

THE EXPERIENCES OF SIBLINGS OF CHILDREN WITH AUTISM

BY

Sunette Bishop

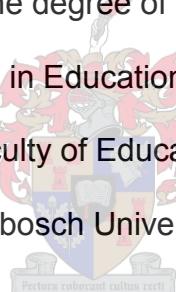
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DECLARATION

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ABSTRACT

Autism or Autism Spectrum Disorder (ASD) is a condition that presently affects approximately 1 out of every 110 children globally and indications are that the prevalence thereof is steadily on the rise. ASD is a complex neurological condition that impairs social interaction, communication and behaviour. Research on the wide-ranging effects of ASD and its unique characteristics in each child with ASD is widely available. Several studies allude to the fact that ASD has an impact on the family unit, but very few researchers have investigated the experience in the Western Cape Province, South Africa, from a sibling's perspective. The current situation leaves researchers, parents and siblings with very little data on the subject and inadequate support is available to address the specific needs of siblings.

The aim of this study was to investigate siblings' views on living with a brother/sister with ASD. The central research question relates to the experiences of siblings of children with ASD. Sub-questions were focused on exploring their perceptions of ASD; relationships with brothers/sisters with ASD, peers and parents; sibling responsibilities and worries; and the extent of the pressure they experience as a result of the related added responsibilities.

This is a qualitative study within an interpretive/constructivist research paradigm. The study was guided by an ecosystemic perspective as the theoretical framework. The methods of data collection comprised semi-structured interviews with siblings of children with ASD and open-ended questionnaires for parents. The qualitative research methods embraced the uniqueness of each sibling's experience and allowed participants the freedom to express this. Eight participants were purposefully selected for this study. The participants were between the ages of seven and seventeen years and each one had a brother who had been diagnosed with ASD. All the siblings lived with the brother with ASD and their parents in the Western Cape Province of South Africa. Siblings were from different genders, as well as diverse socio-economic and cultural groups. All the parents of the siblings were biological parents and in all cases were married with no visible signs of marital stress. Several principles were adhered to in this study, to ensure that the research was ethical.

Several important themes emerged from the study. These include the siblings' need for information pertaining to ASD; worries and feelings of guilt experienced by siblings as a direct result of ASD; responsibilities that siblings feel obliged to take on; the nature of relationships with a brother with ASD, parents and peers; the need for support structures; and an indication of the type of support that siblings require.

OPSOMMING

Outisme of Outistiese Spektrum Versteuring is 'n toestand wat tans na raming 1 uit 110 kinders wêreldwyd affekteer en dit wil voorkom asof die getalle stelselmatig toeneem. Outisme is 'n komplekse neurologiese versteuring wat 'n impak op sosiale interaksie, kommunikasie en gedrag het. Navorsing in die kompleksiteite van Outisme in kinders is redelik vrylik beskikbaar en navorsers dui aan dat die kondisie ook 'n impak op die gesin het. Tans is daar baie min navorsing wat op die ervarings of belewenis van sibbe van kinders met Outisme in die Wes-Kaap, Suid Afrika, fokus. Die gevolg hiervan is 'n daadwerklike tekort aan data tot die beskikking van navorsers, ouers en sibbe ten einde gepaste ondersteuning aan sibbe te bied.

Die doel van hierdie studie was om die sibbe van kinders met Outisme se oogpunt en ervarings te ondersoek. Die sentrale navorsingsvraag het beoog om te ontdek wat sibbe se belewenis van hul lewe saam met 'n broer/suster met Outisme behels. Ondergeskikte vrae hou verband met die sib se persepsie van Outisme; verhoudings met 'n broer/suster met Outisme, eweknieë en ouers; die sib se verantwoordelikhede en meegaande kommer en druk; ondersteuning wat tans beskikbaar is; en die ondersteuning waaraan sibbe 'n behoeftetoon.

Die studie is kwalitatief van aard binne 'n interpretivistiese/konstruktivistiese navorsingsparadigma. Die onderliggende teoretiese raamwerk van hierdie studie is die ekosistemiese perspektief. Data is ingesamel deur middel van semi-gestrukteerde onderhoude met sibbe, asook oop-einde vraelyste aan ouers. Kwalitatiewe navorsingsmetodes het die uniekheid van elke sib se ervaring in ag geneem en sibbe toegelaat om hulle ervarings vrylik uit te druk. Agt deelnemers is doelgerig gekies vir die studie. Die deelnemers was tussen die ouderdomme van sewe en sewentien jaar oud en elk het 'n broer wat met Outisme gediagnoseer is. Die sibbe bly tans saam met hul ouers en 'n broer met Outisme in die Wes-Kaap, Suid Afrika. Die sibbe het vanuit verskillende geslagte, asook verskeie sosio-ekonomiese en kulturele agtergronde gekom. Die ouers van die sibbe was almal biologiese ouers, steeds getroud met geen merkbare spanning in die huwelik nie. Verskeie etiese beginsels is in die studie gehandhaaf ten einde etiese korrektheid te verseker.

Verskeie belangrike temas het na vore gekom. Dit sluit die volgende in: 'n Behoeftet by die sibbe aan inligting rakende Outisme; sibbe se ervaring van bekommernisse en skuldgevoelens as 'n direkte gevolg van Outisme; verantwoordelikhede wat deur sibbe aanvaar word; die aard van verhoudinge met die broer met Outisme, ouers en gelykes; die behoeftet aan ondersteuning; en 'n aanduiding van die tipe ondersteuning wat deur sibbe verlang word.

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ACRONYMS

ASD	Autistic Spectrum Disorder
PDD	Pervasive Developmental Disorder
PDD NOS	Pervasive Developmental Disorder Not Otherwise Specified
ToM	Theory of Mind
ER	Emotion Regulation

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CHAPTER 1

CONTEXTUALISATION, BACKGROUND AND RELEVANCE

1.1 INTRODUCTION

The prevalence of Autism has increased tremendously, though it was initially perceived as a rare disorder, affecting about four children per 10 000 (Tanguay cited in Mash & Wolfe, 2005). Recently, however, it was estimated that one in every 110 children is diagnosed with ASD globally (www.autismwesterncape.org.za). Helen Hayes, the chief executive of Autism Western Cape,¹ was quoted in The Cape Times, stating that an average of 10 children with Autism or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) are diagnosed weekly in the Red Cross, Tygerberg and Lenteguer hospitals, all of which are in the Western Cape Province of South Africa (Jones, 2011).

From an ecosystemic perspective, a diagnosis of ASD does not only affect the child with ASD; individuals and groups at different levels of society are linked in continuously changing, interdependent and interacting relationships (Donald, Lazarus & Lolwana, 2006). In other words, the individual and different systems surrounding the individual need each other for growth and survival. The relationship between the individual and his/her environment is thus seen as a whole system. A disturbance in one part of the system will affect all the other parts of the system and therefore the system as a whole. A diagnosis of ASD affects the whole family and the reactions of the family simultaneously affect the child with ASD, therefore the process is not one-directional but cyclical (Donald *et al.*, 2006). Bronfenbrenner's model of child development thus suggests that people do not develop in isolation; they affect and are affected by multiple systems (Swart & Pettipher, 2011). The characteristics of ASD are therefore expected to have an impact on the rest of the family (Meaden, Stoner & Angell, 2010).

1.2 BACKGROUND TO THE STUDY

Autism or Autistic Spectrum Disorder (ASD) forms part of a group of Pervasive Developmental Disorders including Autistic Disorder, Rett's Disorder, Childhood

¹ Autism Western Cape is the National Body for children and adults with Autism in South Africa.

Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (American Psychiatric Association, 2000; Carr, 2006). In this study, the focus will be primarily on Autistic Disorder and Asperger's Disorder. As both are Autistic Spectrum Disorders, the term ASD will refer to Autistic Disorder and Asperger's Disorder for the purposes of this study. ASD is a complex, neurologically based, pervasive developmental disorder with onset prior to the age of three years. This disorder influences the development and functioning of the brain in various ways (Koudstaal, 2011). Children with ASD have unique characteristics such as impairment in social interactions, communication, and restrictive and repetitive behaviours (American Psychiatric Association, 2000; Carr, 2006; Mash & Wolfe, 2005; Meaden *et al.*, 2010). As a result of these impairments, children with ASD experience difficulties in all aspects of daily interaction with people and their environment (Mash & Wolfe, 2005). Other characteristic features of ASD are: difficulties in integrating and processing sensory experiences; impairment in regulating emotions; unawareness of the mental states of self and others; and impairment in movement and coordination. As the name indicates, ASD is placed on a spectrum (from mild to severe) due to the variance in characteristics and degree of symptoms (Grinker, 2007; Wall, 2004). Thus, each person with ASD is unique, with different combinations of characteristics and a unique experience of these characteristics (Welton, 2004; Williams, 1996). Asperger's Disorder is similar to Autistic Disorder, but people with Asperger's Disorder are usually more capable and thus higher on the spectrum and there are no significant delays in early language development. Regarding ASD, males are affected four times more frequently than females but there are no discernable differences in frequency with regard to social class and culture. Although the prevalence of ASD has increased tremendously, the cause thereof is still unclear. There is general consensus that there is not one, but multiple causes (Barlow & Durand, 2009; Koudstaal, 2011; Mash & Wolfe, 2005). Possible causes include biological-neurological factors, genetic factors, environmental factors, etc. There is no cure for ASD; it is a lifelong condition, but with intervention, children with ASD can show remarkable improvement and learn various skills (Dodd, 2005; Koudstaal, 2011; Mash & Wolfe, 2005).

Although Autism is a well-researched topic, the impact thereof on siblings is usually overlooked (Conway & Meyer, 2008). Previous studies on the impact of ASD on the family have focused mainly on the parents of children with ASD (Meaden *et al.*, 2010; Ross & Cuskelly, 2006; Williams & Piamjariyakul, 2010; Yeal Barak-Levy, Goldstein & Weinstock, 2010). In cases where the influence on the sibling was investigated, many of the studies were quantitative in nature (Dillenburger, Keenan, Doherty, Byrne & Gallagher, 2010; Giallo & Gavidia-Payne, 2006; Orsmond & Seltzer, 2009; Pilowsky, Yirmiya, Doppelt, Tsur & Shalev, 2004; Verte, Roeyers & Buysse, 2003; Yeal Barak-Levy *et al.*, 2010) and data were

usually collected by means of parent reports instead of exploring the siblings' unique views/experiences (Achenbach & Resclora in Orsmond & Seltzer, 2007a; Ross & Cuskelly, 2006; Williams & Piamjariyakul, 2010; Yeal Barak-Levy *et al.*, 2010). Previous studies on siblings of children with disabilities, and more specifically ASD, have shown mixed results; some show positive effects as a result of having a brother/sister with ASD, while others show negative effects (Meaden *et al.*, 2010). Little research on the experiences of siblings has been done in a South African context, especially so in the Western Cape Province. This emphasises the need to continue conducting research in this area.

The Western Cape is one of nine provinces in South Africa, with an estimated population of 5,2 million people (<http://www.southafrica.info>). The Province at present has two Autism-specific schools, namely Vera School and Alpha School, with a learnership of 173 children between the two of them (Jones, 2011). At present, too few resources are available to cope with the ever growing demand for specialist schools catering for children with ASD. The REACH programme, SNAP programme, and On Spectrum are some of several programmes that are available; however, these are often expensive and beyond the reach of those that do not possess the necessary financial capability. In this regard, Macks and Reeve (2007) found that the presence of Autism in a family appears to enhance the psychosocial and emotional development of non-disabled siblings when demographic risk factors, such as financial restraints and resources, are limited. In contrast, if demographic risk factors increase, the presence of ASD seems to have an increasingly unfavourable impact on siblings (Macks & Reeve, 2007). In overseas studies, parents reported financial strain and the need for financial support (Dillenburger *et al.*, 2010), but South African parents with limited resources have to find their own sponsors if they need financial help, as the government is unable to provide relief. Support groups are not available to siblings of children with ASD; several, however, exist to offer support to parents. This lack of support to siblings contributed to the researcher's initial interest in embarking on this study, as this was indicative of a need to explore the needs and experiences of siblings.

1.3 RESEARCH PROBLEM AND AIMS

The problem that faced the researcher was that very little is known about what it is like for siblings in the Western Cape to have a brother or sister with ASD. Previous studies have found that siblings of children with disabilities share most of the experiences that parents usually describe, for instance, isolation, a need for information, guilt, concerns about the future, care-giving demands and sleep deprivation (Doherty; Powell & Gallagher; Seligman cited in Conway & Meyer, 2008). Furthermore, they are faced with issues like resentment,

peer issues, embarrassment and pressure to achieve (Meyer & Vadasy; Naylor & Prescott; Seligman cited in Conway & Meyer, 2008). Very little research has been conducted to investigate these possibilities within families of children with ASD in the Western Cape. It should not be assumed, however, that the experience of having a brother or a sister with ASD is a negative one. While ASD may present many challenges, people are resilient; they are able to bounce back from difficult situations and they are able to adapt (Bayat, 2007). Children with ASD can learn skills which will lessen difficulties and help them to live as normal a life as possible and families can adapt simultaneously and learn to cope with difficulties. The experience of having a brother or sister with ASD might very well be an enriching one (Powers, 2000).

A study by Giallo and Gavidia-Payne (2006) found that parent and family factors were stronger predictors of siblings' adjustment to difficulties than the siblings' own experiences of stress and coping. Parents should therefore be made aware of the needs of the sibling as he/she will be able to cope with difficulties more effectively if they receive support from families. Information gathered during this study could be used in informing parents, teachers, caregivers, psychologists, other professionals and other siblings of children with Autism or other disabilities. It will create awareness of the lives of siblings and challenges they may experience, if any. The information could be used to guide parents and therapists in addressing specific needs of siblings and providing support. While Autism is not something that can be cured, it should not be viewed as the enemy (Williams, 1996). We should learn how to cope with it. We should teach siblings how to deal with it and give them adequate opportunity to express their feelings.

Despite the amount of research on Autism, previous studies have failed to give siblings of individuals with ASD a voice. As mentioned in section 1.2, many previous studies have relied on parent or teacher reports to try to understand the experiences of siblings, instead of relying on reports by the siblings themselves (Achenbach & Resclora in Orsmond & Seltzer, 2007a; Petalas, Hastings, Nash, Dowey & Reilly, 2009a; Ross & Cuskelly, 2006; Williams & Piamjariyakul, 2010; Yeal Barak-Levy *et al.*, 2010). The aim of this study was to give a selected group of siblings of children with ASD in the Western Cape an opportunity to share their thoughts and experiences and enable us to hear their truth. The availability of and possible need for support for these siblings were also investigated.

A personal experience also contributed to the researcher's interest in this study. The researcher worked at a facility for children with special needs where the focus was placed mainly on ASD. Daily interaction with the children also provided the researcher with the opportunity to interact with their families and gain insight into the dynamics at play. It

became clear that the focus usually is primarily on the child with Autism, while the siblings, who often have their own struggles and needs, are left to cope on their own. The researcher decided to conduct this study in order to give siblings a chance to share their experiences and create awareness of the needs these siblings have.

1.4 RESEARCH QUESTIONS

This study was intended to explore the experiences of a selected group of siblings of children with ASD from different cultural and socio-economic backgrounds within the Western Cape. The primary research question was formulated as follows:

What are the experiences of siblings of children with ASD?

Several secondary questions listed below were also included:

1. What are the siblings' perceptions of ASD and does it affect how they deal with the situation?
2. What are the siblings' responsibilities and does this add extra pressure on siblings?
3. What are siblings' experiences of their relationships with others (brothers/sisters with ASD, parents, peers) and what role does ASD play in these experiences?
4. What support is currently available to the siblings, and do they have a need for more support? If so, what kind of support would they like?
5. How do the siblings' lives differ from their friends' lives?
6. What are the parents' perceptions of siblings' experiences?

It was not the intention of the study to explore the role of cultural and socio-economic factors.

1.5 RESEARCH PARADIGM

The research paradigm is central to the research design (Mouton, 2001). The paradigm guides the research and informs the researcher's approach to conducting the study. In this study, a qualitative research design was used within an interpretive/constructivist paradigm. According to the theory, reality is socially constructed; therefore there is no single, observable reality but multiple realities (Henning, 2004; Merriam, 2009). Thus, each individual's reality is influenced by the subjective experiences of the individual and is therefore unique (Terre Blanche, Durrheim & Painter, 2006). The researcher familiarised herself with the participants' reality by exploring their experiences of having a brother or sister with ASD (Nieuwenhuis, 2007). The research paradigm is elaborated on in section 3.3.

1.6 RESEARCH DESIGN

A research design is a 'plan' or a 'blueprint' of how the research is to be conducted (Mouton, 2001, p. 55). In order to execute the plan and answer the research questions, the four dimensions listed below should be cohesive and thus form a consistent research design (Terre Blanche *et al.*, 2006). These dimensions concern the purpose of the study; the theoretical paradigm underlying the study; the context in which the study takes place; and the research techniques for collecting and analysing data (Corbin & Strauss, 2008; Terre Blanche *et al.*, 2006). A basic qualitative research design was used for the study. This design resonates with the study's paradigm, as well as with the methods of data collection. Furthermore, it was suited to the aims of the study, which were to explore the experiences of siblings of children with ASD. Although some of the experiences of siblings in this specific context may be similar to siblings in other contexts, some experiences may also be unique to each individual. The qualitative research method embraces the uniqueness of each sibling's experience and allows participants the freedom to express this, therefore qualitative methodology was deemed the most appropriate for this study.

1.7 RESEARCH METHODOLOGY

Research methodology refers to the actions that were taken in the study and the reasons why those actions were taken (Schensul, 2008). The following are important parts of research methodology: the selection and selection criteria of participants; the methods of data collection and analysis; data verification techniques; and ethical considerations. These issues are discussed briefly in this section and are elaborated on in section 3.5. The purpose of this study was to record the experiences of siblings of children with Autism. Situated within an interpretive/constructivist research paradigm and a qualitative research methodology framework, the methods of data collection were semi-structured interviews with siblings of children with ASD and open-ended questionnaires for parents. The study took place in a South African context.

1.7.1 Selection of Participants and Selection Criteria

Purposive sampling was used to select participants for this study. Purposive sampling is used when a researcher wants to discover, understand and gain insight from participants' specific experiences, therefore a sample from which the most can be learned must be selected (Merriam, 2009). Purposive sampling enabled the researcher to select a sample that met the specific criteria that would provide specific information. It ensured that information-rich data were collected and insight was gained from participants' specific

experiences (Graziano & Raulin, 2010; Patton cited in Merriam, 2009). Eight participants were purposefully selected for the study. They had to be between the ages of seven and seventeen years and had to have a brother or sister diagnosed with Autism Spectrum Disorder. This age range ensured that participants were old enough to express themselves verbally. The siblings had to be living with their brother or sister with ASD and their parents. Adult siblings might record different experiences when reflecting back on their situation when growing up, as opposed to still being in the situation. Siblings could be of any gender. All siblings had to live in the Western Cape in South Africa. There were no preferences with regard to cultural or socio-economic backgrounds. At least one of the siblings' parents had to complete a questionnaire. The parent could be a biological parent, foster or stepmother, or father. The parent also had to be living with the sibling and the child with ASD in the same house.

1.7.2 Context of the study

This study was done in the residences of the participants, as the researcher felt this would be the most comfortable and familiar setting and the most favourable for the acquisition of reliable data. A further consideration in choosing to conduct interviews at their private residences was to accommodate all members of the family. Anonymity is a primary consideration in choosing the location, as privacy is critical to protect participants. The participants all resided in the Western Cape. As mentioned in section 1.2, everyone in the Western Cape Province does not necessarily have access to the resources available in the first world.

1.7.3 Methods of Data Collection

Data for this study were collected through semi-structured interviews conducted with eight siblings of children with ASD and open-ended questionnaires filled in by the parents of these children. Interviewing is one of the most commonly used qualitative techniques. Through interviews, the researcher was able to access participants' experiences directly and to obtain rich descriptions of their experiences (Kvale, 2010). An interview is a way of constructing knowledge through interaction with the participant. By means of a semi-structured conversation, the researcher learns more about the experiences of people and learns to understand people's perceptions. In interviews, however, the researcher is the primary tool of inquiry and should be sensitive to the participant's feelings and capable of addressing interpersonal dynamics within the interview (Kvale, 2010). Interviews are discussed in further detail in section 3.5.3.

A general interview guide (see Addendum C) was used for the semi-structured interviews. An interview guide serves as a checklist during the interview to ensure that key topics are explored (Kvale cited in Taylor & Bogdan, 1998) and still remain flexible so that the researcher can decide which themes will be discussed in further detail. Thus the interview guide is not a 'structured schedule or protocol', but rather a general idea or reminder of what should be covered (Taylor & Bogdan, 1998, p. 105).

Open-ended questionnaires completed by parents and previous literature were also used for triangulation of data. Triangulation is the checking of information collected from different sources for consistency of evidence across sources (Merriam, 2009; Mertens, 1998). This enables the researcher to look from different angles and discover multiple meanings and deeper understanding.

1.7.4 Data Analysis

In the process of data analysis, a substantial amount of qualitative data is transformed into refined interpretations thereof (Gibbs, 2007). The form of data analysis used in this study was qualitative content analysis, by which patterns and themes were identified by grouping data into units of meaning (Corbin & Strauss, 2008). After transcriptions and open coding, themes and categories were identified, which are presented as the findings of this study in Chapter 4; conclusions were drawn from these findings (Charmaz, 2011; Corbin & Strauss, 2008).

