be obtained. In this sense, the first hand accounts by the participants may have been skewed by their desire to portray

themselves in a more favourable light. The more negative views and attitudes the participants held may have been avoided. Gaining collateral information from their parents may have provided information about their adjustment and coping skills that the participants were unable to reflect on. On the other hand, this study was only interested in the experience, as felt from the non-affected sibling's perspective, and was successful in attaining this understanding through using the phenomenological approach.

The choice of participants in this study may have its limitations as all the participants came from financially stable families. In the context of South Africa, this is an important point as not all families are affluent and financially capable of providing the degree of education that both the participants and their siblings were receiving. Similarly, the extra mural activities that the participants took part in would not be affordable for all families in all socioeconomic status groups. As a result, the level of coping and adjustment displayed by the participants in this study is not generalisable to all siblings of children with ASD.

Similarly, the small sample size used for this study limits the generalisability of its findings. The nature, however, of this study was exploratory and was able to generate interesting findings that may contribute to further research, as well as a deeper understanding of the sibling's perspective for both care-givers and professionals. Furthermore, the participants also all came from intact families. It would be interesting to see whether children from broken homes with siblings with an ASD would have similar experiences, or whether this aspect would be an influencing factor. In the same way, the participants from this study were all the older of the two, where being the younger sibling may also have an effect on the experience of having a sibling with an ASD. Similarly, gender and developmental level became influencing factors and may provide grounds for further research.

The use of interviews was an effective method of obtaining the data. The semi-structured nature of the interviews was, perhaps, adhered to more than necessary, disallowing for more spontaneous information to emerge. These interviews could also have been supplemented with participant observation or other techniques such as the transect walk (Theis & Grady, 1991)

where the researcher would have obtained a more detailed picture of how they spend their days. This would have allowed for an even richer account of the participants' experiences.

The focus group was successful and the use of participatory and projective techniques allowed for a more relaxed atmosphere where the participants spoke freely and honestly about their experiences. The group bringing the three participants together seemed to dissolve their inhibitions in talking about the frustrating and embarrassing aspects of their relationship with their siblings. When taking the participants' ages and concentration span into account, the duration of the focus group may have been too long. The ranking exercise focused only on the siblings' behaviours, or situations that were difficult to tolerate. In this sense, the results may have been skewed as more focus was placed on those aspects that were difficult about the relationship and much less focus on the positive aspects about the participants' siblings. Had there also been an exercise looking at the positive attributes of their siblings, the participants may have been given an opportunity to show that the experience of having a sibling with an ASD is less difficult than is illustrated here.

6.3 Recommendations for Future Research and Practice

Based on the abovementioned limitations of this study, the following recommendations are made. Future research could make use of participants from a range of contexts and cultures. It would be interesting to compare accounts cross-culturally, as well as looking at accounts from younger siblings, from children with broken families and from less affluent contexts. Not only would this be useful in looking at alternate ways in which non-affected siblings can cope with the difficulties faced by having a sibling with an ASD, but would also be useful when taking into consideration the diversity of cultures within South Africa.

Should future research be interested in looking at the experience from the non-affected sibling's perspective, it would also be useful to make use of unstructured interviews, participant observation and a wider range of participatory techniques. This would allow for a richer account of the experience and allow more spontaneous information to emerge.

The participants in this study gave voice to feelings of embarrassment and it appeared that this was entwined with feelings of guilt. Future research could explore this emotion in more detail, understanding it from the non-affected sibling's perspective and looking at how it influences the nature of the relationship. Further research could also explore the extent to which the ASD sibling's level of functioning becomes a factor that influences the non-affected sibling's adjustment and/or experience.

Understanding the non-affected sibling's experience in detail will allow for recommendations to be made to parents regarding effective coping strategies that their children could use. It will also allow for parents to be more aware of the difficulties their non-affected children often face and how to assist and support them more successfully. This study has highlighted the areas of difficulty that the siblings of children with ASD face. Parents may use this information to understand and maximize the protective factors available to their neurotypical children, while limiting those stressors highlighted here. Furthermore, the information provided by this study is also useful in creating a deeper awareness of the experience of having a sibling with an ASD for professionals. Again, understanding the stressors faced by these children will assist professionals when called upon to assist with the adjustment difficulties, loneliness and depression that are often found in siblings of children with an ASD.

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APPENDIX A

Semi-structured Interview Guide:

1. Name:
2. Age:
3. How old is your brother/sister?
4. What do you think is important about being a brother/sister?
5. How do you feel about your brother/sister?
6. Do you like spending time with _____?
7. Why?
8. What do you understand about your brother's difficulties?
9. When did you first learn about his difficulty?
10. How did you feel when you were told?
11. Do you like talking about your brother's difficulty?
12. What is it like to be the older sibling?
13. What sorts of games do you play together?
14. What do you like best about your brother?
15. What makes you most angry about your brother?
16. What is the happiest memory you have with your brother?
17. What is the saddest/most scary memory you have with your brother?
18. What sorts of things do you enjoy doing with your family?
19. How many people come to visit your brother?
20. What do you think they are here for?
21. How do you feel when they come to see him?
22. Do you speak to anyone about your brother?
23. What sorts of things do you talk about?
24. How do you think your mom feels about your brother?
25. How do you think your dad feels about your brother?
26. What sorts of things do you do together as a family?
27. What school do you go to?
28. What do you enjoy about school?
29. What don't you like about school?
30. What sports do you play?
31. What do you like best about playing sports?
32. Do you have lots of friends?
33. What do you think is important about having friends?
34. Do you go and play at your friends' house a lot?
35. Do you have your friends over to your house?
36. What sorts of games do you play together?
37. What do your friends think about your brother?
38. What do you tell your friends about your brother?
39. How does it feel when they see your brother?