1.7.5 Data Verification

In quantitative research, reliability and validity is important to ensure that the research is trustworthy. Reliability refers to the consistency with which a construct is measured, whereas validity is synonymous with truth (Foxcroft & Roodt, 2009). There is, however, no single commonly accepted standard for judging or ensuring the validity and reliability of qualitative research (Merriam, 1998). According to Mertens (1998), there is a variety of criteria against which data can be verified in qualitative research; these include credibility, transferability, dependability and confirmability. These criteria are discussed in further detail in section 3.5.5.

1.8 ETHICAL CONSIDERATIONS

All research must be based on ethical principles in order to protect participants, as well as the researchers (Cohen & Crabtree, 2008). In this study, several principles were adhered to, to ensure that the research would be ethical. Firstly, participants could choose whether

they wanted to take part in the study or not. Before making this decision, all ethical issues, the nature of the study and any risks regarding the study were discussed to ensure that the participants could make informed decisions. Parents gave consent to taking part in the study (filling out a questionnaire) and they also gave consent for their children to take part in the study as they were minors² (between 7 and 17 years old). Even though the siblings of children with ASD were minors, they had a choice whether they wanted to take part in the study as well; they also assented. If they had volunteered to be in this study, they could withdraw at any time without consequences of any kind. They could also refuse to answer any questions they did not want to answer and still remain in the study. The researcher could also withdraw the participants from this research if circumstances arose which warranted doing so. In addition, any information obtained in connection with this study that could reveal the identity of the participants will remain confidential and will be disclosed only with their permission or as required by law. Confidentiality is maintained by using pseudonyms, therefore the names of the participants will not become known. Confidentiality is discussed further in section 3.5.6.3.

This research study was aimed at contributing to the general wellbeing of people, thus the participants' rights were not abused for the purpose of gaining information or knowledge. To ensure that any chance of unintended consequences was reduced, the researcher sought ethical clearance from the Division of Research Development of the University of Stellenbosch. Ethical clearance was obtained and the study was given clearance with the reference number 480/2010. A copy of the clearance form is attached as Addendum A.

1.9 KEY TERMS

1.9.1 Autism

Autism or Autistic Disorder is one of the Pervasive Developmental Disorders as classified by the Developmental and Statistical Manual of Mental Disorders, Fourth edition, Text revision (DSM-IV-TR) (American Psychiatric Association, 2000). The Pervasive Developmental Disorders (PDD) include Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified. These Disorders are characterised by severe and pervasive impairment in several areas of development, including reciprocal social interaction skills and communication skills, or the presence of stereotyped behaviour, interests, and activities (American Psychiatric Association, 2000; Carr, 2006; Mash & Wolfe, 2005). Autism is placed on a spectrum from

² From a legal-ethical perspective, minors are people younger than 18 years (Allan, 2008).

mild to severe according to the variance in characteristics and degree of symptoms (Grinker, 2007; Wall, 2004). The terms Autism and Autistic Spectrum Disorder (ASD) will be used interchangeably in this document. Thus, the terms Autism and ASD will refer to the spectrum of Autistic Disorders when used in this document. ASD is discussed in more detail in section 2.3.

1.9.2 Asperger's Disorder

Asperger's Disorder is one of the Autistic Spectrum Disorders, thus it has similar main features to Autistic Disorder, but it does not include delays in early language development. People with Asperger's Disorder are usually high-functioning; this means that they do not have deficits in cognitive abilities and age-appropriate self-help skills. They do, however, have difficulties with social interaction and have restrictive and stereotyped patterns of behaviour, interests and activities (American Psychiatric Association, 2000). Approximately 25% of people with ASD have Asperger's Disorder (Autism Practical Aspects, n.d.). A further discussion of Asperger's Disorder, as well as the diagnostic criteria thereof, is presented in section 2.3.2.

1.9.3 Siblings

A sibling is a brother or sister; siblings are therefore people who share at least one parent (<http://en.wikipedia.org/wiki/Siblings>). Siblings usually grow up together and spend a great deal of time together. These sibling relationships are unique because they are "ascribed rather than achieved" and they typically last the longest of all human relationships (Cicirelli cited in Orsmond & Seltzer, 2007a, p. 313). Emotional bonds form between siblings; these bonds can, however, be complicated by factors such as parental treatment, developmental stages, personality and disability (<http://en.wikipedia.org/wiki/Siblings>; Wait, Meyer & Loxton, 2003).

1.10 CONCLUSION

A personal interest in Autism and the experience of siblings of children with Autism led to the choice of conducting this specific study. The study followed a qualitative research design within an interpretive/constructivist paradigm. The study therefore gave siblings a chance to let their voices be heard. This chapter presents an outline of the study and it also provides a background to the study. The following chapter explores the literature on Autism, as well as the siblings and families of children with Autism. Chapter 2 furthermore presents an inquiry into where the need for further investigation in this field is.

1.11 OUTLINE OF THE STUDY

This study is reported as follows:

Chapter 1: Introduction, rationale and contextualisation

Chapter 1 provides a background to the study, as well as the primary research questions and the purpose of the study.

Chapter 2: Literature review

The literature review is an overview of the literature on Autism, siblings, and previous studies on Autism and families. Current gaps in knowledge are also explored.

Chapter 3: Research design and methodology

The research paradigm, as well as the research design, are described. The research methodology describes characteristics of qualitative research, selection of participants, methods of data collection, data analysis and verification of data. The context in which the study takes place is explained. Lastly, a discussion of the ethical considerations taken into account during the study is presented.

Chapter 4: Presentation of the findings

Chapter 4 provides a description of the data, as well as the findings.

Chapter 5: Discussion, limitations, recommendations and reflection

This chapter presents a discussion of the research findings and the implications of the study. The researcher discusses the strengths and limitations of the study and makes recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

According to an ecosystemic perspective, a diagnosis of ASD affects the whole family (Donald *et al.*, 2006). Every person with ASD is unique and therefore every sibling's experience of having a brother or sister with ASD will be unique. In this chapter, the theoretical framework is explained first, followed by a discussion of ASD. The discussion of ASD includes a definition, the prevalence, aetiology and the characteristics of ASD, as well as the possible influences thereof on siblings. A review of previous research studies is presented, and gaps within these studies (specifically within a South African context) are discussed.

2.2 THEORETICAL FRAMEWORK: ECOSYSTEMIC PERSPECTIVE

A theoretical framework is like the lenses through which you view the world.
(Henning, Janse van Rensburg & Smit, 2005, p. 25)

In this study, the researcher looks through the lenses of an ecosystemic perspective. The ecosystemic perspective originated from a blend of ecological and systems theories. This perspective emphasises the dynamic, interdependent and interacting relationships between individuals and groups at different levels of society. The ecological theory is a holistic view of the interdependence of organisms and their environment. Thus, according to the ecological theory, organisms and their environment depend on each other for survival and therefore anything "that happens in one part of the system can affect other parts" (Donald *et al.*, 2006, p. 37). Donald *et al.* (2006) used the example of worker bees and flowers to explain this phenomenon. The bee needs the flowers to collect pollen and nectar to feed itself and its young and the flower needs the bee to spread its pollen so that new flowers can grow. Thus, the flower and the bee are interdependent. However, if this system is disturbed by insect poisoning, both the flower and the bee will die. In other words, if there is a balance within the system, it can be sustained, but a disturbance in one part of the system will threaten the whole system and the whole environment will struggle to recover its balance and sustain itself (Donald *et al.*, 2006).

This concept has also been applied to the relationships between human beings and interactions between groups of people within their social contexts. Families and schools are also interactive systems which function as a whole and are dependent on interaction between different parts, e.g. families communicate with schools. Usually the systems can also be divided into subsystems, e.g. parents communicate with children. Patterns of communication take place between systems. The clearness and directness of communication between these subsystems is important for their functioning and interaction. People are also assigned different roles within these systems, e.g. parent, child, caregiver. These roles are important for how the systems function as a whole. Human systems, however, change over time and with development (Donald *et al.*, 2006). The systemic framework is based on the idea that people do not develop in isolation, but affect and are affected by multiple systems (Swart & Pettipher, 2011). Therefore, something that happens to one member of the family affects everyone else in the family (Kaur, Scior & Wilson, 2009; Petalas, Hastings, Nash, Lloyd & Dowey, 2009b). A diagnosis of ASD therefore does not only affect the individual but the entire family. Usually when such a diagnosis is made all the emphasis is on the child with ASD and some focus might be on parents, but the needs of siblings are overlooked (Conway & Meyer, 2008). If parents do not communicate the effects of the diagnosis of ASD to siblings of the children with ASD, it can influence siblings' functioning and interaction with the other subsystems. At times, siblings of children with ASD have contradictory roles within the family system; the siblings might have the role of a child, as well as of a caregiver for the child with ASD. These contradictory roles may create problems for siblings with regard to how people in the system relate to them, e.g., it might create problems in the relationship between siblings and parents, as siblings want to be treated as children but parents might treat them as co-carers (Donald *et al.*, 2006).

Bronfenbrenner's bio-ecological model of child development further explains how children's development is shaped by their social contexts (Donald *et al.*, 2006). According to the bio-ecological model, the child with Autism must be viewed as a part of the entire family system, and not as a separate entity (Meaden *et al.*, 2010). Central to Bronfenbrenner's bio-ecological model of development are four interacting dimensions, namely: person factors (e.g. the temperament of the child or parent); process factors (e.g. the forms of interaction that occur in the family); contexts (e.g. families, schools or local communities); and time (e.g. changes over time in the child or the environment). Proximal interactions, which are close, face-to-face and usually long-term relationships (e.g. between mother and child, teacher and student, child and a close friend, and between siblings), are the most important in shaping lasting aspects of development. These proximal interactions are influenced by person factors and the social contexts in which they occur. Person, process and context factors all change

over time due to changes within the child/person, as well as the environment (Donald *et al.*, 2006; Swart & Pettipher, 2011).

The model emphasises the "interaction between an individual's development and the systems within the social context" (Swart & Pettipher, 2011, p. 10). According to Bronfenbrenner (in Donald *et al.*, 2006), child development happens within four nested systems, the micro-, meso-, exo-, and macrosystems, and these systems interact with the chronosystem (Donald *et al.*, 2006). **Microsystems** are those systems in which people are closely involved in proximal interactions – any contexts with which the person has immediate experience and personal interactions in a direct way. This includes interactions in the family, with teachers and learners in the school, friendship networks and sports teams (Swart & Pettipher, 2011). **Mesosystems** are continuous interactions between Microsystems. Therefore, what happens in the family can influence peer relationships (Donald *et al.*, 2006). "Bronfenbrenner proposes that development will be enhanced if the different settings in which the developing person is involved are strongly linked" (Visser, 2007, p. 25). Thus, the child is more likely to learn certain values if the values that the child learns at school and at home correspond. **Exosystems** are systems in which a child is not directly involved, but which influence the people with whom the child has proximal relationships, therefore it indirectly influences the child. For instance, a parent's workplace might cause stress to the parent which, in turn, is felt at home by the child. **Macrosystems** refer to dominant social and economic structures, as well as values, beliefs and practices inherent in the systems of the specific society or culture to which a person belongs (Donald *et al.*, 2006; Swart & Pettipher, 2011; Visser, 2007). All these systems in which developing children are involved continuously change and develop. The **Chronosystem** represents the effect of time on all other systems. It considers how time relates to the interactions between systems and their influence on the individual's development (Donald *et al.*, 2006; Swart & Pettipher, 2011; Visser, 2007). These systems continuously interact and affect one another; changes in one system affect and are affected by other systems (Swart & Pettipher, 2011). Many metaphors have been used to explain this phenomenon. For example, it is like the ripple of water when you throw a rock into a dam; the initial action causes a series of reactions similar to the stone causing a series of ever widening ripples.

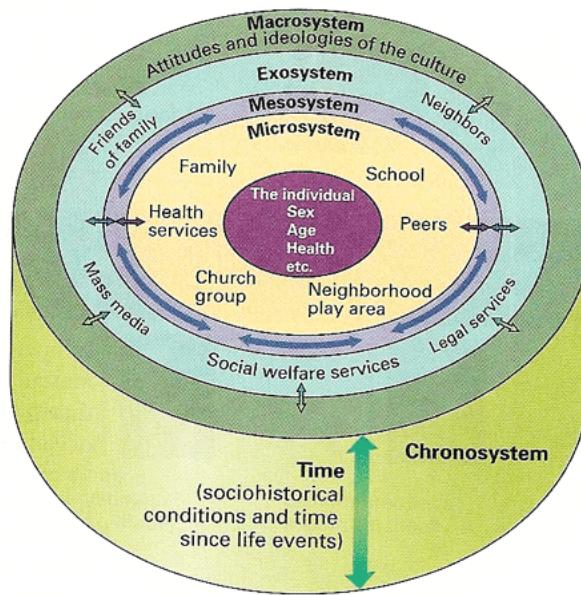


Figure 2.1: The Bio-ecological Model

Source: <http://www.aifs.gov.au>

Autism could also be seen as the metaphorical rock; it does not only affect the individual but the various interacting systems as well. At the same time a sibling's experience of having a brother or sister with Autism will also be influenced by the various interacting systems, for instance, the support available to the sibling and the reactions from others in the micro-, exo- and macrosystems. The bio-ecological framework correlates well with the interpretive/constructivist paradigm, as it aims to understand how different interacting systems influence the individual's development and experiences and therefore also recognises that each individual's reality is unique and is influenced by their specific context. The importance of taking the individual's context into consideration was shown in a study by Macks and Reeve (2007) in which they compared the psychosocial and emotional adjustment of siblings of children with Autism to that of siblings of non-disabled children. They found that the presence of Autism in the family appears to enhance the psychosocial and emotional development of non-disabled siblings when demographic risk factors such as financial strain are limited. On the contrary, if demographic risk factors increase, the presence of Autism seems to have an increasingly unfavourable impact on siblings.

In this study, the focus is on the sibling of the child with ASD; the one usually overlooked is given a voice. This study was aimed at understanding the experiences of siblings. An ecosystemic perspective was used as a framework to gain a better understanding of siblings' experiences through enquiring specifically about the different systems that interact, for instance: the relationships within the family; relationships with peers; and what support the siblings have available in their communities. It was important to know what the siblings'

perceptions of ASD were, as "[c]hildren's perceptions of their context are central to understanding how they interact with their environments" (Swart & Pettipher, 2011, p. 15). Thus, the siblings' perceptions may be expected to influence how they experience living with a brother or sister with ASD.

2.3 DEFINITION OF AUTISM

Some decades ago people with Autism would have been diagnosed with mental retardation or schizophrenia, because the diagnosis of Autism was unknown. Leo Kanner first identified and named Autism in 1943 (Grinker, 2007). Autism forms part of a group of Pervasive Developmental Disorders, as discussed in section 1.9.1. This section provides a more detailed description of Autistic Disorder and Asperger's Disorder. It is important to note that both of these are considered Autistic Spectrum Disorders (ASDs), thus the term ASD is used interchangeably with the term Autism in this document, referring to both Autistic Disorder and Asperger's Disorder. Furthermore, this section provides information regarding the prevalence and aetiology of ASD.

2.3.1 Autistic Disorder

Autistic Disorder is a severe developmental disorder which involves many parts of the brain. As discussed in section 1.9.1, it affects the child's social functioning, language, communication, behaviour and interests. Evidently it "touches every aspect of the child's interaction with his or her world" (Mash & Wolfe, 2005, p. 284). The main features of the DSM-IV-TR criteria for Autistic Disorder are presented in Table 2.1 (American Psychiatric Association, 2000, p. 75). If these criteria are met, a child will be diagnosed with Autism. The characteristics are discussed further in sections 2.3.6.1 to 2.3.6.8. These core features of ASD vary with regard to levels of cognitive ability. In accordance with this, Autism is placed on a spectrum ranging from high-functioning individuals with normal or superior intelligence to individuals with severe intellectual disability (Dodd, 2005).

Table 2.1: The Main Features of the DSM-IV-TR Diagnostic Criteria for Autistic Disorder

Diagnostic criteria for 299.00 Autistic Disorder	
A.	A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
(1)	qualitative impairment in social interaction, as manifested by at least two of the following:
	(a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, 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 other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
	(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 total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
	(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
	(c) stereotyped and repetitive use of language or idiosyncratic language
	(d) lack of varied, spontaneous 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 either in intensity or focus
	(b) apparently inflexible adherence to specific, non-functional routines or rituals
	(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
	(d) persistent preoccupation with parts of objects
B.	Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
C.	The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Source: American Psychiatric Association, 2000, p. 75

2.3.2 Asperger's Disorder

Hans Asperger in his doctoral thesis in 1944 described a group of four boys who had unusual social, linguistic and cognitive abilities (Attwood, 2000). He provided a description of

symptoms similar to that of Leo Kanner, but the children described by Kanner had more severe expressions of Autism, while the boys described by Hans Asperger were more capable (high functioning). While Hans Asperger used the term "autistic psychopathy" when describing these boys (Attwood, 2000, p. 14), the term Asperger's Syndrome was first used by Lorna Wing in 1981. Asperger's Disorder thus is similar to Autism and is now considered a subgroup in the Autistic Spectrum (Attwood, 2000). Asperger's Disorder does, however, differ from Autism as there are no significant delays in early language development (e.g., single words used by age 2 and communicative phrases used by age 3) and it has its own diagnostic criteria. The main features of Asperger's Disorder, as presented by the DSM-IV-TR, are provided in Table 2.2 (American Psychiatric Association, 2000, p. 84).

Table 2.2: The Main Features of the DSM-IV-TR Diagnostic Criteria for Asperger's Disorder

Diagnostic criteria for 299.80 Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) failure to develop peer relationships appropriate to developmental level
 - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (4) lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
 - (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (2) apparently inflexible adherence to specific, non-functional routines or rituals
 - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (4) persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Source: American Psychiatric Association, 2000: 84

2.3.3 Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS)

Pervasive Developmental Disorder Not Otherwise Specified, or Atypical Autism, are terms used to refer to those people who exhibit impairment in the development of reciprocal social interaction, communication or stereotypic behaviours, interests and activities, but do not meet the full criteria for a diagnosis of Autistic Disorder (American Psychiatric Association, 2000; Dodd, 2005).

2.3.4 Prevalence and Course

The prevalence of ASD has increased tremendously over the past decades. Recent findings indicate that it affects 1 in 158 children under the age of 8 years worldwide. Unfortunately there are no official statistics available for South Africa (Koudstaal, 2011). There is uncertainty as to what this dramatic increase can be ascribed to, more specifically whether it is simply a result of the broadening of diagnostic criteria and increased awareness, or whether there is an actual increase in people affected by ASD (Dodd, 2005; Vermoter, 2003; Wing & Potter cited in Mash & Wolfe, 2005). Nash (cited in Vermoter, 2003) claimed that these numbers are real and a cause for concern. ASD is about four times more common in boys than in girls, but in the cases where girls are affected it is usually accompanied with more severe intellectual impairment (American Psychiatric Association, 2000; Mash & Wolfe, 2005). There are no apparent differences regarding the prevalence of ASD in different social classes or cultures (Koudstaal, 2011).

The onset of Autistic Disorder occurs prior to the age of three. In some cases, symptoms can be identified from birth, but the deficits of ASD usually become increasingly noticeable around the age of two years. In most cases, there is not a period of normal development before symptoms become noticeable, but in a small percentage of cases parents report that there was relatively normal development for the first two years (e.g., acquiring of words). This, however, seems to be lost before the age of three; it seems as though development stagnates (American Psychiatric Association, 2000; Mash & Wolfe, 2005). ASD is a lifelong condition as there is no known cure, but many children and adults with ASD show remarkable improvements in their range of skills (Dodd, 2005).

2.3.5 Aetiology

Although much research is being done to try and find the cause of ASD, there are no definite answers yet. The general consensus is that there is not one, but multiple causes (Barlow & Durand, 2009; Koudstaal, 2011; Mash & Wolfe, 2005).

Kanner (cited in Mash & Wolfe, 2005, p. 284) initially concluded that Autism was the result of a genetic inability to form loving relationships with people. Although he ascribed Autism to a genetic deficit, he further implied that the parents of children with ASD contributed to such children becoming Autistic. The mothers of children with ASD were accused of being 'cold' towards them, which presumably caused them to withdraw. He referred to these parents as 'refrigerator parents' (Mash & Wolfe, 2005, p. 284), but this theory of Kanner's (Rutter cited in Mash & Wolfe, 2005) did not gain support.

Some possible causes are listed below, but there is no certainty in this regard. The following causal factors are still being investigated:

- Biological-neurological problems affecting certain parts of the brain (Dodd, 2005)
- Genetic factors might play a significant role, although no specific genes have yet been identified (Koudstaal, 2011; Dodd, 2005)
- ASD is frequently associated with other medical conditions, such as tuberous sclerosis, fragile-X syndrome, Ito's hypomelanosis, Angelman's syndrome and metabolic disorders (Koudstaal, 2011; Mash & Wolfe, 2005)
- ASD may be triggered by something in the environment, either during pregnancy or after birth. Exposure to drugs, infections and heavy metals, metabolic disorders, genetic/chromosomal factors, viral infections, extreme reactions to vaccinations, or development of subclinical seizures are all possible environmental risk factors mentioned in research (Dodd, 2005)
- The measles, mumps, rubella (MMR) vaccine has also raised concerns with regard to the cause of ASD. However, an association between the two could not be proved (Dodd, 2005)
- Genetic factors in conjunction with the environment. It was suggested that something in the environment may trigger the disorder in children who are genetically susceptible to ASD (Dodd, 2005). This probably represents the current thought on aetiology best.

Although there is no certainty as to what causes ASD, there is agreement that it is no-one's fault. It is not a psychological or emotional disorder, nor is it caused by bad parenting (Dodd, 2005). Due to its specific characteristics, it does, however, have a profound impact on both the child with ASD and the rest of the family.

2.3.6 Characteristics of Autism

"No two children with Autism will present the same characteristics to the same degree, just as no two children are the same." (Wall, 2004, p. 8)

The above quotation emphasises the uniqueness of each child with ASD, therefore it is crucial to remember that, although general descriptions of the various characteristics of Autism follow below, each person with Autism is unique, with different combinations of characteristics and a unique experience of these characteristics; Autism affects each person differently (Welton, 2004; Williams, 1996). At the same time, it is essential to remember that these characteristics may also be experienced differently by each family member. The characteristics may cause much distress, disruption and need for adjustment on the part of the family (Aronson, 2009). They may also change over time, as individuals with Autism can learn skills and techniques – ways to deal with and compensate for the communicative, cognitive and behavioural deficits which are characteristic of Autism (Carr, 2006). Feelings of embarrassment, anger, shame and guilt possibly felt by family members may also change dramatically over time and as the child with ASD receives treatment (Aronson, 2009). The focus of this study is indeed on the siblings of children with ASD. Therefore we must consider how the characteristics might influence the siblings, and not only the child with ASD.

Impairment that may cause difficulty for children with Autism as well as their families involve social interaction, communication difficulties, behavioural aspects, sensory integration, emotion regulation, intellectual impairment and motor skills. The deficits occurring in social interaction, communication and behaviour (specifically imaginative or make-believe play, poor abstract reasoning, concrete thinking and a strong desire for consistency), which are the core features of ASD are also known as the Triad of Impairments, or Wing's triad, after the researcher Lorna Wing (Carr, 2006; Dodd, 2005; Wall, 2004). A visual representation of the Triad of Impairments is provided in Figure 2.2. The different dimensions of the Triad of Impairments, as well as other characteristics of Autism, are discussed separately in this document. However, the dimensions of the triad of impairments have continuous interaction with each other and should not be seen as separate developmental entities (Koudstaal, 2011).

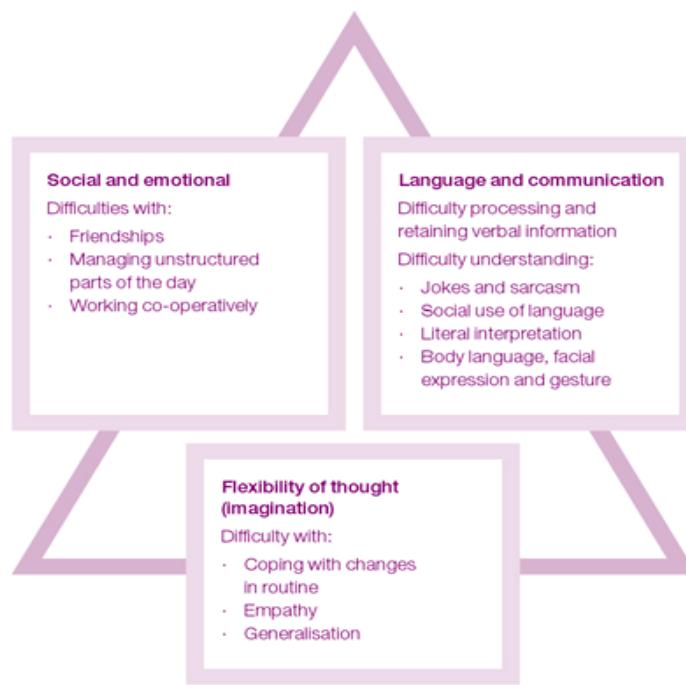


Figure 2.2: The Triad of Impairments

Source: www.autism.org.uk

2.3.6.1 Social Interaction

One of the defining characteristics of children with ASD is that they do not develop age-appropriate social relationships (Durand cited in Barlow & Durand, 2009; Mash & Wolfe, 2005; Nevid, Rathus & Greene, 2003). This includes impairment in the use of non-verbal behaviours such as eye contact, facial expressions, body postures and gestures to regulate social interaction (American Psychiatric Association, 2000; Carr, 2006). Children with ASD do not naturally know much about what another person is feeling or thinking, as they cannot naturally understand non-verbal behaviours (for example expressions, gestures, body movements and tone of voice), although they can be taught how to understand body language, different emotions and facial expressions (Welton, 2004).

From a very young age babies explore, relate to, and interact with their environments. In the process of exploring they start making sense of the world around them and become interested in this world and people. This process enables children to interpret and react to facial expressions, which comprises the beginning of the development of basic skills of social interaction (Wall, 2004). This process often does not occur in children with ASD and therefore these children have difficulty in integrating social, communicative and emotional behaviours. They process social information in unusual ways (Mash & Wolfe, 2005). As has been noted, children with ASD have difficulty reading and interpreting social cues and facial

expressions (for example, whether someone is happy, sad, or annoyed) and they have difficulty understanding people (Mash & Wolfe, 2005; Wall, 2004). As discussed later, children with ASD also have difficulty interpreting tone and intonation of verbal interactions (Wall, 2004). Evidently, not understanding social interaction and, in fact, finding it scary and confusing, may be the reason for not wanting social interaction with others. These children do, however, show more responsiveness to caregivers than to unfamiliar adults (Mash & Wolfe, 2005).

Impairment in social interaction manifests as a failure to develop age-appropriate peer relationships (American Psychiatric Association, 2000; Carr, 2006). Some children with Autism often prefer playing alone because they do not understand the rules of games or the concept of turn taking and often are not 'tuned in' to others (Welton, 2004, p. 19). Furthermore, they want to get away from all the noise (sensory difficulties are discussed in section 2.3.6.4) and confusion (Welton, 2004). Therefore, they develop their own rigid patterns of play, for instance lining up cars and doing the same thing over and over instead of playing interactively with other children (Wall, 2004). These children might be described as aloof, withdrawn or indifferent to people (Koudstaal, 2011). However, John Elder Robinson (2007) in the book on his life with Asperger's Disorder, says that he never wanted to be alone; he simply played by himself because he did not know how to play with others. In fact, he describes being alone as "one of the bitterest disappointments of [his] young life" (Robinson, 2007, p. 210). Some children with ASD do want to interact and they want attention from people, but they do not know how to initiate this need for contact or how to respond appropriately to others. They do not know what is expected in social situations (Robinson, 2007). They are described as "active but odd" (Koudstaal, 2011, p. 345). Playing skills can be developed, but where there is no intervention in this area, it might cause a gap between a young child with ASD and their peers/siblings. Sibling relationships normally develop from birth and play time is a time of great bonding for them. However; if play between these siblings is inappropriate or absent, the bonding might not occur and the sibling relationship might not develop. It might be difficult for a young sibling to understand why their brother/sister with ASD does not want to play with him/her; on the other hand, many young siblings may be aware that their brother/sister is different and they may become very protective and form a strong bond, in spite of the absence of play (Wall, 2004).

It is often written that children with Autism use people as 'tools' to get what they want, without necessarily worrying about the social contact with another person (Barlow & Durand, 2009, p. 512). This may be the result of a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, or a lack of social or emotional reciprocity

(American Psychiatric Association, 2000; Carr, 2006). This means that children with ASD fail to engage with others by showing, bringing or pointing to objects of interest, because they are less interested in the social situation and more interested in the object itself (American Psychiatric Association, 2000; Barlow & Durand, 2009; Carr, 2006; Mash & Wolfe, 2005). They do not actively participate in social play or games and prefer solitary activities and often merely engage others as 'tools' or 'mechanical aids' (American Psychiatric Association, 2000, p. 70). This impairment in social interaction may cause frustration or sadness for families/siblings at times. The following quote allows a glimpse into a sibling's perspective on the impairment in social interaction:

I have lots of different feelings about Eric (my brother with Asperger's). I show him these feelings in my face, with my body, and with my voice ... but he doesn't always seem to understand them, or know how to respond, when I communicate them (Frederick & Schiffmiller, 2007, p. 11).

2.3.6.2 Communication difficulties

Another characteristic of Autism is the delay in, or total lack of, the development of spoken language, which is not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime (American Psychiatric Association, 2000).

Individuals with adequate speech may show marked impairment in the ability or willingness to initiate or sustain a conversation with others (American Psychiatric Association, 2000; Barlow & Durand, 2009). They rarely engage in extended conversation focusing on social or affective topics and display little creativity in language use (Carr, 2006). Children with ASD are often unaware of the protocol of conversations. They might not understand that two or more people participate in a conversation; that you take turns to talk; and that you follow a topic in a conversation (Robinson, 2007; Wall, 2004). People with ASD are often oblivious to the fact that a conversation requires not only talking about a specific topic of interest, but also listening to the other person. Or that, as Robinson (2007, p. 11) describes it, "[s]uccessful conversations require a give and take between both people". Sometimes children with Autism do want to engage in conversation with others, but they only want to talk about a specific topic which they find interesting. As a result, others might get bored or frustrated, but children with Autism might not pick up on the non-verbal cues of others and will therefore keep on talking. This might result in a socially awkward situation, which may cause embarrassment to the rest of the family (Wall, 2004).

In contrast, other individuals may never acquire speech, or unusual communication may occur. Some examples of unusual communication are echolalia; stereotyped and repetitive use of language; idiosyncratic language; delayed language comprehension; and disturbance in the pragmatic (social use) of language (American Psychiatric Association, 2000).

Echolalia occurs when a child repeats what you say instead of answering a question, for example if the question "My name is Anne. What's yours?" is asked, a child with Autism might reply "Anne, what's yours?" Often they repeat the words as well as the intonation of the person who asked the question (Barlow & Durand, 2009; Carr, 2006; Mash & Wolfe, 2005; Nevid *et al.*, 2003). However, echolalia is a normal phase in the development of speech and therefore should not be seen as a symptom of Autism in all circumstances (Barlow & Durand, 2009). At times, echolalia might be the result of not understanding the question asked. The child might know that the listener expects an answer to the question but he/she does not know the answer, therefore he/she repeats the question and hopes that it satisfies the questioner (Wall, 2004). The pitch, intonation, rate and rhythm or stress of speech may also be abnormal, e.g. the person's tone of voice may be monotonous or inappropriate for the context, or it may contain question-like rises at the end of statements (American Psychiatric Association, 2000). Idiosyncratic language is language that has meaning only to those familiar with the individual's communication style (American Psychiatric Association, 2000; Carr, 2006). A delay in language comprehension may result in the individual being unable to understand simple questions or directions (American Psychiatric Association, 2000). As children with ASD have difficulty interpreting or making sense of spoken language and get confused when a conversation is directed to them, they may resort to stimulatory behaviours (hand-flapping, covering eyes or ears) or simply avoid the situation in order to avoid confusion and discomfort (Wall, 2004). Children with ASD tend to take very literal meanings to spoken language (Mash & Wolfe, 2005). This means that they do not understand sarcasm, metaphors and jokes and therefore get confused in conversations with neurotypical people, e.g. expressions like "It's raining cats and dogs" or "It's a piece of cake" confuse them because they interpret it literally. Hence, children with ASD find it difficult to distinguish between joking, teasing and bullying, which might make them the victims of bullies (Welton, 2004; Van Roekel, Scholte & Didden, 2010).

Communication impairments cause frustration to children with Autism because they are not understood by others, nor do they understand others. This frustration may lead to a tantrum. Temple Grandin (cited in Wall, 2004: 73) explained it as follows: "Screaming was the only way I could communicate. Often I would logically think to myself, 'I am going to scream now because I want to tell somebody I don't want to do something'." Consequently, children with

Autism might be frustrated and upset because they are not understood and siblings, teachers or parents might be frustrated or upset because they do not know why the child with Autism is upset/what is wrong/what is going on in his or her mind: "... I found my mom with tears streaming down her face, pleading with my hysterical sister [with autism] to tell her what was wrong. But my sister just couldn't do it ..." (Macfarlane, 2001, p. 190).

2.3.6.3 Behavioural Aspects

According to the DSM-IV-TR, another characteristic of Autism is restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as produced by at least one of the following:

- Encompassing preoccupations with one or more stereotyped and restricted patterns of interest that are abnormal in either intensity or focus
- Apparently inflexible adherence to specific, non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms (e.g. Hand or finger flapping or twisting, or complex whole-body movements)
- Persistent preoccupation with parts of objects (American Psychiatric Association, 2000).

Children with ASD sometimes have non-functional and unreasonable insistence on specific routines and rituals and they might be very resistant to change (American Psychiatric Association, 2000; Carr, 2006). The 'maintenance of sameness' or insistence on having things stay the same (Mash & Wolfe, 2005: 284) gives children with ASD some comfort and security in an otherwise very confusing world (Welton, 2004). Jolliffe, Lansdown and Robinson (cited in Attwood, 2007, p. 243) describe it as follows:

Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearable chaotic life.

Donna Williams (a woman with Autism) explains how she found pleasure and comfort in doing the same things over and over again: "This was a way of getting a grip on consistency in an otherwise upside down world. Rituals and ordering things is a way of making order out of chaos" (Williams cited in Attwood, 2007, p. 243). In reality, the world cannot be controlled and change is inevitable; this might lead to distress for the whole family. The maintenance of sameness might also cause much frustration for siblings who might crave change and

excitement from time to time, but are stuck in the same routine because they do not want to upset their brother/sister with ASD. There are ways, however, to prepare children with ASD for changes, either planned or unexpected. The use of Social Stories and calendars can be very useful in these preparations. Carol Gray developed Social Stories to share accurate social information in a patient and reassuring manner that is easily understood by the child with ASD (Chan, O'Reilly, Lang, Boutot, White, Pierce & Baker, 2011).

Undesirable and challenging behaviour often is a secondary consequence rather than a feature of ASD. Thus, socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming, running away and self-injury are often associated with ASD but these behaviours in actual fact are reactions to the environment or a desperate attempt to communicate. The following might lead to disruptive behaviours: Sensory deprivation, high levels of frustration, unidentifiable pain, a lack of understanding, a lack of effective language and communication (Koudstaal, 2011). Unfortunately, siblings are often also still young and do not understand why their brother or sister acts in this way. Research on siblings of individuals with disabilities have shown that behaviour problems in children with Autism, Down Syndrome or intellectual disabilities predict later adjustment problems in their siblings (Hastings cited in Orsmond & Seltzer, 2009). Furthermore, the presence of behaviour problems in children with disabilities has a negative impact on sibling relationships, according to studies cited in Orsmond & Seltzer (2009). Various patterns of behaviour that occur in children with ASD might influence the rest of the family. Thus, repetitive behaviours such as continuously flushing the toilet or playing with light switches, combined with the need for only a few hours of sleep, will disturb the rest of the family's sleep as well (Koudstaal, 2011). As a consequence, siblings who need eight hours of sleep might struggle to stay awake in school the following day.

Self-stimulatory behaviours, another form of stereotyped and repetitive body movement, or movement of objects commonly occur in children with ASD, although not exclusively. Examples of self-stimulatory behaviours that may persist from childhood to adulthood are hand flapping, spinning of objects, moving the fingers in front of the eyes, etc. Self-stimulation may involve one or more of the senses (e.g., staring at lights, rocking, smelling objects, or carrying a piece of wool around for an entire day). Different theories have been suggested to explain these behaviours, but exact reasons have not been determined. One theory is that children with ASD crave sensory input, thus self-stimulation excites the nervous system. Another theory suggests that they might engage in repetitive behaviours to block out or control unwanted stimulation in an environment that is too stimulating. Other

theories suggest that self-stimulation is simply maintained because of the reinforcement it provides (Mash & Wolfe, 2005). Sensory Sensitivity will be discussed in more detail next.

2.3.6.4 Sensorimotor Development

Many children with ASD have difficulties with integration and processing of sensory, motor and perceptual experiences (Koudstaal, 2011). This happens when all the senses, i.e. sounds (auditory), textures (tactile), light, taste and texture of food and smells are intensified or not present at all. This difficulty is often called sensory integration dysfunction. We need our senses to function and participate in the world around us, thus sensory difficulties make it difficult to understand the environment around us and to decide what actions we should take in specific situations (Attwood, 2007; Wilkes, n.d.). According to Koudstaal (2011), some learners with ASD find it difficult to control incoming sensory stimuli. As a result, many sights, sounds, smells, or textures that most children find normal can be confusing or even painful to children with ASD and exposure to these elements might be overwhelming and cause anxiety (Attwood, 2000; Mash & Wolfe, 2005; Welton, 2004). Consequently, it may result in unexpected negative behaviour such as the following: covering the eyes or ears; moving away from the source; resisting participation; or crying (Koudstaal, 2011). In contrast, the person with ASD will have a very high pain threshold and may express minimal reaction to levels of pain or temperatures that would be unbearable to others (Attwood, 2000). The families of children with ASD might find these behaviours puzzling (Wilkes, n.d.).

Children with ASD can be under- or oversensitive to sensory experiences and the consequences thereof. One example is sound sensitivity. In clinical observation, as well as in personal accounts from people with ASD, it was suggested that there are three types of noise that are found particularly intense. The first is sudden, unexpected noises such as dogs barking, people coughing, a telephone ringing or a pen clicking; these are described as 'sharp' noises (Attwood, 2000 p. 129). The second is continuous, high-pitched noises such as electric motors used in kitchens and bathrooms, a baby crying and garden equipment. The third is confusing, complex or multiple sounds which usually occur in shopping malls, at social gatherings or even in large classrooms. The child might hear sounds too faint for most other people to hear, therefore the loud noise of a lawn mower or vacuum cleaner can be unbearable (Attwood, 2007). The oversensitivity to sound furthermore makes it difficult to concentrate on what another person is saying: an inability to block out all the other sounds most people do not even hear makes it difficult to listen selectively (Attwood, 2007; Mash & Wolfe, 2005; Welton, 2004). For example, in a conversation with someone, most people will block out all other sounds and focus on the other person's voice. People who are oversensitive to sounds cannot block out all the sounds to focus on the other person's voice

because they hear others talking in the distance, the wind, birds chirping outside, the fluorescent light, the air conditioner, cars driving past, etc., all at the same time. Sensory sensitivity has been considered to have a greater impact on the individual's life than difficulties in making friends, managing emotions or, for adults, finding appropriate employment (Attwood, 2007). Families may adapt by celebrating birthdays very quietly to minimise distress/panic/anxiety for the child with ASD. This might cause feelings of resentment in siblings because they are not allowed to have birthday parties like their peers and they might feel that they are missing out on the excitement of the occasion (Wall, 2004).

Another example of Sensory Sensitivity is Tactile Sensitivity. It is the extreme sensitivity to touch. Often children with ASD do not want to be touched or hugged by their families; they might resist touch by flinching or pulling away. The feeling of clothes or shoes on their feet or on their bodies might also be overwhelming. Tactile sensitivities cause discomfort for children with ASD and distress for the rest of the family in various situations, e.g. social situations where greetings require touch; in morning routines of getting dressed; and during trips to the hairdresser, to name a few. Occupational therapists may help to reduce Tactile Sensitivity by means of Sensory Integration Therapy. Massage, brushing, deep pressure or squeezing and vestibular stimulation such as rocking and spinning can also desensitise children with ASD (Attwood, 2000).

Sensitivity to the taste and texture of food may result in extreme food fads. Some children with ASD are extremely picky eaters as a result of their taste buds being extra sensitive or because they do not like the texture of certain foods. They will often touch the food with their fingers to see how it feels before they will put it in their mouths. They are also resistant to trying new foods, flavours and textures. In these cases, children are not deliberately defiant, thus parents should practise tolerance towards the child in terms of tastes and textures. Parents should, however, ensure that the child eats an appropriate range of foods and may gently introduce new food when the child is relaxed or distracted. In contrast, other children with ASD may eat anything from play dough to shaving foam. This can be very dangerous as they may be exposed to toxins (Attwood, 2000; Koudstaal, 2011; Wilkes, n.d.).

Visual Sensitivity (e.g., sensitivity to bright light, colours, or a distortion of visual perception) and Smell Sensitivity also occur. Parents and teachers should be aware of these and address it by providing sunglasses and not using overpowering perfumes and cleaning detergents (Attwood, 2000).

As mentioned in section 2.3.6.3, children with ASD often create rituals or practise self-stimulatory behaviours to help them gain control over these circumstances (Wilkes, n.d.).

These sensitivities should also be kept in mind when trips to the doctor, hairdresser or shops are planned. Parents can attempt to minimise discomfort by taking ear plugs, earphones or sunglasses with them. They can also try to schedule appointments for the first or last hour of the day as it might not be so busy then (Autism Practical Aspects, n.d.).

These sensory processing difficulties also affect the rest of the family, as all activities are planned to accommodate the sensory needs of the child with ASD. Families have to adapt their daily routines and constantly monitor the environment to which the child with ASD will be exposed. As a result, siblings do not get sufficient attention from their parents and the family unit becomes fractured as parents often have to split up in order to attend to the different needs of the sibling and the child with ASD (Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011).