APPENDIX B

Focus Group Guide

Icebreaker:

- Action/naming game.
- Associations game.
- Discussion about expectations and anxieties regarding the exercises.
- Clarification of confidentiality and limits thereof.

Above in order to create rapport and 'safe' environment to openly discuss topics.

Topics	Method
1. My Family	<ul style="list-style-type: none"> • Kinetic Family drawings • Informal discussion
2. Difficult situations with my sibling	<ul style="list-style-type: none"> • Ranking Exercise • Discussion
3. People and my sibling	<ul style="list-style-type: none"> • Informal discussion
4. I wish....	<ul style="list-style-type: none"> • Incomplete sentence exercise
5. Me	<ul style="list-style-type: none"> • Draw a person
6. Ending	<ul style="list-style-type: none"> • Debrief from focus group topics • Discuss any negative emotions

APPENDIX C

Participatory Techniques

- *Sentence Completion Exercise:*

1. My favorite _____
2. I am excited when _____
3. It is scary when _____
4. I don't understand _____
5. My mom sometimes _____
6. Sometimes it feels _____
7. I love _____
8. I am happy when _____
9. At dinner time _____
10. My teacher _____
11. When it is holidays _____
12. During the week _____
13. Its fun _____
14. People always _____
15. Going away with _____
16. My brother/sister _____
17. I think about _____
18. I really don't like it when _____

- *Kinetic Family Drawing*

Each participant will be asked to draw a picture of their family where each family member is doing something. They will be asked to include themselves in the picture.

- *Draw-a-Person*

Each participant is asked to draw a picture of a person, any person, trying not to make it a stick-figure.

APPENDIX D

School of Psychology
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PIETERMARITZBURG, 3209
South Africa
Phone: +27 33 2605853
Fax: +27 33 2605809



Dear _____

I am conducting a research project as partial fulfilment of my Masters degree in Psychology at the University of KwaZulu Natal in Pietermaritzburg. In this study I am interested in the experiences of siblings of children who have an Autistic Spectrum Disorder. The purpose of the study will be to highlight the different ways in which children perceive experience and cope with having a sibling with an Autistic Spectrum Disorder.

The results of the study will be released in the form of a thesis to the School of Psychology at UKZN. However, no identifiable details will be released. I will not be recording the names of participants anywhere and the details of you and your family will remain entirely confidential.

I have selected your children as participants due to the fact that they fall within the selected age bracket and have a sibling that has been diagnosed with an Autistic Spectrum Disorder. In combining the information obtained from my various participants, I hope to learn more about the subjective world of living with a child who has Autism from the siblings' perspective, which may help in making useful recommendations for future research and/or interventions.

Please understand that your child's participation is entirely voluntary and s/he is not being forced to take part in the study. I will be conducting two interviews with your child and asking him/her to participate in a focus group. Some questions will be of a personal and, perhaps, sensitive nature and some may be questions that your child has not thought of before. While I will really appreciate it if they share his/her thoughts with me, it is their choice entirely and they may choose not to answer certain questions. If you and your child agree that they should participate, I want you to know that your child may stop at any time and discontinue participation. Should this happen, there will be no penalties toward him/her and s/he will not be prejudiced in any way.

Once my research is complete, I will make the findings available to you and we may discuss them should you wish to do so. Furthermore, should you wish to speak with a professional person about this study, or wish to make a complaint about any aspect of the study; you are free to contact my supervisors (details below).

Carol Mitchell
 Email: Mitchellc@ukzn.ac.za
 Tel: 0332605853

Angela Hough
 Email: Hough@ukzn.ac.za
 Tel: 0332606054

Please complete the following section and return:

I hereby agree/do not agree to let my child, _____ participate in the research regarding siblings' perspectives of living with a sibling with an Autistic Spectrum Disorder. I understand that s/he will be participating freely and may withdraw at any time. The decision to stop participating will not affect me or my child negatively in any way.

The purpose of the study has been explained to me and I understand what is expected of my child's participation. I also understand that this is a research study whose purpose is not necessarily to benefit me or my child personally. I have been given contact details should I wish to discuss this research with somebody other than the researcher. Lastly, I understand that the findings and feedback will be provided once the research is complete.

 Signature of parent/guardian

 Date

I hereby agree to the audio recording of the interviews and focus group for the purposes of data capture. I understand that all information will remain confidential and mine and my child's details will not be linked to the results.

 Signature of parent/guardian

 Date

School of Psychology
P/Bag X01 Scottsville
PIETERMARITZBURG, 3209
South Africa
Phone: +27 33 2605853
Fax: +27 33 2605809



Dear: _____

I am doing a study on what it is like to have a brother or sister with Autism. As you have a brother or sister with this disorder, I would really like to hear about your experience, and use the information you give me in my study. I will be asking quite a few questions about you and your family and the kinds of things you like and don't like. I will be asking lots of questions about how you get along with your brother or sister. I will also be asking you to join in with two other children like yourself and to have a talk together about your experiences. I hope this activity will be fun, as it will include a few activities and games that we will play.

If you ever feel like the questions are too hard to answer, or you just don't feel happy about being a part of my study, all you have to do is say so and you may stop at any time. Nothing will happen to you, and no one will be angry. It is all your choice and I would like for you to have a good time while talking to me.

All your answers will be recorded so that I can remember all the important things you tell me, but I will never use your name and no-one will ever know that I spoke to you. When I am finished with my study, I will come and talk to you and your family about the findings.

If you are happy about being in my study and would like to talk to me, please write your name on the line below and sign it. This is to show that you understand and have chosen to take part in my study.

Signature of child