2.3.6.5 Emotion Regulation

Emotion plays an important part in a child's everyday life because it shapes the way children experience and deal with certain situations. Emotion Regulation (ER) refers to the behaviours involved in coping emotionally with positive and negative feelings. It involves the regulation of these emotions by monitoring expressive behaviour in order to achieve one's goals (Thompson cited in Glaser & Shaw, 2011). ER is an important developmental task for children, as effective regulatory strategies play a significant role in guiding early social relationships. Emotion regulates behaviour and, according to Thompson (cited in Glaser and Shaw, 2011), emotion is deemed particularly important in social communication with primary caregivers, siblings and peers and the inability to regulate emotions therefore lead to peer difficulties such as hostility, irritability and non-compliance during play (Bieberich & Morgan cited in Glaser & Shaw, 2011). Because children with ASD have difficulty regulating their emotions, they have difficulty in returning to homeostasis after having an emotional or stressful experience; it is difficult to soothe them and they struggle to maintain positive affect (Keenen in Glaser & Shaw, 2011). They often display intense negative emotions and tantrums (Carr, 2006) which may cause distress to the siblings observing it.

2.3.6.6 Theory of Mind

According to the DSM-IV-TR (American Psychiatric Association, 2000), children with ASD may be oblivious to other children (including siblings); they may have no concept of the needs of others, or may not notice another person's distress. Much research has been devoted to this field. Uta Firth made significant advances in her research; she and her colleagues hypothesised that children with ASD have an impairment of the ability to "mind

read" (Firth cited in Attwood, 2000, p. 112). The development of the awareness of mental states of self and others is referred to as Theory of Mind (ToM) (Mash & Wolfe, 2005). Attwood (2007, p. 112) describes the term as follows:

The psychological term Theory of Mind (ToM) means an ability to recognize and understand thoughts, beliefs, desires and intentions of other people in order to make sense of their behaviour and predict what they are going to do next.

The Sally-Anne Test can be used to determine children's ability to detect the mental states of others. An illustration of this simple test is provided as Figure 2.3.

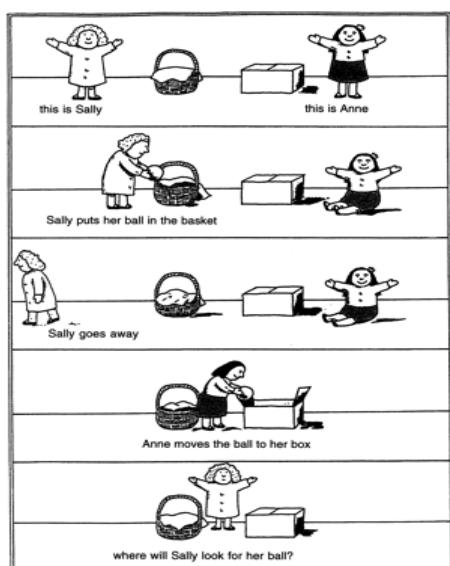


Figure 2.3: The Sally Anne Test

Source: <http://www.asperger-advice.com>

In the Sally-Anne Test, a child is presented with the following scenario: Sally puts her ball in the basket. Sally goes for a walk. Anne removes Sally's ball from the basket and puts it into the box. Sally comes back; where will she look for her ball? Children with ToM will answer that Sally will look for her ball where she had left it because she does not know that Anne had moved it. Thus they are able to put themselves in Sally's shoes. On the other hand, children without ToM will answer that Sally will look for the ball in the box because that is where it is, thus they are unable to put themselves in Sally's shoes. This is referred to as mindblindness. Children with ASD are usually mindblind or, as Dennet (cited in Lind & Bowler, 2009) described it, unable to ascribe false beliefs. Another way to test this ability to ascribe a false belief is to use a See-Know task. In a See-Know task participants are required to ascribe knowledge or ignorance of a content of a box to individuals who either have or have not looked inside the box. It assesses children's understanding that visual

access to information is a way of gaining knowledge of that information, thus children who have the ability to ascribe false beliefs will only correctly attribute the knowledge of the box's content to those who have seen the inside of the box (Lind & Bowler, 2009). However, passing or failing this test will not be conclusive about whether a child has ASD or not. Most children under the age of four years have not developed ToM yet, and will get this wrong (Mash & Wolfe, 2005).

As has been noted, children with ASD have difficulty reading others' behaviour by looking at their outward appearance; they cannot understand or interpret what others are thinking, feeling or planning (Attwood, 2007; Koudstaal, 2011), therefore they seem to be 'mind blind' or 'socially blind', which leads to difficulty in predicting others' behaviour; showing empathy; realising the effect they have on how others feel or think; and understanding social rules in interactions with others (Koudstaal, 2005, p. 345). This has also been described as difficulty in "putting oneself in another person's shoes" (Attwood, 2007, p. 112). However, it would be incorrect to say that people with ASD do not have empathy. They have impaired ToM abilities or empathy, but not an absence thereof. Attwood (2007, p. 114) describes the injustice one would do by inferring that a person with ASD does not have empathy:

To imply an absence of empathy [implies] that the person does not recognize or care about the feelings of others. The person does care, very deeply, but may not be able to recognize the more subtle signals of emotional states or 'read' complex mental states.

As a result of impaired ToM, children with ASD experience many difficulties. For instance, they have difficulty reading the social/emotional messages in someone's eyes; they arrive at very literal interpretations of what someone says (e.g. because of difficulty in understanding metaphors, irony, sarcasm); they are sometimes considered disrespectful and rude; they are extremely honest and not able to use deception to avoid negative consequences; they have difficulty distinguishing between deliberate and accidental actions of people (e.g. to distinguish between jokes, accidents and bullying/teasing); they have difficulty solving problems as they do not realise that they can ask other people for help because they do not have automatic insight into the abilities of others; they have difficulty managing conflict and understanding embarrassment; and they experience increased uncertainty and anxiety because they are unsure of what others are feeling and thinking (Attwood, 2007; Mash & Wolfe, 2005).

ToM plays a role in everyday conversations and social interactions and might thus cause conflict or distress between children with ASD and their siblings or other children (Peterson,

Garnett, Kelly & Attwood, 2009). Some strategies to improve ToM abilities are: Social Stories, Theory of Mind teaching programmes, Comic Strip Conversations and computer programs (Attwood, 2007). Some research suggests that a person with ASD does have knowledge about other people's minds, but is unable to apply that knowledge. In other words, children with ASD might be able to intellectualise what a person might feel when they take his favourite toy without asking, but it seems that this thought does not enter their minds when they take the toy. These children need to be taught to stop and think about how their actions might make someone else feel, before they act (Attwood, 2000; Peterson *et al.*, 2009).

2.3.6.7 Intellectual Impairment

Children with ASD vary widely in intelligence. This may range from persons with severe intellectual impairment to persons with superior abilities (Mash & Wolfe, 2005). However, this 'intelligence' is usually based on standardised tests which cannot fairly convey their intellectual abilities. The results achieved on formal intelligence scales are usually significantly lower than would be expected and thus not a true reflection of the child's abilities. This is because they might do well in some of the subtests which require short-term memory for numbers or forming patterns with blocks (e.g. Memory for Digits and Block Design) but they might struggle with subtests which require social knowledge (e.g. comprehension) (Attwood, 2000; Mash & Wolfe, 2005). The following quote sheds more light on this:

It is another reason why I find it easy to sympathise with autistic humans; for many years their intelligence has been measured with IQ tests that are designed to measure the intelligence of non-autistics. The abilities of autistics, while 'invisible', are so unusual that no existing test can measure them. As autistic individuals have different information processing strategies and styles, they might struggle with tasks presented in a conventional non-autistic way (Daria, 2008, pp. 41-42).

Approximately 5% of people with ASD develop so-called Savant Skills. These skills are isolated and often remarkable talents that exceed normally developing children of the same age, e.g. supernormal abilities in calculation, memory, music, drawing or assembling jigsaw puzzles (Mash & Wolfe, 2005).

Even without accurate knowledge of the intellectual abilities of a person with ASD, it is clear that all children with ASD need support in school and in their daily lives, whether the support is for cognitive, sensory or social difficulties. Children with severe intellectual impairments

need support in all areas of functioning. Although children with Asperger's Disorder do not experience developmental delays, they still require support as the Triad of Impairments (discussed in section 2.3.6) cause multiple barriers to learning which influence their performance negatively. Providing sufficient support to children with ASD requires a lot of attention from parents and teachers (Koudstaal, 2011). Intervention does, however, play a crucial role in the development of children with ASD and with sufficient intervention and support, children can show remarkable progress (Dodd, 2005). Williams (1996, p. viii) describes the role of parents and teachers in the following quote:

The battle against 'autism' is a big one and if no-one expects you to be capable of climbing a mountain, then maybe you wouldn't even consider doing so, nor look for the tools with which to do so. My philosophy is that it is not everyone who is a good mountain climber but that with the right coaching, everyone is capable of taking a few steps more than they might if not challenged nor expected to do so.

All the time and attention spent on the child with ASD may lead to siblings feeling left out or neglected at times, as they also want special attention from their parents and teachers.

2.3.6.8 Movement and Coordination

Clumsiness is a characteristic associated with ASD, even though it is not part of the diagnostic criteria of the DSM-IV-TR or the ICD-10 criteria of the World Health Organisation (American Psychiatric Association, 2000; Attwood, 2007; Carr, 2006). People with ASD might have a different way of walking or running, their coordination might be immature and they can have a strange, sometimes idiosyncratic gait that lacks fluency and efficiency. These children have difficulty knowing where their bodies are in space. This may cause them to trip, spill or bump into things. They often struggle with activities that require balance and coordination; some examples of such activities are riding a bicycle, skating or using a scooter. Poor muscle tone usually affects their body posture negatively (Koudstaal, 2011). As a result of poor muscle tone, children often struggle to concentrate in a classroom. This is because it takes a lot of effort for them to sit up straight in a chair and, in the effort to do this, they often forget to concentrate on their school work. They also struggle with fine motor activities like using scissors and writing (Attwood, 2007). As the child with ASD might be clumsy and might take longer to do activities than siblings, it often requires patience from the rest of the family and might cause frustration to siblings.

In brief, from an ecosystemic perspective it is clear that ASD does not affect the individual only, but all the different systems which interact with the child as well; "anything that

happens in any part of the spider's web is felt in all other parts" (Donald *et al.*, 2006). As described by Aksoy and Bercinyildirim (2008, p. 775), the above-mentioned characteristics of ASD cause many difficulties to which significant others need to adapt: "...having a sibling diagnosed with Autism is difficult for a child, as well as for the family, to understand and accept since with Autism, one has to deal with the unexpected at all times".

However, this does not imply that the experience of having a brother or sister with ASD is necessarily a negative experience. While Autism may present many challenges, people are resilient; they are able to bounce back from difficult situations (Bayat, 2007) and they are able to adapt. Children with Autism can learn skills which will lessen difficulties and help them to live an as 'normal' a life as possible, and families also adapt and learn to cope with difficulties. The experience of having a brother or sister with ASD might thus be an enriching one (Powers, 2000).

As this research study focuses on the experiences of siblings of children with ASD, it was deemed necessary to look deeper into this grouping. The following section therefore focuses on siblings, firstly defining the terms and then looking at the literature regarding siblings' experiences as recorded in previous studies.

2.4 SIBLINGS

The term 'sibling' was fully described in section 1.9.3. A sibling is a person's brother or sister; therefore siblings are people who share at least one parent (<http://en.wikipedia.org/wiki/Siblings>). It was not the intention of the researcher to explore factors such as the number of siblings, ordinal rank of siblings, etc., but to look specifically at relationships within the family and experiences as voiced by the siblings. The developmental stages of the siblings were, however, taken into account.

The work of Erikson and Piaget (cited in Wait *et al.*, 2003) place children between the ages of 6 and 12 years in the developmental stage of middle childhood. During this stage, children become aware of social norms and are sensitive to peer pressure. Around the age of 10 children become very aware of what their friends think of them and they might try various methods (some to personal disadvantage) in attempts to be socially acceptable. This is also a stage of self-evaluation; the child probably participates in some competitive activities/sports and is being compared to other children at school, being evaluated by their teachers, their friends and even their parents. If a good balance does not exist between criticism, praise and motivation from the individual as well as the social environment, the child might end up with a low self esteem and feelings of worthlessness. From the ages of

10½ or 11½ until approximately 17 years, the child is in developmental stage of adolescence. Conformity and peer pressure are exacerbated during this stage. Adolescents experience intense and fluctuating emotions, therefore this period is also known as the 'Sturm und Drang' period. At the same time, adolescents develop their own identity and morals, and become more independent (Wait *et al.*, 2003).

Taking the above into consideration, the developmental stages might play an important role in siblings' experiences at different ages. Experiences at the age of ten might differ substantially from experiences at the age of sixteen as a result of the characteristics of developmental stages. At the same time, siblings' needs and support requirements may differ at different ages.

Being the sibling of a child with ASD can be very stressful. Siblings may try to cope but adjustment may be complicated by conflicting emotions. Siblings

... may feel ambivalent, for instance, about helping a sibling who is so disruptive and takes up so much precious parent time. They may at times feel unloved, rejected, embarrassed, or neglected, but attempt to hide their feelings or act them out in inappropriate ways (Powers, 2000, p. 141).

In this regard, Frender and Schiffmiller (2007, p. 12) quote: "I love [my brother with Asperger's] very much. I can't imagine life without him ... but life with him is sometimes tough."

A sibling's perception of Autism will influence the experience of having a brother or sister with Autism. These perceptions might change over time as siblings get older and learn more about what ASD is and why their brother/sister or even their parents act in certain ways.

2.4.1 Siblings' Perceptions of Disabilities (and Autism)

Some young children have difficulty in understanding less visible disabilities (Maras & Brown cited in Hames, 2008). Children with Autism do not have physical signs of a disability, which might make it more difficult for siblings to understand their behaviour. There is little research on how and when siblings understand that they have a brother/sister with a disability (Conger, Stocker & McGuire, 2009). Girli (in Aksoy & Bercinyildirim, 2008) has mentioned that non-visibility of disabilities makes it difficult for siblings of disabled children to cope with such challenges or disabilities that are difficult to see, thus it creates more stress compared to those that are easier to see and understand. "By learning more about [Autism], I can understand my brother better" (Frender & Schiffmiller, 2007, p. 61).

Vermoter (2003) found that siblings have a need for increasingly more accurate information regarding their brother/sister with ASD disability, in order to understand why their brothers/sisters display certain behaviours and to inform others about the disability. It is important to explore what siblings' perceptions are and whether there are places in their environments where they can learn about Autism and talk to others in order to understand Autism better. Learning and understanding might change their perception of Autism, which, in turn, will play a significant role in their experience thereof.

Studies conducted by Rossiter and Sharpe (cited in Orsmond & Seltzer, 2007a) found that there was a small negative effect on the psychological functioning (depression, anxiety, and behavioural adjustment in terms of internalising and externalising behaviours) of siblings. Furthermore, the negative effects were reported during childhood and adolescence, but positive effects were reported during adulthood. In a study on "Reflections from adult siblings who have a brother or sister with an Autism Spectrum Disorder", the distinction between the impact on childhood or adolescence and adulthood was also mentioned: "In adolescence, I felt it was a negative impact, but now in adulthood, a positive impact" (Krauss & Seltzer, 2010, p. 40). As it was reported that one's perceptions are usually different while in the situation compared to when reflecting back, participants who still live with their brother or sister with ASD were chosen for this study. This was done because the researcher wanted to explore siblings' experiences while they were still in the situation, as opposed to reflecting back on their childhood. The difference in the perceptions of children/adolescents and adults possibly arise due to more mature and effective coping strategies (Orsmond & Seltzer, 2007a). If this is the case, it emphasises the importance of support groups for siblings to enable them to learn about Autism and how to cope with it. According to Vermoter (2003), information regarding the aetiology of ASD might provide relief for siblings in terms of guilt and anger.

2.4.2 The Sibling Relationship

Sibling relationships are unique because they are "ascribed rather than achieved" and they typically last the longest of all human relationships (Cicirelli in Orsmond & Seltzer, 2007a: 313). Nurturing and conflict in such a relationship provide siblings with unique experiences which can foster the development of emotional understanding, self-regulation and a sense of belonging and comfort (Brody in Orsmond & Seltzer, 2007a). However, the sibling relationship is influenced by different interacting systems, such as relationships within and between family and peers; support within the family, school or community; and the characteristics of Autism. The characteristics of Autism, such as impairment in social reciprocity and the presence of rigid behaviour, might affect how siblings bond (American

Psychiatric Association, 2000). According to previous studies, siblings of children with Autism spend less time together than siblings of children with Down Syndrome, and brothers/sisters with Autism respond less positively when their siblings initiate interaction (Orsmond & Seltzer, 2007a). Siblings of children with disabilities share most of the experiences that parents usually describe, for instance, isolation, a need for information, guilt, concerns about the future, care-giving demands and sleep deprivation (Doherty; Powell & Gallagher; Seligman cited in Conway & Meyer, 2008). Furthermore, they are faced with issues like resentment, peer issues, embarrassment and pressure to achieve (Meyer & Vadasy; Naylor & Prescott; Seligman cited in Conway & Meyer, 2008). In Schuntermann's (2007) study on sibling experiences, siblings in families with high marital stress reported less satisfaction with sibling relationships; higher negative behaviour and less positive behaviour towards their autistic siblings; and more positive behaviour when social support was provided in the family. On the other hand, in reviewing self-reports from siblings with brothers/sisters with Autism, siblings expressed primarily positive feelings about their sibling relationships (Rivers & Stonemann cited in Orsmond & Seltzer, 2007a). Siblings can help to dignify the lives of a brother or sister with a disability (Conway & Meyer, 2008). While children with Autism want to have friends but are not always sure how to make friends (Grinker, 2007), a sibling might be a friend to a brother or sister with Autism, as Powers (2000, p. 140) explains:

Your child's autism will definitely affect the way she relates to her brothers and sisters and the way they relate to her. Do not assume, however, that all these ways will be bad. Far from it. Having a sibling with autism is stressful and enriching, exasperating and fun, distressing and rewarding. In other words, it is not much different from being the brother or sister of any other child.

This study explored the different relationships within the family as well as siblings' relationships with peers, as the relationships within the family could affect the experiences of siblings. For instance, support in relationships between siblings and peers or parents might help the sibling to cope emotionally with other stresses in the family (Orsmond & Seltzer, 2009).

2.4.3 Siblings' Emotions

According to previous research, siblings experience various emotions with regard to a brother or sister with ASD. These emotions range from feeling doomed, overwhelmed, annoyed, afraid, disappointed, worried, embarrassed, resentful, lonely, angry, frustrated, rejected, obligated to help and pressured (Freder & Schiffmiller, 2007; Yeal Barak-Levy et

al., 2010) to feeling protective, optimistic, compassionate, happy and proud (Freder & Schiffmiller, 2007).

Siblings' emotions change as they grow and develop. During the preschool years, siblings are sensitive to their parent's anxiety, they do not understand what Autism means and therefore resent it when parents spend more time with the brother/sister with ASD. They might also try to regress in order to get the same attention as the disabled sibling, but they are also non-judgmental and will accept and love their brother or sister with Autism. During school years, siblings might start to wonder what is wrong with their brother/sister; start questioning the transmittal of Autism (e.g. worrying about catching autism); start feeling guilty about their negative thoughts towards their brother/sister (e.g. they feel guilty about the envy when parents spend more time with the child with Autism); try to make up for the problems with a child with ASD by being extra well behaved (e.g. they are excessively helpful and obedient, beyond what is good for them or the rest of the family); or they may misbehave deliberately to get attention. As they get closer to adolescence, they start having conflicting emotions about the sibling with a disability. They might feel good about being needed, but simultaneously feel that the brother or sister is a 'pest'; they might be very protective of their brother or sister, but at the same time resent all the chores they have to do for the brother or sister with Autism. During adolescence, there is pressure to conform and fit in with a crowd. During this time, siblings may easily be embarrassed and may not want their friends or dates to come to their house; they may not want to be seen with their brother/sister in public. They are torn between their love for their brother/sister with Autism and their natural desire for freedom and independence. Siblings might resent all the responsibilities placed on them and worry about the future of their brother/sister and the effect it might have on their own lives (Powers, 2000). It has also been reported that siblings of children with disabilities are fearful of having their own children (Abrams, 2009).

However, the above-mentioned studies were not conducted in a South African context and might not be the same for children in South Africa. Furthermore, as mentioned earlier, each sibling has a unique experience, just as Autism affects each child differently.

Siblings should realise that they are entitled to their own feelings and emotions (Wall, 2004) and that it is acceptable to have those feelings (Freder & Schiffmiller, 2007). They should therefore be given the opportunity to express their feelings and emotions in a safe space. Sharing such feelings and emotions with others is valuable. Siblings need time to feel valued, respected and loved equally, and be allowed time to talk (Wall, 2004). It might also be valuable for siblings to realise that they are not alone, in other words, that there are many other siblings with brothers or sisters with ASD (Freder & Schiffmiller, 2007).

2.4.4 Siblings' Roles and Responsibilities

Studies have shown that siblings often take on a child-care or parental role in relating to their brother/sister with a disability (Orsmond & Seltzer, 2007a; Tsibidaki & Tsamparli, 2009). Parents might have excessive expectations of assistance with the child with a disability. Siblings then take on too much responsibility with the result that they often do not have time for extracurricular activities (Yeal Barak-Levy *et al.*, 2010). As siblings are expected to take on responsibilities, there may be a loss of childhood because they have little opportunity to play and discover, and they then might mature prematurely (Abrams, 2009; Aronson, 2009). According to Orsmond and Seltzer (2007a), the sibling's gender is important with regard to the effects of care giving and involvement, as girls have a tendency to show and report more affection and intimacy in their relationships with siblings than boys would usually exhibit. These care-giving roles are often long-term roles, as siblings have to continue to take care of their brother or sister with Autism when their parents are no longer able to do so (Orsmond & Seltzer, 2007a). Adult siblings reported their worries over the future of their brother/sister with Autism; taking responsibility for a brother/sister with Autism affects many choices in life, such as where you live, your career, marriage, etc. (Krauss & Seltzer, 2010). This is all the more reason for support services for siblings of children with Autism (Orsmond & Seltzer, 2007a).

Sibling or peer tutoring has received increased attention of late. Siblings or peers are able to tutor children with ASD at home in a playful way. Siblings, for example, can model the correct steps in performing a social task like brushing teeth to the child with ASD. This can also be videotaped or recorded in a sequence of photos, for the child with ASD to watch it when necessary. In this way, skills that are taught at school can also be generalised by repeating the teaching of such skills in different settings (Carothers & Taylor, 2004). According to Robinson (2007, p. 21), siblings play an important role in teaching their brother/sister with Autism as they are able to teach in a way that grown-ups are not always able to use. Robinson describes it as follows:

Adults ... would approach me and say something to start a conversation. If my response made no sense, they never told me. They just played along. So I never learned how to carry on a conversation from talking to grown-ups, because they just adapted to whatever I said. Kids, on the other hand, got mad or frustrated.

Siblings learn from each other; while a typically developing sibling is socialising the sibling with a disability, the typically developing sibling gains personal strength and develops social competencies with sibling disability (Dykens; Gold cited in Conger *et al.*, 2009). Previous

studies have found that peer tutoring is a positive experience for children in schools that teach children with ASD and that it brings about a positive change in the attitudes, perceptions and knowledge of typically developing peers. Peers reported personal benefits of tutoring children with ASD, such as confidence building, caring for others, acknowledging diversity and learning responsibility (Jones, 2007). This does not, however, prove that siblings will have a positive experience thereof.

2.4.5 The Role of a Support Group

According to Lock and Finstein (2009), siblings of children with disabilities are faced with various issues, challenges and disruptions. All aspects of daily living are affected by the characteristics of Autism; Autism may cause disruptions in family routine (Thara cited in Lock & Finstein, 2009), emotional strain (Wing cited in Lock & Finstein, 2009) and various additional demands not experienced in the typical family situation (Harris & Glasberg cited in Lock & Finstein, 2009).

Some needs of siblings have been identified by Conway and Meyer (2008), Frender and Schiffmiller (2007) and Aronson (2009). They are:

- a forum to express their concerns and address their needs
- a need for someone to listen to them and hear their stories
- a place to share information with their peers about their sibling's disability
- recognition of the important role they play in their brother/sister's life and the need to understand their own feelings
- a place where they can learn coping skills and a place where they can learn about Autism, where myths and misperceptions of autism can be corrected
- a need to be reassured that they are not alone, but that there are many others with similar challenges.

Conway and Meyer (2008, p. 113) suggested the following:

As the people who, over the course of their lifetimes together, will be most involved with their siblings with special needs, it is important that typically developing brothers and sisters are involved and empowered in their growing relationship with their sibling.

Pilowsky *et al.* (2004) have suggested that support groups for individuals and their families may play an important role in helping families of children with Autism to cope with the stress they may experience. Schunerman (2007) found that positive behaviour remained higher

when social support was provided in families. A study on Chinese families' needs and available support suggested that families with a child with severe disability need more community services, information and family and social support (Wang & Michaels, 2009). In the United States of America and the United Kingdom, there are programmes to address siblings' need for support and information (Conway & Meyer, 2008). According to Conway and Meyer (2008) it is important to support siblings from an early age, rather than waiting for problems to arise. Research also supports the development of support groups for siblings of children with ASD (Lock & Finstein, 2009). Although siblings did show interest in opportunities to learn from others with similar experiences to their own, they articulated less enthusiasm for support groups, according to the study by Lock and Finstein (2009), with possible reasons being related to low interest, lack of experience (uncertainty as to what a support group is), anxiety about the implications thereof, and the location of the group meetings (Lock & Finstein, 2009).

The expectation was that it would be valuable to investigate how siblings in South Africa feel about support groups. This study was therefore used to explore the support currently available in the Western Cape Province in South Africa for the group of siblings who participated in this study, and whether these siblings experienced a need for more support.

2.4.6 Resilience

Resilience refers to the ability to bounce back after dealing with hardships and adversities and to become stronger and more resourceful as a result thereof (Walsh cited in Bayat, 2007). There has been a growing interest in studying family resilience in studies that determine what factors contribute to families becoming stronger in spite of the difficulties they face. According to a study by Bayat (2007), a considerable number of families with children with Autism displayed factors of resilience and it was reported that they become stronger because of the disability. The study by Bayat (2007) reported factors that made families of children with Autism more resilient as in mobilising resources; making positive meaning of the disability; becoming closer as a family; developing greater appreciation of life; and gaining spiritual strength. Tsibidaki and Tsamparli (2009) identified other factors which influence resilience, namely communication between parents and harmony in parenting, coping style, supportive social network and problem-solving skills. Knestrict and Kuchey (2009) deemed the following as crucial in the development of resilience: having the time and ability to reflect; rules, rituals and routines in the family; and the socio-economic status of the family.

2.5 CONTEXT OF THE STUDY

This study was undertaken in the Western Cape Province in South Africa. The context of the study is discussed in sections 1.7.2 and 3.5.2. As discussed in section 1.2, the presence of Autism in a family appears to enhance the psychosocial and emotional development of non-disabled siblings when demographic risk factors such as financial restraints and resources are not limited. In contrast, if demographic risk factors increase, the presence of ASD seems to have an increasingly unfavourable impact on siblings (Macks & Reeve, 2007). In overseas studies, parents reported financial strain and the need for financial support (Dillenburger *et al.*, 2010). In South Africa, most parents have to get their own sponsors if they need financial support, thus the local picture may be very different from that presented by studies undertaken overseas.

2.6 PREVIOUS RESEARCH STUDIES

Many studies on the individual with ASD are reported. Some of these focus on the following:

- The specific symptoms/characteristics and impairments associated with Autism (Chiang, 2009; Dritschel, Wisely, Goddard, Robinson & Howlin, 2010; Eigsti, De Marchena, Schuh & Kelley, 2011; Haeson, Boets & Wagemans, 2011; Hobson, 2010; Mayes & Calhoun, 2011; Meirsschaut, Roeyers & Warreyn, 2011; Nadon, Feldman, Dunn & Gisel, 2011; Stauder, Bosch & Nuij, 2011; Zahavi, 2010)
- Cognitive abilities (Christ, Holt, White & Green, 2007)
- Treatments for Autism (Baltruschat, Hasselhorn, Tarbox, Dixon, Najdowski, Mullins & Gould, 2011; Chan *et al.*, 2011; Mesibov & Shea, 2011)
- Quality of life (Billstedt, Gillberg & Gillberg, 2011)
- Experiences of attending mainstream schools (Humphrey & Lewis, 2008)

Other studies focus specifically on parents/mothers of children with ASD, as well as the relationship between parents and their Autistic children (Balfour, 2007; Chamak, Bonniau, Oudaya & Ehrenberg, 2011; Dale, Jahoda & Knott, 2006; Estes, Munson, Dawson, Koehler, Zhou & Abbott, 2009; Shu, 2009). Siblings, however, are often overlooked (Conway & Meyer, 2008). Usually the focus is on addressing the needs of the child with a disability and this can interfere with addressing the needs of the other siblings (Schuntermann, 2009). Although having a sibling with a disability can have negative effects on the typically developing sibling, it can also have many positive effects and elicit strengths in those

siblings (Schuntermann, 2009). It is important to address the needs of the sibling without a disability, however, to ensure positive outcomes.

Many studies focus on the influence of a child with a disability on the rest of the family (Breen, 2009; Conger *et al.*, 2009; Dyson, 2010; Davis & Gavidia-Payne, 2009; Giallo & Gavidia-Payne, 2006; Knestrict & Kuchey, 2009; Mulroy, Robertson, Aiberti & Bower, 2008; Schuntermann, 2009; Tsibidaki & Tsamparli, 2009; Wang & Michaels, 2009; Williams & Piamjariyakul, 2010; Yeal Barak-Levy *et al.*, 2010). The results of these studies are inconclusive (Meaden *et al.*, 2010; Orsmond & Seltzer, 2009; Schuntermann, 2007; Schuntermann, 2009). While some studies focus on the negative effects or challenges, others focus on the resilience of families and how they benefit from having a child with a disability. According to these studies, the negative effects on families/siblings include:

- A high risk of internalising problems, resulting in stress and depression (Conger *et al.*, 2009; Dyson, 2010; Gold in Yeal Barak-Levy *et al.*, 2010; Mandleco, Frost-Olsen, Dyches & Marshall cited in Tsibidaki & Tsamparli, 2009; Ross & Cuskelly, 2006; Schuntermann, 2007)
- Lowered self-esteem (Schuntermann, 2007)
- Adjustment problems (Fisman cited in Schuntermann, 2009)
- Behaviour problems (Bagenholm & Gillberg cited in Schuntermann, 2009)
- Time constraints (Aronson, 2009; Dillenburger *et al.*, 2010; Mulroy *et al.*, 2008)
- Less participation in extracurricular activities, less socialising and isolation/loneliness (Breen, 2009; Dillenburger *et al.*, 2010; Dyson, 2010; Mulroy *et al.*, 2008; Yeal Barak-Levy *et al.*, 2010)
- Strain on relationships within the family/marital strain (Aronson, 2009; Breen, 2009)
- Excessive responsibility (Abrams, 2009; Breen, 2009; Mulroy *et al.*, 2008; Yeal Barak-Levy *et al.*, 2010)
- Sacrifices (Yeal Barak-Levy *et al.*, 2010)
- Emotional burden, such as feelings of worry, repressed anger, resentment, guilt, jealousy, pressure to take care of the sibling with a disability, and pressure to succeed and not be a burden to parents (Abrams, 2009; Aronson, 2009; Breen, 2009; Dillenburger *et al.*, 2010; Mulroy *et al.*, 2008; Williams & Piamjariyakul, 2010; Yeal Barak-Levy *et al.*, 2010)
- Academic problems (Williams & Piamjariyakul, 2010)
- Financial strain/burden (Breen, 2009)
- Social stigma (Breen, 2009)

- Sibling competition, fear, anxiety and overprotection (Williams & Piamjariyakul, 2010).

However, many families are resilient and are able to endure stressful situations, adapt successfully and continue functioning similarly to families without a child with a disability (Tsibidaki & Tsamparli, 2009). Positive effects on families include:

- Greater resilience in dealing with difficulties (Tsibidaki & Tsamparli, 2009)
- Family closeness (Williams & Piamjariyakul, 2010)
- Personal growth and maturation (Mulroy *et al.*, 2008; Williams & Piamjariyakul, 2010)
- Becoming an advocate for people with disabilities (Dyson, 2010)
- Becoming more accepting of diversity and having more empathy with people (Conger *et al.*, 2009; Dyson, 2010; Williams & Piamjariyakul, 2010).

However, many studies also report both disadvantages and benefits of having a child/sibling with a disability (Dyson, 2010; Mulroy *et al.*, 2008; Williams & Piamjariyakul, 2010).

Although there are many similarities between families of children with other disabilities and families of children with Autism, ASD can be distinguished from other disabilities because of its unique characteristics (Aksoy & Bercinyildirim, 2008). In comparison with siblings of children with mental disabilities, siblings of children with Autism have expressed more negative views about sibling relations, more loneliness and more concern for the future (Aksoy & Bercinyildirim, 2008; Schuntermann, 2007). Although findings with regard to gender differences in sibling wellbeing are inconsistent, some studies have found that sisters of children with autism have more favourable psychological outcomes than brothers (Ferrari; Hastings; Ross & Cuskelly cited in Orsmond & Seltzer, 2009). A considerable amount of research has been conducted on how sibling relationships are affected and whether the wellbeing of the non-disabled sibling is impacted by a sibling with a developmental disability (Orsmond & Seltzer, 2007a; Tsibidaki & Tsamparli, 2009) or how parents adapt to having a child with a disability (Orsmond & Seltzer, 2009), but, as pointed out earlier, there is little research on sibling relationships when one sibling has ASD (Orsmond & Seltzer, 2007a).

Previous studies on siblings of children with ASD focus on:

- Identifying atypical patterns in development or abnormalities in the abilities (e.g. language abilities) of siblings of children with Autism (Ibanez, Messinger, Newell, Lambert & Sheskin, 2008; Pilowsky *et al.*, 2004)

- Comparing the development (e.g. language development) of siblings with and without ASD (Chuthapisith, Ruangdaraganon, Sombuntham & Roongpraiwan, 2007; Gamliel, Yirmiya, Jaffe, Manor & Sigman, 2009)
- Comparing siblings' adjustment to the adjustment of siblings of normally developing children or children with other disabilities (Macks & Reeve, 2007; Petalas *et al.*, 2009b; Verte *et al.*, 2003)
- Gender differences in sibling well-being (Orsmond & Seltzer, 2009)
- Sibling relationships (Orsmond & Seltzer, 2009)
- Comparing sibling relationships of children with ASD/PDD and Down Syndrome/other disabilities (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b; Schuntermann, 2007)
- Determining psychological wellbeing and adjustment of siblings (Hastings, 2007; Orsmond & Seltzer, 2007a; Orsmond & Seltzer, 2009; Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004; Verte *et al.*, 2003; Yeal Barak-Levy *et al.*, 2010)
- Parent-child interactions and parenting styles (Yeal Barak-Levy *et al.*, 2010)
- Family functioning and coping behaviours of parents (Altiere & Von Kluge, 2009).

Many of these are quantitative studies (Dillenburger *et al.*, 2010; Giallo & Gavidia-Payne, 2006; Orsmond & Seltzer, 2009; Petalas *et al.*, 2009; Pilowsky *et al.*, 2004; Verte *et al.*, 2003; Yeal Barak-Levy *et al.*, 2010). Questionnaires and checklists to acquire data, e.g. the Vineland Adaptive Behaviour Scale, the Weinberger Adjustment Inventory and the Child Behaviour Checklist, were used in previous studies (Pilowsky *et al.*, 2004; Ross & Cuskelly, 2006). Furthermore, data were collected by means of parent or teacher reports in many of these studies (Achenbach & Resclora cited in Orsmond & Seltzer, 2007a; Petalas *et al.*, 2009a; Ross & Cuskelly, 2006; Williams & Piamjariyakul, 2010; Yeal Barak-Levy *et al.*, 2010), and not by the siblings themselves. This is explained further by Verte, Rogers and Buysse (cited in Yeal Barak-Levy *et al.*, 2010, p. 163):

Self report tools are essential in order to fully understand the distress that healthy siblings feel ... tools using parental or teachers' reports show the adult's view of the child's feelings based on comparison with other children. When the other child is disabled, the comparison may be distorted. Thus, compared to a child with autism, a healthy child may seem overly social and happy.

Discordances were found in a comparison of sibling and parent reports of sibling adjustment to chronic illness and developmental disability (Guite, Lobato, Kao & Plante, 2004). This emphasises the need to hear the sibling's voice and not only rely on reports of teachers or

parents to attempt to understand the sibling's experience of having a brother or sister with a disability, in this case with Autism.

The sibling has been given a voice in very few studies, especially in South Africa. Overseas, one qualitative study has focused on the perceptions and experiences of siblings of a brother with ASD (Petalas *et al.*, 2009a). In South Africa, similar studies were undertaken by Botes (2008), Buys (2003) and Vermoter (2003). These studies were not conducted in the Western Cape, however. One other study explored the experiences of siblings of children with Autism in the Western Cape, but this study focused on their experience of the family and not on other systems such as relationships with peers (Louw, 2006). Another South African study focused on the effects of a person with autism on the life stories of people surrounding her (Pentz, 2010). This study focused on the alternative stories, but the stories of the siblings were told in retrospect, while the aim of the current research study was to explore what siblings' experiences are while they are in the situation. From the above, it is clear that little research has been focused on the siblings' experiences.

2.7 CONCLUSION

Caring for a child with ASD is a full-time occupation which frequently requires parents' undivided attention and crisis management (Freder & Schiffmiller, 2007). Siblings deal with many difficulties, including not being the focus of their parent's attention; enduring temper tantrums and dealing with social awkwardness; and they often have to make sacrifices (give up play dates, etc.) (Freder & Schiffmiller, 2007); "Everything functions and is organized around the child with a severe disability" (Tsibidaki & Tsamparli, 2009, p. 254).

Having a child with ASD in the family involves hard work and tremendous adjustment, but it may also enrich a family's life in unexpected ways (Macfarlane, 2001; Powers, 2000). Macfarlane (2001, p. 190) testifies: "Growing up with [my autistic sister] has been anything and everything but easy, but she has been the best thing that has ever happened to me", while Powers (2000, p. 144) focuses on a negative aspect:

Listening to normal brothers and sisters talk about family life, I am struck by a paradox about disability. In the world outside the family, in school and in the neighbourhood, children long to fit in, to resemble everyone else. In these contexts ... a sibling's disability stigmatizes them as different. Inside the family, however, each child wants to be special. Each needs assurance that he occupies a unique place in the family circle. Here disability confers a certain advantage, a passport to special

attention, recognition, and privileges. In consequence, many able bodied brothers and sisters remember a childhood tinged by jealousy and resentment.

Despite such difficulties, though, the experience of having a brother or sister with ASD can be beneficial, as siblings may develop an increased sensitivity and sense of responsibility; awareness of the difficulties others with disabilities experience; a sense of pride in achievements; and they may become well-informed adults who are open to difference and can celebrate difference (Wall, 2004). Siblings develop their own feelings about ASD; their own knowledge and awareness of Autism and their own needs; and they adjust in diverse ways. Every sibling's experience is therefore unique (Giallo & Gavidia-Payne, 2006; Wall, 2004).

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

According to Merriam (2009), the starting point for any study is identifying something which you are curious about and thus identifying what you want to learn from the study. This, in turn, will determine the research design and the specific framework and paradigm that will inform the study, which then forms the core of the research problem (Merriam, 2009).

As discussed in section 1.3, the researcher's curiosity was kindled while working with children with ASD when it became clear that the focus usually is on the needs of the child with ASD and siblings often are overlooked (Conway & Meyer, 2008). The aim of this study was to explore siblings' experiences and perceptions of living with a brother or sister with ASD, from a standpoint of their unique contexts and backgrounds (Henning, 2004). This study gave siblings, the ones usually overlooked, a chance to let others hear their voices. It was focused on exploration in order to satisfy the researcher's curiosity and desire for better understanding (Babbie, 2011). The purpose of the study was to achieve an understanding of how people make sense of their lives or interpret their unique experiences (Merriam, 2009). The emphasis was therefore on obtaining in-depth information (Nieuwenhuis, 2007).

This chapter is the guide or framework within which this study took place. It provides a description of the four components of the research design. This includes the research paradigm, the purpose of the study, the context of the study and the research methodology. The research methodology includes a discussion of the following: the selection of participants and selection criteria; the methods used to answer the research questions; data-analysis; data-verification; and ethical considerations.

3.2 RESEARCH QUESTIONS

To satisfy the researcher's curiosity, this study involved research into the experiences of siblings of children with ASD in the Western Cape in order to answer the following primary research question:

What are the experiences of siblings of children with ASD?

The secondary questions were:

1. What are the siblings' perceptions of ASD and does it affect how they deal with the situation (of having a brother or sister with ASD)?
2. What are the siblings' responsibilities and does this add extra pressure on siblings?
3. What are siblings' experiences of their relationships with others (brothers/sisters with ASD, parents, peers) and what role does ASD play in these experiences?
4. What support is currently available to the siblings, and do they have a need for more support? If so, what kind of support would they like?
5. How are the siblings' lives different from their friends' lives?
6. What are parents' perceptions of siblings' experiences?

The research paradigm, methods of data collection, selection of participants and analysis of data had to be designed to answer these research questions. The next subsection provides a discussion of these aspects of the research and an explanation for choosing these approaches for the study.

3.3 RESEARCH PARADIGM

The research paradigm is central to the research design. A paradigm is a way of understanding the world (Donald *et al.*, 2006). According to Donald *et al.* (2006), a person's perception of the world is influenced by the paradigm through which he or she views the world. Thus, a paradigm forms the rationale for the research and therefore informs the researcher's particular methods of data collection, observation and interpretation (Terre Blanche *et al.*, 2006).

This is a qualitative study within an interpretive/constructivist paradigm. The researcher decided that an interpretive/constructivist research paradigm would be most suited for this study as it explores the participant's realities within their context and gains understanding of their perceptions (Merriam, 2009). The focus of qualitative research is meaning and understanding; hence the researcher aims to understand how people interpret their experiences, how they construct or make sense of their worlds and what meaning they attribute to their experiences (Henning, 2004; Kvale, 2010; Merriam, 2009; Nieuwenhuis, 2007). Thus the researcher's interest is in uncovering meaning, rather than determining cause and effect or predicting a specific outcome (Merriam, 2009). In other words, the process of qualitative research is inductive, which means that the researcher will first

observe aspects of social life and then seek to discover patterns (Babbie, 2011). The researcher therefore builds on concepts, hypotheses or theories, rather than testing a hypothesis (Merriam, 2009). The ontology and epistemology underlying an interpretive/constructivist paradigm will give more insight into the nature of reality and the nature of knowledge as seen from within this paradigm.

Ontology refers to the question enquiring about the nature of reality. The nature and form of reality is defined differently in quantitative research as opposed to qualitative research. Interpretive/constructivist research assumes that reality is socially constructed; therefore there is no single, observable reality but multiple realities (Henning, 2004; Merriam, 2009). Nieuwenhuis (2007, p. 54) described the social construction of people's ideas and concepts as follows:

[I]t is assumed that reality consists of an individual's mental constructions of the objects with which he or she engages, and that the engagement impacts on the observer and the situation being observed. We can therefore say that it is about the 'deeper' meanings of social actions; how these are interpreted, understood and appreciated by individuals and groups and how they have been shaped over time and history by a series of social, political, cultural, economic, ethnic and gender factors and then crystallised into a series of structures that are now taken as 'real'.

Central to qualitative research is the assumption that individuals construct reality in interaction with their social worlds (Merriam, 2009). Therefore, the interpretive paradigm is often used in conjunction with social constructivism as it requires the researcher to see "through the eyes of the participant" (Nieuwenhuis, 2007, p. 51). As has been noted, the purpose of an interpretive/constructivist research study is to understand how people make sense of their lives and experiences (Merriam, 2009).

In an interpretive/constructivist paradigm, individuals seek understanding of the world in which they live and work; they develop subjective meanings of their experiences. These meanings are varied and multiple and the researcher looks for complexity of views rather than the narrowing of meanings. The research must therefore rely as much as possible on the participant's view or experience of a situation that is being observed or studied (Creswell, 2009). In an interpretive/constructivist paradigm there is not one objective reality independent of the frame of reference of the observer/researcher. Interpretive/constructivist research emphasises that reality is mind-dependent and influenced by the process of observation, and therefore covers the multiple perspectives of participants (Henning, 2004). Evidently, this research is well suited for giving a voice to siblings of children with ASD.

Epistemology, on the other hand, refers to the question: What is the nature of knowledge? (Merriam, 2009) or How can things be known? (Nieuwenhuis, 2007). Epistemology looks at how one knows reality, which assumes a relationship between the knower and the known.

Qualitative researchers ... believe that the world is made up of people with their own assumptions, intentions, attitudes, beliefs, and values, and that the way of knowing reality is by exploring the experiences of others regarding a specific phenomenon – an attempt to see how others have constructed reality by asking about it. (Nieuwenhuis, 2007, p. 55)

An interpretive/constructivist paradigm observes human events in a more holistic way that attempts to look at local individual actions in their cultural context (Nieuwenhuis, 2007).

A theoretical framework underlies all research (Merriam, 2009) and acts as the lens through which the researcher views the world (Henning *et al.*, 2005, p. 25). In this study, an ecosystemic perspective was used as a framework. The theoretical framework is elaborated on in section 2.2.

3.4 RESEARCH DESIGN

A research design is a 'plan' or 'blueprint' of how one intends to conduct the research (Mouton, 2001, p. 55). Thus, the research design is needed to execute the plan and answer the research questions (Terre Blanche *et al.*, 2006). As discussed in section 1.6, a basic qualitative research design was chosen for this study, as it was best suited to the aims of the study: to explore the experiences of siblings of individuals with ASD. For a research design to be consistent, the purpose, paradigm and methodology of the study, as well as the context in which the study takes place, must be cohesive (Terre Blanche *et al.*, 2006). The purpose of this study was to record the experiences of siblings of children with ASD. This study was situated in an interpretive/constructivist research paradigm and therefore within a qualitative research methodology framework that allowed participants freedom to express their unique experiences.

3.5 RESEARCH METHODOLOGY

It is important to identify one's research paradigm, which is the theoretical framework underlying the study; one's research design, which is the plan of how the research should be conducted; one's research methodology, which comprises the specific procedures used by the researcher to gather data; and the research tools, which are the techniques for collecting

and analysing data (O'Leary, 2010). Research methodology refers to the actions taken in the study and the reasons why those actions are taken (Schensul, 2008). The following are important parts of research methodology: The selection and selection criteria of participants; the methods of data collection and analysis; data verification techniques; and ethical considerations.

3.5.1 Selection of Participants and Selection Criteria

For this study, purposive sampling was used to select participants. Purposive sampling is based on the assumption that the investigator wants to discover, understand and gain insight from the participant's specific experiences and therefore must select a sample from which the most can be learned (Merriam, 2009). In other words, the sample was not randomly selected but was selected to fulfil specific criteria (Graziano & Raulin, 2010). According to Patton (cited in Merriam, 2009), purposive sampling is used to select information-rich cases for in-depth study.

There were several criteria that the study's participants had to meet. Firstly, participants had to have a brother or sister with ASD in order to provide rich descriptions of what it is like to live with a brother or sister with ASD. Secondly, the siblings participating in the study had to be between the ages of 7 and 17. This age range accommodated different developmental stages and ensured that the participants were able to express themselves verbally. Developmental stages also influence one's understanding and therefore one's perception. Section 2.4 presents a discussion on the developmental stages of siblings. The participants furthermore had to be living with their brother or sister diagnosed with ASD. This was required because previous studies have shown that one's perception of an experience in retrospect differs from when one is in the situation (Krauss & Seltzer, 2010; Orsmond & Seltzer, 2007a). The participants could be male or female and from any cultural and socio-economic background.

The parents of siblings were asked to complete a questionnaire and thus were also participants. The parents had to be living with the siblings in the same house and had to be biological or step parents. The parents did not need to fulfil any additional criteria.

In order to take ethical considerations into account, respect the privacy of people and ensure that all participants were involved voluntarily, great care had to be taken in obtaining participants. The researcher sent out an invitation to take part in this study to various professionals working with families of children with ASD. This invitation consisted of a description of the nature of the study, the ethical considerations, a request for an indication

of willingness to take part and the researcher's personal contact details. The form is attached as Addendum B. The professionals could thus give the form to families without exposing any identifiable information. If the families decided that they wanted to participate, they could contact the researcher directly; in that way no-one else would have to know whether they took part or not.

Although more than 50 invitations were handed to professionals, the researcher only received nine replies. One of these could not be used in the study as the sibling (a 4-year-old female) was too young, according to the selection criteria. Thus, eight participants were selected. Three of the participants were boys and five were girls. All of the participants had brothers diagnosed with ASD. They were all living with both their biological parents. See section 4.2 for further details on participants.

3.5.2 Context of the Study

The research context is a term that refers to the physical, cultural and social space in which research occurs, thus the milieu of the study (Bhattacharya, 2008). The physical context of the research was the Western Cape in South Africa. The study was therefore not bound to one specific physical space, but rather to a range of spaces stretching from Stellenbosch to Cape Town. The families who took part in the study were from different cultural and socio-economic backgrounds. Interviews and completion of questionnaires took place at the homes of participants. It was decided to follow this course because of several factors that had to be taken into consideration. Firstly, the researcher saw it as important to interview siblings in a setting where they were comfortable and where their privacy was respected. This also ensured confidentiality in the sense that they were not identified in a public setting. Secondly, the researcher chose to do interviews at the participants' homes as this was more convenient for the parents. It eliminated difficulties regarding transport and accommodated the schedules of the parents, the siblings and the children with ASD.

3.5.3 Methods of Data Collection

The aim of a qualitative study is to obtain rich descriptions. In order to fulfil this aim, the researcher decided on conducting semi-structured interviews with the siblings of children with ASD to gather data. Furthermore, the parents of these siblings were asked to complete questionnaires. Information obtained from questionnaires and reviewing of literature was used for triangulation of data, which is discussed in section 3.5.5.1.

Kvale (2010, p. 8) defines a semi-structured interview as "an interview with the purpose of obtaining descriptions of the life world of the interviewee with respect to interpreting the

meaning of the described phenomena". As mentioned earlier, an interview is a way of constructing knowledge through interaction with the participant. By means of a semi-structured conversation, the researcher can learn more about the experiences of people and gain understanding of their perceptions. In interviews, however, the researcher is the primary tool of inquiry and should be sensitive to the participants' feelings and capable of addressing interpersonal dynamics within the interview. An interview differs from everyday conversations as the interviewer determines the structure and purpose of the conversation. The research interview might be an enriching experience for subjects because the interviewer shows an interest in them, is sensitive to their needs and feelings and attempts to understand their experiences. This might be a rare occurrence for them and siblings might also obtain new insights into their own life situations (Kvale, 2010).

The researcher should be aware of the possible power imbalance between the interviewer and participant, as this might lead to a one-way dialogue, or participants may give answers that they think the interviewer wants to hear (Kvale, 2010). In this study, the ages of siblings were taken into consideration when planning the interviews (Marshall & Rossman, 2006). The researcher started the interview by building rapport with the participants to ensure that they were comfortable and that the interviewer was operating on the interviewee's level. Aids such as play dough were used to make the interview situation less intimidating. The participants enjoyed playing with play dough during the interview. The researcher also had paper and crayons at hand in order to provide an alternative way of communication, should the siblings struggle to express themselves verbally; pictures could then be used as prompts for further conversation. It was, however, not necessary to use drawings.

An interview guide was used during the semi-structured interviews. The questions in the interview guide were derived from a detailed reading of the literature. A good interview guide is essential as the interview is the primary method by which data is gathered. However, as the name states, this served as a guide and thus the interviews did not always proceed strictly according to it. According to DiCicco-Bloom and Crabtree (2006), an advantage of semi-structured interviews is that they are task-orientated as structured interviews and adaptable as unstructured interviews. The interview guide is attached as Addendum C. The questions were adapted to the level of the child being interviewed. A number of sub-questions were asked under each main question, to serve as prompts for conversation.

The questions mentioned above were open-ended questions. Open-ended questions were designed to encourage full and meaningful answers from siblings' and parents' own knowledge and feelings as opposed to closed-ended questions which only evoke short or single-word answers. Open-ended questions also tend to be more objective and less leading

than the latter. By asking open-ended questions, the researcher could obtain in-depth information of siblings' experiences (Roulston, 2008)., According to Kvale (2010), a qualitative interview does not focus on the facts only, but also on the meanings expressed by siblings. While listening to the siblings' expressions of their experiences, the researcher could ask further questions to gain deeper insight into these experiences. The open-ended questionnaires completed by parents consisted of questions similar to the questions asked of siblings (see Addendum D). This provided insight into parents' perceptions of the siblings' experiences and data could be compared with information obtained from siblings.

The interviews were conducted in a private space in the participants' homes. With seven of the participants, the parents were not present. One participant's mother and grandmother were in the room while the interview was conducted. This was a fairly young participant and the researcher therefore respected their decision to be present. The interviews were approximately one hour long and each participant was only interviewed once. Of the eight interviews, four were conducted in English and four in Afrikaans. The interviews were recorded with a video camera. The participants had the opportunity to express what they were comfortable with and two of the participants decided that they did not want to be visible on the videos, therefore the camera was turned away from those participants and only their voices were recorded. The eight interviews were transcribed in the language in which they were conducted. After data analysis, only the parts of the Afrikaans interviews that are documented in Chapter 4, were translated. It was decided to follow this course instead of translating entire interviews to contribute to the accuracy of translations. Notes made by the interviewer during the interviews were used to ensure that the interviewer's understanding of what the interviewees were conveying was accurate.

After the researcher has chosen a specific subject, reviewed the literature, formulated the purpose of the research and research questions, identified a sample group, considered relevant ethical issues and collected the data, the process of data analysis takes place (Boeije, 2010). However, in qualitative research the process of data collection and analysis is a dynamic process and changes may therefore occur during the process. Data collection and analysis thus goes 'hand in hand' in qualitative research (Taylor & Bogdan, 1998, p. 141).

3.5.4 Data Analysis

According to Gibbs (2007), data analysis implies that data is somehow transformed from a substantial amount of qualitative data to refined interpretations thereof. The form of data analysis used in this study was qualitative content analysis. In this process, patterns and

themes are identified by grouping data into units of meaning (Corbin & Strauss, 2008). The first step of analysis was to transcribe the interviews. An example of a transcription is provided in Addendum E. Then open coding was used to code these transcripts. In open coding, themes are derived directly from the text. This approach was chosen because the themes created are specific to the responses of the participants and therefore also contextually specific to participants. This is different from other approaches in which codes are derived from a review of literature (Corbin & Strauss, 2008; Charmaz, 2011).

Initially, the researcher familiarised herself with data by reading and re-reading transcripts and questionnaires while starting to locate units of meaning and naming them. Following this, a second reading took place and the formal coding process was begun. Several readings of the transcripts were required before the coding process was completed. During this process, the units of meaning which were identified received codes consisting of words or phrases. Certain codes occurred more regularly than others. Codes which occurred too rarely were not used, as the relevance thereof was questionable. It was decided that codes which occurred repeatedly provided the best representation of siblings' experiences and such codes were therefore chosen as themes of the study. An example of a section of a coded transcript can be found in Addendum F and the themes that emerged in the various interviews can be found in Addendum G. This was used to manage some of the data. The themes were adjusted as the researcher gained more insight and information. Information obtained from parent questionnaires were added to the data. The next step in data analysis was categorising the themes identified during open coding. Categorisation refers to the grouping of themes that seem to be connected. This helps to form a more holistic view of the data, which can then be used during interpretation and discussion of data. Themes and categories were continually revised throughout the process of data analysis. This led to the final list of themes and categories which are presented as the findings of this study in Table 4.2. Conclusions were drawn from these findings (Corbin & Strauss, 2008; Charmaz, 2011).

3.5.5 Data Verification

Every research methodology has strengths and weaknesses and therefore it is important to determine the accuracy of data (Rubin & Babbie, 2007). In qualitative research, the researcher must ensure that data is trustworthy in order to improve the quality of the study. The trustworthiness of data is obtained by ensuring that data is reliable and valid. In quantitative research, reliability refers to the consistency with which a construct is measured, whereas validity is synonymous with truth (Foxcroft & Roodt, 2009). There is no single commonly accepted standard for judging or ensuring the reliability and validity of qualitative research (Merriam, 1998). Therefore, qualitative data can be verified by addressing a variety

of issues which include credibility, transferability, dependability and confirmability (Lincoln & Guba cited in Ballinger, 2008; Mertens, 1998).

3.5.5.1 Credibility

The term 'credibility' in qualitative research is similar to the term 'internal validity' in quantitative research. Credibility, therefore, refers to the degree to which the study measures what it attempts to measure. In other words, credibility determines whether there is "correspondence in the way the respondents perceived the social constructs and the way the researcher portrays their viewpoints" (Mertens, 1998, p. 181). In qualitative research, the researcher is a primary instrument in collecting and interpreting data and it can therefore be seen as a strength if the researcher understands the perspectives of the participants. Triangulation is a commonly used method for enhancing the credibility of qualitative studies (Flick, 2007). Triangulation involves using separate methods of data collection which are then compared to ensure consistency of evidence across sources (Merriam, 2009; Mertens, 1998; Taylor & Bogdan, 1998). Initially, three or more separate methods of data collection were regarded as necessary for triangulation. This has changed, and triangulation now refers to any approach which combines two or more methods of data collection in order to increase validity (Rothbauer, 2008). The researcher is able to gain deeper and clearer understanding of the settings and people being studied by drawing on different sources of data (Taylor & Bogdan, 1998, p. 80).

In this study, triangulation was performed by using two separate methods of data collection: Semi-structured interviews with the siblings and questionnaires completed by the parents of siblings. The questionnaires completed by parents in addition to the semi-structured interviews by siblings allowed the researcher to gain insight into the parents' perceptions of siblings' experiences. The reviewing of literature enabled the researcher to gain insight into the experiences of siblings in different contexts. In this way different perspectives on the same issues were gathered.

3.5.5.2 Transferability

Another important aspect of trustworthiness is transferability. This refers to the extent to which findings of the research can be applied to other groups within the wider population (other situations or settings) (Boeije, 2010; Merriam, 2009); in other words, the degree to which the context of a study has been described so that other researchers may know the extent to which the study can be applied to other scenarios (Jensen, 2008c). The term is similar to the concept of generalisability in quantitative research, in which a study is

generalisable when its results can be applied across a wide range of environments. Transferability likewise implies that the finding of a particular study can be transferred to populations and circumstances other than those of the study itself.

Transferability is addressed in this study through describing each step of the research process, both its scope and its limitations, and referring specifically to the context of the study. Thus the nature of the participants is discussed in detail in order to allow other researchers to determine whether other populations are similar enough to be compared with the participants in this study. In addition, purposeful sampling was used as this is one method of increasing transferability. Purposeful sampling ensures that the study's participants are representative examples of the population being studied (Jensen, 2008c). In this study, this was done by purposefully sampling siblings of children with ASD. The siblings were between the ages of 7 and 17 and were living with a brother or sister with ASD.

3.5.5.3 Dependability

Dependability is similar to reliability in quantitative research. In broad terms, it can be described as the degree to which different researchers will arrive at similar conclusions when working on similar projects. This is problematic in the social sciences as human behaviour can never be static (Merriam, 1998), therefore the term dependability is preferred in qualitative research. The idea is that, if a study's researcher were replaced with a different researcher, both would come to similar conclusions, which would imply that the researcher's findings are based upon the actual data received and have not been influenced in any way (Jensen, 2008b). In order to enhance dependability, Mertens (2005. p. 256) suggests a "trail of evidence" whereby the researcher describes in detail how data were produced, how decisions were made and how data were analysed. This trail of evidence allows other researchers to examine the steps of the research process and explore whether the findings are indeed representative of the data (Davies & Dodd, 2002). This issue is dealt with in this study by providing detailed descriptions of steps taken during the research and providing documentary evidence of data in the form of transcripts of semi-structured interviews. An example of a transcript is provided in Addendum E.

3.5.5.4 Confirmability

Confirmability is considered a parallel concept to objectivity in quantitative research. It can be described as the degree to which the conclusions drawn from a study are based on the actual data that were obtained (Jensen, 2008a). In other words, confirmability refers to the process of providing evidence to support the idea that the researcher's understanding of the

participant's experience is accurate. It therefore minimises the influence of the researcher's judgement. In order to assess the credibility and confirmability of this study, the researcher has supported each statement made about participants' experience by quotations from transcripts of the study. This will enhance confirmability as readers will be able to determine why particular conclusions were drawn.

3.5.6 Ethical considerations

Ethics form a crucial part of qualitative research as it involves "collecting data from people, about people" (Punch in Creswell, 2009, p. 87). The qualitative researcher can thus be seen as a 'guest' in the personal space of the participants (Stake, 2005, p. 459). Ethical considerations should therefore be an integral part of the planning and implementation of the research process (Mertens, 1998). This provides a framework that guides research into being non-harmful to participants and respectful of their status as human beings (O'Leary, 2010). As the researcher was allowed into the world of her participants, she had to protect them, develop trust with them, promote integrity and guard against misconduct (Israel & Hay in Creswell, 2009, p. 87). Ethical principles like respect, justice, beneficence and non-maleficence form an integral part of this study and will be discussed next, as will the ethical steps that were taken during the planning and implementation of this study.

3.5.6.1 Respect for dignity, moral and ethical rights of people

Kant's point of view is reflected in this principle. He argued that people are "rational and therefore intrinsically valuable and consequently their dignity and their moral and legal rights must be respected irrespective of who they are, where they come from and what they believe" (Allan, 2008, p. 122). This principle is also reflected in the Universal Declaration of Human Rights (Allan, 2008): "... those who are researched have the right to know they are being researched, and they should actively give their consent" (Bulmer cited in Boeije, 2010: 45).

The human rights of a participant should always be considered when making a decision whilst conducting research. In cases where one does research with under-aged children, the researcher should have consent from parents and assent from the child before doing research (Allan, 2008).

3.5.6.2 Informed consent

Informed consent concerns one of the fundamental rules and attitudes that must be respected for research to be ethical. The aim of obtaining informed consent is to ensure that

participants are able to decide whether or not to take part in a study while being fully aware of the risks and benefits thereof (Endacott cited in Boeije, 2010). Thus informed consent is the result of a process of reaching an agreement to work collaboratively, rather than simply having a consent form signed. According to a legal-ethical perspective, children under the age of 18 are considered minors and need assistance from adults when making legally binding decisions. There are differences in the types of decisions minors have to make and therefore adjustments are sometimes made to the ethical principles of psychologists (Allan, 2008). However, the researcher decided to adhere to the ethical principles central to the legal-ethical position of minors. Thus, the participants were viewed as minors and in situations where research is done with minors the researcher has to get the consent of the parents, as well as assent from under-aged participants, as children are considered a vulnerable population (Creswell, 2009).

In this study, both parents and siblings were participants, therefore parents had to give informed consent for their own, as well as the sibling's participation. Although parents gave consent, the siblings had a choice whether they wanted to participate in the study or not. Thus assent was obtained from the siblings. In order to get informed consent and assent, the researcher had to inform the participants of the purpose and main features of the study, as well as of possible risk factors and benefits, should they decide to participate (Henning, 2004; Kvale, 2010). Participants were informed through briefing and debriefing. Issues like confidentiality; the rights of the researcher and of participants; who will have access to the interview recordings and transcriptions; and issues regarding withdrawal were discussed with participants (Kvale, 2010). The participants had the right to withdraw at any time without consequences (Boeije, 2010). They could also refuse to answer any questions they didn't want to answer and still remain in the study. The researcher could also withdraw the participants from this research if circumstances were to arise which warranted doing so. Participants only signed the consent and assent forms once they were fully informed and had decided that they wanted to participate. These forms acknowledge that participants' rights were protected during data collection (Kvale, 2010; Creswell, 2009). Examples of a consent form and an assent form are attached as Addendum H.

Once the consent forms were signed, the researcher could start with data collection. Further ethical issues, however, needed to be considered throughout the study. Confidentiality, another ethical consideration which is important in protecting participants, is discussed next.

3.5.6.3 Confidentiality

Privacy and confidentiality are "to be considered essential for the preservation of human dignity and people's physical, psychological and spiritual well being" (Hall cited in Allan, 2008, p. 124).

Confidentiality refers to how data will be handled to ensure the privacy of participants (Boeije, 2010). Information obtained from participants was protected and the information was only viewed, interpreted and read by the researcher and her supervisor Mrs C. Louw (Lecturer and Educational Psychologist at the Department of Educational Psychology at Stellenbosch University). The semi-structured interviews were recorded with permission of participants and only the researcher had access to these recordings. After transcribing the interviews, the participant had the right to review transcriptions. In addition, the tapes will be erased after the completion and examination of the thesis. Transcriptions and interpretations thereof are stored on the researcher's personal laptop computer protected by a password. Non-electronic data are stored in a locked cabinet in the researcher's home. Therefore the researcher is the only one who has access to the data.

Privacy refers to the control participants have over the access that others have to them (Sieber cited in Boeije, 2010). According to Allan (2008, p. 125), "information is anonymous if the name of the person to whom information relates is unknown". The information regarding participants remained anonymous in this study, as the researcher assigned pseudonyms to the participants (Creswell, 2009; Kvale, 2010). The researcher also ensured anonymity by replacing the names of friends, family members and pets that were mentioned during the interview. These names were replaced with a code (X, ***, +++). The researcher treated signed consent forms with discretion, as private matters could be directly related to the signed consent form, which bears a signature that facilitates identification (Henning, 2004, p. 73). It is clear that individuals decide to whom they give information about themselves and researchers may not disclose such information to others (Boeije, 2010) except when required to do so by law or when the participant may cause harm to self or others (Allan, 2008).

3.5.6.4 Non-maleficence

The principle of non-maleficence "is captured by *primum non nocere*, 'first do no harm'" (Sadock & Sadock, 2003, p. 1365). "From a utilitarian ethical perspective, the sum of potential benefits to a subject and the importance of the knowledge gained should outweigh the risk of harm to the subject and thus warrant the decision to carry out the study"

(Guidelines cited in Kvale, 2010, p. 28). It is the duty of the researcher to avoid inflicting physical and emotional harm on participants (Allan, 2008, Sadock & Sadock, 2003). When working with people, harm is inevitable and it is impossible for the researcher to avoid all harm. The researcher must therefore have steps in place to correct the effects of any harm that might be caused (Allan, 2008). The interview and the need to reflect on experiences could have been uncomfortable to parents and siblings. As mentioned in section 3.5.6.2, the participants could withdraw from the study at any time without consequences and they also had a choice whether they wanted to answer the questions. After the interviews, the participants were given ample time to debrief and ask any further questions. The researcher compiled a booklet for participants to provide them with further information regarding Autism, as well as contact details of professionals such as psychologists or counsellors who could be of help, if needed. The sibling booklet is attached as Addendum I.

3.5.6.5 Beneficence

"Beneficence is defined as a *prima facie* moral obligation to act to the benefit of humanity", to prevent or remove harm and promote wellbeing ('do good') (Allan, 2008, pp. 112, 135). This principle is based on the Virtue ethics perspective, which states that psychologists should have a benevolent trait that makes them want to promote the welfare of others, as well as the Utilitarian perspective according to which the psychologist must achieve the greatest good (welfare) for the greatest number of people (Allan, 2008). Beneficence is distinguishable from paternalism (the use of judgement about the best course of action) because psychologists should respect autonomy (Allan, 2008; Sadock & Sadock, 2003). If a psychologist were to take on a purely paternalistic role, the misuse or exploitation of patients would occur regularly, either intentionally (for research) or unintentionally. According to Boeije (2010), the principle of beneficence should be translated to be of practical relevance for research. In research, beneficence is usually addressed in three dimensions, namely: informed consent; privacy and confidentiality; and anonymity (Boeije, 2010). These issues were dealt with in this study and are discussed in sections 3.5.6.1 to 3.5.6.3.

To ensure that all issues relating to the ethics of the study had been dealt with, the researcher was required to obtain approval from the Ethics Committee of the University of Stellenbosch before commencement of the study. This committee regulates research in the field of Educational Psychology and prevents the likelihood of harm befalling the participants (Hennink, 2007). Ethical clearance was obtained and the study was given the clearance number 480/2010. The ethical clearance form is attached as Addendum A.

3.6 CONCLUSION

The research paradigm, design and methodology enabled the researcher to formulate a plan for a study that resulted in answering the research questions. Verification of data ensured that the results are trustworthy. As this is a qualitative study it entailed collecting data from people and thus the researcher had to incorporate ethical considerations throughout the study in order to protect participants. Once a research 'plan' had been carefully formulated, the researcher could continue with data collection and interpretation. The following chapter provides a description of the data, as well as the findings.

CHAPTER 4

PRESENTATION OF FINDINGS

4.1 INTRODUCTION

As mentioned in section 2.2, a diagnosis of ASD does not affect the child with ASD only, but also the rest of the family. The purpose of this study was to explore the experiences of siblings of individuals with Autism, in order to discover how they see living with a brother or sister with ASD affecting their lives and how they would like to be supported. The findings of this study are presented in this chapter and are discussed according to the main themes that emerged during the study. Following the discussion of these themes, is a concluding section. An interpretation of the themes is presented in Chapter 5 in order to answer the research questions.

4.2 PARTICIPANTS, SETTING AND PROCEDURE

Discussion in sections 1.7.1 and 3.5.1 noted that all the participants were siblings of children with ASD in the Western Cape in South Africa. The parents of these siblings also participated in the study. Participants were purposefully sampled in order to fulfil certain requirements. The first of these requirements was that they had to have a brother or sister with ASD. The second was that they had to be between the ages of 7 and 17 and still be living with their brother or sister with ASD. Data gathering took the form of semi-structured interviews with siblings and completion of questionnaires by the parents of these siblings. This took place at the participants' homes.

Three boys and five girls participated in this study. Of the eight participants, only two were younger than their siblings with ASD. The rest of the participants were the eldest children in their families. All the participants' siblings with ASD were boys between the ages of six and ten years old. All the participants came from families where the parents are married. Table 4.1 provides the demographic information of participants. While comparing siblings' experiences with the parents' perceptions of siblings' experiences, it became clear that all the participants had good family relationships and the parents' perceptions often correlated with siblings' verbal reports.

As discussed in sections 1.8 and 3.5.6.3, all the names of the participants were replaced with pseudonyms to protect the participants' right to privacy and anonymity. These pseudonyms are used in Table 4.1. In each transcript, the interviewer is always referred to as 'S' and participants are given codes according to their pseudonyms. E.g. Anni (pseudonym) is referred to as 'A'. These codes are also presented in Table 4.1. Additionally, any information that could possibly violate a participant's anonymity, such as names of friends, schools, pets or any other identifying information, was deleted from transcripts and replaced with a code (such as ***) or a generic term in brackets. An example of a transcript can be seen in Addendum E.

As the siblings of children with ASD were mostly still young and the nature of human speech is sometimes chaotic, some of the transcripts initially contained utterances that were confusing or irrelevant. In this section, unnecessary utterances are deleted to ensure that the participants' meaning will be clear to the reader. Furthermore, some of the interviews were conducted in Afrikaans and had to be translated for this section. The danger of editing and translating quotations, as well as taking them out of context, is that the meanings of statements may be lost or changed. Thus, the researcher took great care in ensuring that all quotations would have exactly the same meaning out of context as within context.

Table 4.1: Demographic Information of Participants

Participants -Codes -Pseudonyms and the meaning of the names	Age	Gender	Number of Children in the Family	Position of Participant in the Family	Marital Status of Parents	Age of Child with ASD	Gender of Child with ASD
'A': Anni (Gracious, one who gives)	17	Female	3	Oldest sibling	Married	6	Male
'T': Tabitha (Beauty, grace)	9	Female	2	Oldest sibling	Married	7	Male
'Hu': The Hulk (Strength)	11	Male	2	Oldest sibling	Married	8	Male
'H': Hannah (Gracious, merciful, one who gives)	11	Female	2	Oldest sibling	Married	10	Male
'L': Lily (Innocence, purity and beauty)	7	Female	2	Younger sibling	Married	9	Male

Participants -Codes -Pseudonyms and the meaning of the names	Age	Gender	Number of Children in the Family	Position of Participant in the Family	Marital Status of Parents	Age of Child with ASD	Gender of Child with ASD
'E': Eli (Strong)	9	Male	4	Second-oldest sibling	Married	10	Male
'Li': Lizzy (God's promise)	11	Female	2	Oldest sibling	Married	8	Male
'W': William (Will, desire and protection)	11	Male	2	Oldest sibling	Married	9	Male

4.3 PRESENTATION OF THEMES

The data obtained in this study are presented through the most important themes that emerged from the study. Although all information obtained from participants was valuable, some themes came across more strongly in transcribed data. Themes were merged to form categories; seven categories emerged from the data. These categories and themes are presented in Table 4.2.

Table 4.2: Categories and Themes

CATEGORIES	THEMES
Information	Siblings' perceptions of ASD A need for information in order to understand their brothers Need for others to understand their brothers Guilt
Worries	Worries about the future Worries about impairment in social interaction
Responsibilities	Sibling as Carer Sibling as Protector Sibling as Teacher Pressure of responsibilities on siblings
Relationship with brother with ASD	Special bond between siblings Hopes and dreams for their brothers

CATEGORIES	THEMES
	How siblings experience the characteristics of ASD Changes over time What siblings have learned from their brothers
Relationship with parents	Unfair treatment Feeling left out A chance to shine
Relationships with peers	Bullying Siblings as Advocates
Support	How siblings currently deal with difficulties Current availability of support A need for more support How siblings would like to be supported Privacy

Another theme that was presented less frequently in data, but is nonetheless important, was:

- Siblings' perceptions of their lives being different from their friends' lives.

The themes mentioned above are outlined here, along with quotations from interview transcripts to illustrate points and support findings. The quotations are placed in italics to make it easier for the reader to identify them.

4.3.1 Information

4.3.1.1 *Siblings' perceptions of ASD*

Throughout the interviews it became clear that siblings have a need for more information about ASD. Participants revealed that it was difficult for them to say what Autism is because they did not always understand it themselves. One participant said: "*When I was small I got mixed up and everyone started to get all confused.*" Furthermore, most participants had a very broad idea of what Autism is. The following are some examples of participants' descriptions of ASD:

- "*They go into their own little world*"
- "*It's something with his brain*"

- "Someone who is different"
- "A bit crazy"
- "Autism is like, the person is no different from anybody else, his brain is just wired differently"

This was also confirmed in parent reports. Most parents mentioned that siblings knew "*their brothers are different*" but they only had a general idea of what Autism is. There were still uncertainties and confusions.

Sometimes not having the right information can cause distress for siblings. For example, one participant thought that his brother might have to get an operation which might kill him. This was very upsetting for that participant; he started to cry while he was talking about it. He said: "*When he has to go to the operation to get the Autism out of his brain, that means cutting it open, I'm worried about that because he can die.*"

Children with ASD do not present with any physical signs of a disability. According to Girli (cited in Aksoy & Bercinyildirim, 2008), siblings of children with disabilities experience more stress when they do not see physical signs of the disability and have difficulty understanding certain behaviours. The siblings' need to understand their brothers (or the characteristics of ASD) is discussed in the next section. See section 2.4.1 for further discussions on siblings' perceptions of ASD.

4.3.1.2 A need for information in order to understand their brothers

Siblings themselves expressed a need for more information in order to understand why things happen and what it will be like in the future. One participant expressed her concerns as to why her brother acts in certain ways: "*Why is he like this? Can't they heal him? Because at night he bites and he pinches . . .*" Another participant expressed uncertainties about what would happen in the future: "... *in a later stage, how will he be then? And how will he react?*" Participants want information about what will happen to their brother in order to give themselves peace of mind. One participant expressed her worries and uncertainties about the future. She said: "*Will he be able to go to a normal school one day? Will he ever get better? Will he be able to go and study after school?*"

Siblings would also like to know how to deal with difficult situations (e.g. tantrums). Thus, most participants thought that an advantage of a support group for siblings would be to learn from the experiences of others. One participant said: "*I'd like to know how do they [other*

siblings of children with ASD] cope with it or what do they usually do when they [children with ASD] throw into a tantrum?"

The need for more advice to help a brother with ASD was also expressed. This was seen as a type of support the sibling would like. The participant said: "*I would want support, advice on how to help [brother's name].*"

Some participants mentioned that the uncertainty of what was happening to their brothers was upsetting. One participant felt "very sad" because of this. He said: "*But that time I didn't know what was wrong with him, he acted strangely but then I didn't know what was happening to him. I felt very sad.*"

Another participant described what it was like for her when they didn't know what was wrong with her brother. She said:

"It was actually very traumatic. In the beginning we thought he was deaf in his one ear and before they diagnosed him with Autism they said he was deaf. And sometimes it felt as if he was deaf and sometimes you got kind of irritated, like you'll call him and he doesn't hear you."

The literature indicated that siblings find it easier to understand their brothers/sisters with ASD and to deal with the situation when they are well informed (Freder & Schiffmiller, 2007; Vermoter, 2003).

On the other hand, one participant mentioned that her parents informed her well and told her everything she wanted to know. She said: "*My parents told me [brother's name] had Autism and they told me everything I wanted to know.*"

Although it would make it easier for participants to deal with the situation if parents inform them about ASD, it is not always so easy for parents to do this, as parents also have many uncertainties. One participant said: "*But she [mother] said she didn't know because she didn't know how to explain it to me.*"

Vermoter (2003) mentioned the increased pressure on mothers as they fulfil multiple roles within the family; they are a source of support, the primary caregiver, marital partner, etc. No studies were found with regard to how equipped mothers are to provide information to siblings of children with ASD. Vermoter (2003) suggested that mothers should not only have information on characteristics of ASD in order to support siblings, but also information about the feelings of the siblings.

4.3.1.3 A need for others to understand their brothers

Participants also expressed the need for other people, especially their friends, to know and understand more about ASD. Most of their friends and people in their neighbourhoods did not know what ASD is. One participant said "No" they do not understand, "*but all they understand is that they shouldn't tease [brother's name] because he will bite or hurt you.*" Another participant said that other people do not know what Autism is "*and when I try to explain to them they think there's something wrong with his brain ... they still don't understand*". Another participant was quite shocked and disappointed that a grown woman did not know what Autism was when someone was trying to bully her brother. She said: "*Then I told her that he is Autistic and she said 'What's Autistic?' Then I said 'Never mind'. She is older than I am!!*"

Participants expressed some misperceptions that people had about their brothers with ASD. They did not like people to have these misperceptions. Here are some quotes to verify this statement:

- "*But when my friends forget I tell them not to call it an illness or a disease or a disability because it's none of those things, he's brain is just wired differently.*"
- "*I think that they think that he's just some weirdo ... Even my best friend, she doesn't fully understand when I talk to her about it because she doesn't experience it every day.*"
- "*Sometimes they think that he's weird because of how he reacts.*"
- "*People don't really get Autism, like when you live with someone with Autism you actually get it. Like they're not someone who sits there drooling and don't know what to say, they're completely like anyone else they just think differently.*"

A lack of information and understanding can sometimes lead to teasing and bullying. One participant said that he thinks his brother gets bullied because he "*stims*"³ and "*they have never seen someone that is Autistic.*" This can be linked to the section on Bullying (see section 4.3.6.1).

On the other hand, because some children do not understand ASD they will "*ignore*" it, which leads to exclusion of the child with ASD. One participant described how his friends react towards his brother with ASD when they come to visit their house. He said: "*When they*

³ Stims refers to Self-stimulating Behaviour (see section 2.3.6.3)

come to play here, then [brother's name] is in his own little world and he stims and then they just play with me... They ignore him completely." Most participants expressed a concern for their brothers with regard to making friends (see section 4.3.2). Equipping people with information might eventually lessen siblings' worries.

Parents also expressed a need for others to understand ASD. One parent explained that it becomes more difficult as the child with ASD gets older. For example, when they go to visit friends, the children do not want to play with the brother with ASD. This puts parents in an awkward position; the participant explained it as follows: "*We don't want to make a scene every time, because then we won't be invited anymore.*" She also said: "*It is easier to put a label on it, then others accept it easier.*"

Similar to siblings not understanding non-visible disabilities (as discussed in sections 2.4.1 and 4.3.1.1), other people might also have difficulties understanding the behaviour of children with ASD, as they cannot see any physical signs of a disability (Maras & Brown cited in Hames, 2005).

4.3.1.4 Guilt

Some participants felt guilty when they got angry with their brothers. One participant explained how she sometimes reacts when she is upset, and how she feels afterwards. She said: "*Sometimes I don't even want to listen to him [brother] and then I say '[brother's name] I'm sad, leave me alone. And then I sit there in a corner and at night then I don't understand and I think 'O, I was so rude to him!'*"

Another participant sometimes blamed herself for her brother's tantrums. She said: "*Because sometimes it's me that started a fight because you heard what I said, I told him he was lazy. And then he probably thinks 'I'm not lazy, why is she calling me lazy?'*"

One participant felt guilty because he and his brother got the same injection when they were little, and his brother became Autistic but he did not. This was very sad for him, his voice started trembling while talking about it. He said:

"You know that injection that you get when you're a baby. He got Autism from that. I also got that but luckily I didn't get Autism, the same thing but luckily I didn't get Autism. So I should've given mine to [brother's name]." S: "*Would you like to change places with him?*" W: "*Well it's too late now.*"

In a study by Vermoter (2003) it was stated that the provision of information might relieve feelings of guilt.

4.3.2 Worries

4.3.2.1 Worries about the future

Four of the eight participants were worried about the future. One said: "*Will he be able to lead a normal life one day?*" Another participant started to cry while he spoke about his worries for his brother in the future. He said: "*I'm worried that he won't be able to do things on his own one day.*" Another participant said: "*I really don't know what's going to happen to him when he's older. Hopefully he'll live a normal life when he's older and he'll be able to do stuff*"

Parents also reported that siblings were worried about the future. Firstly, with regard to ASD, e.g., "*What will he be like as a grown up?*" and whether "*he will get better*" and secondly, with regard to care. Most parents mentioned that siblings worry that their brothers will not be able to take care of themselves and, therefore, about who would take care of their brothers when they are older. One parent reported: "*I think she knows that she has to look after him when we are not there anymore.*"

According to Orsmond and Seltzer (2007a), the responsibility of caring for one's brother/sister with a disability may give rise to worries. In a study by Krauss and Seltzer (2010), adult siblings reported that their worries about the future affected their life choices. Orsmond and Seltzer (2007a) suggest that siblings should be provided with support to relieve these worries.

Another parent reported that the sibling was worried about regression in the future. She reported that she was worried "*That he will slip back into a physically aggressive brother he used to be.*"

Some participants were worried that something bad would happen to their brothers. One participant had nightmares about how he tried to run away and she was alone and had to stop him. She said: "*I had a nightmare; he wanted to go outside so then I quickly put on [his favourite movie]. And then he ran fast, so I locked the garage door.*" The other participant talked about her brother's "*weird memory*" and that sometimes when you say something to him, "*he'll only remember after a while*". This participant was afraid that her brother might feel very hurt about something she or anyone else has said or will say to him, and that it might cause him to hurt himself. She said:

"But I'm scared that he might take it very sensitively and he might start thinking 'I'm not worth much' or 'I'm not going to do anything, why am I so stupid?' And then I'm

scared that he might do something else you know, or he might just stop thinking about life, he'll think 'Why must I live anyway? I mean I'm not worth much in this world'. So I'm scared that I or anyone else will say something to him and then he might take it to heart."

One parent reported that the sibling was worried that his brother would die. The parent reported the following: "*He worries that [brother's name] will die, that is his biggest fear. When he talks about it, he worries that something will go wrong in his brain and that will kill him.*"

Another participant was worried about her brother's health. She said: "*All of a sudden he fainted and we all got very worried.*"

4.3.2.2 Worries about impairment in social interaction

A number of participants were worried about their brother's ability to make friends and "fit in" in social situations. One participant said: "*I'm worried that he can't fit in with friends, my friend's brother hates him.*" This can be related to section 4.3.6.1 on Bullying. Siblings reported that their brothers were bullied as a result of their impairment in social interaction. Other children who do not understand this impairment might get frustrated. One participant said: "*... because he [her brother's name] always plays with [the boy's] stuff in his room and [the boy] doesn't like him to touch it. And he [her brother] doesn't ask and sometimes when he asks and the boy says no, he still touches it. And he interrupts our games.*"

Another participant was worried that her brother might be bullied in the future, as others might misinterpret his intentions. She said:

"... the dude thinks he's hitting on my girlfriend and he might get angry at my brother and then he might do something and then nobody will understand. Everyone will just think he's a rude person and they don't understand that he's actually just with autism."

4.3.3 Responsibilities

Apart from the average responsibilities (e.g. cleaning their rooms, feeding pets, etc.) most responsibilities that participants mentioned had to do with protecting, taking care of, and teaching their brothers. These different roles are discussed separately.

4.3.3.1 Sibling as Carer

One participant said: "*I have to see to it that [younger brother] and [brother with ASD] does not fight, and that [younger brother] sleeps when he is supposed to. And further it is just to make sure those two [brothers] don't do anything wrong.*" Another participant talked about her role as carer for her brother. She said: "*I don't really want anything to happen to me because I know him more than anybody on this planet does.*"

Most parents reported that the siblings often share care-giving responsibilities with the parents. Siblings are often expected to help their brothers (e.g. make cereal, bath, dress them) and to look after them. One parent reported: "*She [sibling] has to look after him if they go to the park, even though he is the oldest.*" Another parent reported that the sibling took on the responsibilities of "*mothering*" and "*calming*" her brother.

This was also found in studies by Orsmond and Seltzer (2007a) and Tsibidaki and Tsamparli (2009). Refer to section 2.4.4 for a discussion on the roles and responsibilities of siblings.

4.3.3.2 Sibling as Protector

It was found that children with ASD often are the victims of bullying and teasing. Thus, the participants often had to protect their brothers. This section can be linked to section 4.3.6.1 on Bullying.

Whether siblings are younger or older than their brothers with ASD, they are the ones to protect them. Only two participants were younger than their brothers with ASD. One of these said: "*Sometimes I protect him; he doesn't protect me because he doesn't know how to protect me.*" The other younger participant said: "*Mostly I have to protect him. When he tries to attack the other one, he is stronger than [brother's name], then I have to protect him.*" Another participant described herself as a protector in various ways: "*I'm like a cat and he [the bully] is the dog and then we fight*", later she also described herself as "*a bull*", and at another time as "*almost like a mother lion and her cub which I take care of*". This participant even followed her brother with ASD when he went for a bicycle ride to make sure no-one hurt him; she said: "*When he goes for a bike ride I secretly follow him to see what they [the other children/bullies] do.*"

As the protector, one participant took the blame on behalf of her brothers with ASD when there was a fight. She said: "*Then I said, [brother's name] go, go, run to the house ... and I showed her, you don't mess with him ... scold me, I take the blame.*"

Siblings even saw this role as protector as one of their responsibilities. One participant gave the following reply when the researcher asked what would happen if she did not protect him: "*Then he will get hurt* [her voice was trembling as though she wanted to cry], *bad things will happen to him.*" Another participant, however, said that "*nothing will happen*" if he did not protect his brother, he said: "*Then my mom will just see to it that they don't fight*". Thus, he didn't feel pressured to take on this responsibility.

However, from parent reports, it appeared that parents were not always aware of this role taken on by the siblings. There were some inconsistencies in parent reports and interviews with siblings in this regard. While one participant spoke extensively about her responsibility to protect her brother, and how she sometimes got involved in fights in order to do so, her mother reported that she sometimes "*bullies*" her brother and was impatient with him.

Although previous studies have investigated bullying amongst children with ASD (Humphrey & Symes, 2010; Van Roekel, Scholte & Didden, 2010) no studies regarding the role of the sibling of the child with ASD in situations where bullying occurs were found.

4.3.3.3 Sibling as Teacher

The role of the participant as teacher was mentioned in many interviews as well as parent reports. A parent reported that "*She [sibling] is the main person in his [brother with ASD] life, from whom he learns and watch*". A participant said that it was her responsibility "*to respect*" her brother "*and to teach him*". A parent reported that the sibling would help with her brother's "*tutoring*". Furthermore, one participant said that she "*had to be an example for [brother's name]*".

In the literature on peer tutoring, it is reported that, when siblings teach their brothers or sisters with ASD, it can have a positive effect on both the sibling and the child with ASD (Carothers & Taylor, 2004; Jones, 2007; Robinson, 2007). Thus, according to the literature, siblings play an important role in the development of their brothers with ASD.

4.3.3.4 Pressure of responsibilities on siblings

These roles often were taken on by the siblings themselves. While some siblings enjoy these roles, others feel that it puts pressure on them. This depends on the personality of the sibling. Many parents reported that the siblings were extremely responsible and took on roles which were not expected of them. One parent reported that the sibling had an "*overactive sense of responsibility*" and "*that he automatically took responsibility since he was only 2 years old.*" Another parent reported: "*She takes the lead herself, because she*

likes to be in charge anyway." One participant mentioned that he enjoyed being the one to take care of his brothers. He said:

"It's actually quite fun, because when [younger brother's name], he's hyperactive which means he's very wild, jumps on [brother with ASD] then I can use one of my moves [wrestling], because I'm strong, so then I catch him before he can jump on [brother with ASD]."

Another participant, however, mentioned how it puts pressure on her to be an example for her brother. She said: *"If I think about it too much it's a lot of pressure, like should I do this, should I not do this? So I just forget about it."* Another participant said that she is *"always scared of messing up"*. She provided an example of when she feels this way. She said: *"for example if someone counts on you a lot then I feel scared that I'll mess it up"*. After exploring further why she felt there was pressure on her in the sense that she might be letting someone down, she said: *"I think it's actually just me putting pressure on myself."*

A parent reported that she explained the purpose of responsibilities to her daughter in the following way:

"Life has ups and downs, nothing is fair and one has to take responsibility for one's actions – the good and the bad. Life is a balance. You want, you must work for it!"

In some cases, however, siblings are expected to help because parents feel the entire family is *"in this together"* and thus everyone has to help. A parent reported: *"The family didn't ask for Autism, why us? But we are all in this together."*

Yeal Barak-Levy *et al.* (2010) reported that parents might have excessive expectations of siblings with regard to assisting parents, which might lead to siblings maturing prematurely (Abrams, 2009; Aronson, 2009).

4.3.4 Relationship with brother with ASD

4.3.4.1 Special bond between siblings

All the participants seemed to have a good relationship with their brothers with ASD. They all expressed love and concern for their brothers. Participants mentioned their brothers' *"kindness"*, *"innocence"* and how *"lovable"* they were. Furthermore they described the closeness in their relationships. One participant said: *"[M]y parents always say I pick his side."* She also said, *"you get this soft spot for him ... he makes me feel calm"*. Another participant said that, of everyone in her family, she has the best relationship with her brother.

In response to the question concerning the best relationship, she said: "*My brother. Literally, it's my brother.*" She further explained the special bond they share. She said: "*And there's like little stuff that usually a brother and sister share you know, not like similarities but things that only you two will understand.*" Another participant said that she is "*really happy that he's not like any other brother ... [brother's name] is really nice and kind*".

Some parents also reported that there is a special bond between the siblings. One parent reported: "*She [sibling] has the closest relationship with her brother [with ASD]. She is very fond of him. He is just as fond of her.*"

All the participants knew very well what their brother's likes, dislikes and routines and quirks were. For example:

- "*He likes jumping on the jumping castle. And he eats only one thing at the Spur, the quarter chicken.*"
- "*He's good at building puzzles, and he draws well, and he likes playing with cars.*"
- "*He likes anything with a screen. But he doesn't sleep with a teddy but I still do.*"
- "*He really likes a specific card game, which my mom bought him, and every time he plays it he looks at the cards and then he says: 'Aaaaa ha! Now I know exactly what I will do' and then he puts down the card. And he says: 'Mmmmm what can I do here?'*"

According to some previous studies, siblings and their brothers with ASD spend less time together than siblings who develop typically; children with ASD respond negatively to their siblings when they initiate interaction (Orsmond & Seltzer, 2007a); and siblings show negative views of their relationships with brothers/sisters with ASD (Aksoy & Bercinyildirim, 2008; Schuntermann, 2007). This is not consistent with what was found in the current study. The marital status of parents and close relationships between family members might have played a role here. In Schuntermann's study on sibling experiences (Schuntermann, 2007), siblings reported less satisfaction with sibling relationships; higher negative behaviour and less positive behaviour towards their autistic siblings in families with high marital stress; and more positive behaviour when social support was provided for the family. In the current study, all the participants came from families where parents were married and where there were close family relationships. Although siblings also expressed some difficulties brought on by the characteristics of ASD (see section 4.3.4.3), they all mentioned that they had very close relationships with their brothers and most participants also spent much time with their

brothers with ASD. This was consistent with self-reports from siblings that primarily expressed positive feelings about their sibling relationships (Rivers & Stonemann in Orsmond & Seltzer, 2007a).

4.3.4.2 Hopes and dreams for their brothers

All the participants' hopes and dreams for their brothers had to do with their ASD getting better; that they would have fewer difficulties with social interaction and making friends; and that they would have bright futures. Participants said the following:

- *"Well I only have one ... That his autism will go away [starting to cry]"*
- *"That he will get better and better"*
- *"I would wish that he can be normal again and that he will make friends and that he won't stim as such and try harder to make friends"*
- *"That he will be successful one day"*
- *"That he will be ok"*
- *"I think he will be able to become a champion in swimming if he tries"*
- *"Well I hope that his social skills will go up a bit"*
- *"That he can fit in with my friends and that he's not so jealous of my boyfriend, and that he stops hitting me and calling me names, and that he stops getting in trouble"*
- *"And I was thinking that maybe X will do something awesome"*
- *"I wish that he could understand things as fast as we could. Wish number 2, I wish that he could socially understand what's happening to him, or for example, say like a girl likes him but he doesn't know what it is if she's flirting with him and then he doesn't understand so I'd like him to understand what is happening to him, and that he'll know how to take it in socially. And wish number 3, I wish that everybody would understand about the Autism thing that he has, but they won't like talk about it and stuff, they'll just understand and that they'll except him"*

This can be linked to a need for information and worries about their brothers.

4.3.4.3 How siblings experience the characteristics of ASD

Relationships between siblings and their brothers also present difficulties, however; a parent reported:

"She [sibling] is a very considerate and loving sister. She wants to help him to help himself. She loves [brother's name] but can also get frustrated with him and his weird behaviour."

Some frustrations expressed by participants indicated that their brothers with ASD did not always understand what they were trying to tell them or were not able to express themselves. One participant said: *"Sometimes they don't really understand what you are trying to tell them and also sometimes they get really angry because sometimes they can't express themselves. Like they know what they want to say but they don't know how to say it."* It is often the impairment in social interaction which occurs in ASD (see section 2.3.6.1) which causes frustrations. A participant expressed her frustration as follows:

"And also when we are like talking and I am about to say something that I really wanted to say a lot over supper and then just in the middle of a conversation he starts talking ... but then we're trying to get him to stop that."

Another aspect of ASD which complicates relationships between siblings are difficulties around behaviour. Section 2.3.6.3 provides more insight into behavioural aspects. The participants mentioned the following:

- *"With [brother's name] it's very difficult because he can really act out in the shops. Some days he is ok in the shops, it's just the days that he decides he doesn't feel like it, then all of us have to suffer under it."*
- *"He gets aggressive and he doesn't stop."*
- *"He walks right over my toys."*
- *"We used to play together a lot but sometimes we didn't play together that much because he would be a little too rough and I was a little sensitive and fragile so we didn't play together a lot but we did play together."*
- *"My brother whines when he doesn't get what he wants to eat and he is very fussy, so yeah, that gets pretty annoying."*

- *"He moans all the time. And he starts crying and then it gets so irritating for me that I actually yell at him, just to keep him quiet."*
- *"It was also difficult [describing the time], he was hitting his head all the time and he was busy scratching people, sometimes he also hits people. That's where I got my first bite."*
- *"My brother hits me. And he calls me names a lot."*
- *"He bites and pinches you at night and then I slept in school the next day and then there were complaints (from the school), that is how it went."*
- *"And he also gets this tantrum thing you know ... he cracks and then he screams and he starts to cry and he tries to hit me and he used to bite people. He doesn't bite anymore but he does punch and it's really sore."*
- *"He gets frustrated a lot. Once at [the store's name] he bit his tutor. And he also bit his teacher."*
- *"He also gets very difficult when he's sick."*

Participants mentioned that it is upsetting at times to witness some of their brothers' behaviour. Some examples of upsetting behaviour were given by participants. One participant said:

"When [brother's name] was little there was glass at the back somewhere and he walked through it and his feet were bleeding. And then he took something, I think a needle or something, and he pushed it through his tongue. Then his tongue bled."

Another participant felt upset by her brother's tantrums. She said:

"He also gets this tantrum thing you know. And it's not so nice because sometimes he goes on and on and on and he won't stop. He starts tearing and crying, he starts shouting at me and then he punches me unnecessarily and then he walks away to his room or something and he slams the door."

Yet another participant felt upset when his brother "went crazy" and "broke everything".

Different feelings and emotions were evoked by participants when these behaviours occurred. One participant started crying and did not want to talk about his feelings. Two participants felt sad when they witnessed these behaviours. One said: *"I felt sad, I felt sorry*

for him because when he gets crazy then he doesn't calm down easily." The other participant said: "I don't like it because it's not nice seeing someone you love acting all angry and stuff, you'd rather see them looking happy and instead he gets these mood swings and stuff." At the same time she felt angry as she had to be the victim of her brother's tantrums. She said: "Say you didn't do much and now you're just minding your own business and then someone breaks into a tantrum and punches you, you get angry don't you?" Another participant felt that it was "traumatic" to see it. She said: "It was very, actually very traumatic."

According to the literature on the characteristics of Autism and sibling relationships, characteristics such as the impairment in social reciprocity and the presence of rigid behaviour might affect how siblings bond and have a negative impact on sibling relationships (American Psychiatric Association, 2000; Orsmond & Seltzer, 2009). As discussed in section 2.3.6.3, undesirable and challenging behaviour is often a secondary consequence rather than a feature of ASD. Thus, socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming, running away and self-injury are often associated with ASD but, in actual fact, these behaviours are reactions to the environment or a desperate attempt to communicate (Koudstaal, 2011). If siblings do not understand the causes of these behaviours, it may cause distress or later adjustment problems in siblings (Aronson, 2009; Hastings cited in Orsmond & Seltzer, 2009).

4.3.4.4 Changes over time

Five of the eight participants said that their relationship with their brothers got much better over time. One participant said:

"Our relationship has changed a lot over the years, because when he was small I would just look at him and say 'You're really annoying' because when he didn't get his way he didn't know how to say it, and he would just hit his head at the back of the chair when he got annoyed. So our relationship has changed a lot because we have grown a bit closer, when we were small we weren't really close."

Another participant mentioned that "*in the beginning he wasn't used to us at all, he didn't even know us. He had to learn our names all over again*" Another participant said: "*Yes you get used to it, you get used to it quickly.*"

According to Aronson (2009), the characteristics of ASD may cause much distress to, disruption of and a need for adjustments by the family. Relationships between family members may change over time. These changes may be the result of the changes in the

behaviour of children with ASD when they learn skills and techniques to compensate for their deficits and of family members adapting to the situation (Aronson, 2009; Carr, 2006).

One participant, however, felt that he needed some more time to "get used to" his brother. He said: *"But I'm not quite used to him, but some day I will be."*

4.3.4.5 What siblings have learned from their brothers

The participants who are older than their brothers with ASD mentioned various qualities they had learned from there brothers. Older participants mentioned the following:

- *"I guess that [brother's name] has learned to toughen up quite a lot because he's been through quite a lot during the past ten years. I guess I've learned that no matter how bad things get you should push through."*
- *"His differentness, that's the one conclusion I got that everyone is unique, you should be different. We're all different and [brother's name] showed me that he's different but there's nothing wrong with him, he's just different and he's unique and I like him the way he is ... so that's why he taught me that it's ok to be different."*
- *"That there is someone that loves me."*

On the other hand, the two siblings who were younger than their brothers with ASD felt that they did not really learn anything from their brothers. They felt that they were the ones to teach their brothers. Their responses were:

- *"But he doesn't actually teach me anything, even though he is older than me."*
- *"When we wrestle [play] then I feel sorry for him, because he is trying to show me a move but then it is a dumb move. And then all I do is I make that move better."*

4.3.5 Relationship with parents

4.3.5.1 Unfair treatment

Participants mentioned that their brothers with ASD required a lot of attention and help from their parents. One said: *"Yes, they need more attention than normal children."* Another one said: *"[brother's name] usually needs help. Their [friends'] brothers and sisters don't need as much help as [brother's name] does sometimes ...".*

Furthermore, they mentioned how they sometimes felt it was unfair that their brothers with ASD were always put first. One participant felt that she was treated unfairly in terms of attention; she felt that their parents paid more attention to her brothers than to her. She said:

"Although I know that he's got Autism, I tell her [mom] 'Yes, I know he's got Autism but that doesn't make him a hundred times different than me'. You know, in a sense that he deserves more attention than the average person."

As a result, she also felt that her parents liked her brother more than they liked her. She said: *"I've had quite a few times when I asked my mom 'Mom, why is it that, it's like you like [brother's name] more than me, is that why you're paying more attention to him than to me?'"*

One participant mentioned that she felt it was unfair that her accomplishments were not recognised, but her brother's were. She said:

"that is what I don't feel good about. He [brother] copies everything I do and then they laugh at it. When I come up with something new, then they don't want to laugh. And then when he does it, then they want to laugh. Sometimes I feel that it's so unfair."

Another participant felt that she was treated unfairly in terms of material possessions. She felt that her brother *"always comes back with something"* when he goes somewhere with their mother, while, when she is with them *"none of us are allowed anything"*. She said that *"sometimes it feels pretty unfair"*.

Previous studies have also found that children with disabilities usually become the centre of the household (Tsibidaki & Tsamparli, 2009). According to Frender and Schiffmiller (2007), caring for a child with ASD is a full-time job which frequently requires parents' undivided attention and crisis management. In the study by Vermoter (2003), siblings were also reported as stating that parents treated them differently to their brothers/sisters with ASD. They felt that parents had different sets of rules and punishment for their brothers/sisters with ASD and themselves and that their parents paid more attention to their brothers/sisters with ASD. That siblings feel left out in terms of attention from parents was also found in this study.

4.3.5.2 Feeling left out

Two participants talked extensively of how they sometimes felt left out at home. They made the following statements:

- *"Sometimes when I'm in my room, all of a sudden I hear the car starting and it goes and then later my brother and my mom or dad comes back carrying all these shopping bags and my brother always gets something and he always manages to go and no one ever tells me because my room is like completely separate from the house so no one would come and tell me 'Would you like to come to the shops with us?' So it's really annoying because sometimes it feels like they're giving [brother's name] more support than me because sometimes it's makes me a little bit jealous but I know that he needs it but I think sometimes I need more support."*
- *"Say in the afternoons when dad comes home we like spend some time together and then we've got these like family games where [brother's name] will go on my dad's back like a piggyback ride and then my mom will like chase them around everywhere cause [brother's name] thinks it's fun cause he's like on my dad's back and then she hides somewhere and then she'd like attack. But obviously I'm not involved in that... So I try to get involved but I mean it's not fun because I'm too old to like get on a piggyback ride or something ... so then I'm usually in my room reading or something ... So then I feel very left out and I once tried to get involved and [brother's name] was like 'Noooo' as in I do something wrong and then I really felt as in ... this is just flat."*
- *"I've had quite a few times in grade 3 or 4 where I kept thinking nobody really loves me in this world, nobody really cares about me."*

Another participant explained how she feels when her friends pay more attention to her brother than to her. She said:

"They [her friends] laugh and then they play with him [brother with ASD] and then I feel so... almost jealous. Then I feel like I want to shout at them (uitskel). Then I sit there and watch how they laugh with [brother's name] and then I get so angry. One I did shout [sic] at them and I said: You are here to play with me so why are you playing with [brother's name]?"

Some siblings also showed concern about being excluded in the future. One participant said: *"I'm also scared that I'll mess up with my friends like I'll say something wrong and they won't want to be my friends ever again."* Two other siblings felt that they might be excluded if they attended support groups. One participant explained these concerns by making up a scenario of what it might be like. He said:

"... they'll [hypothetical children at support groups] be like closed because if I asked them if they have a brother or sister that is Autistic and if I can see them, that I can just talk to them, they might be worried that ... they might take that a personal way so they won't let me in or they'll just pretend that they don't have a brother or sister that's autistic. And sometimes they do let me in and when I was talking to them that person gets a bit worried and they'll, you know, start kicking me out of the house."

Another participant explained how she thinks other children at a support group might exclude her. She said: *"If they only play with the other children and then I'll sit out, and then they also tease sometimes."*

4.3.5.3 A chance to shine

One participant expressed a need to be *"put first sometimes"* as this is not usually the case in her home. She said:

"And then from time to time like once a week type of thing she sits by me and then I just talk to her as in let my emotions out but it's not so often that I get to and it's usually [brother's name] that gets the things first so I'd like it if she'd spend a bit more time with me."

Some participants expressed a need to be acknowledged. One participant told the researcher about all her accomplishments right at the beginning of the interview. She also said that what she liked about Autism is *"when their parents see them (she and her brother with ASD) together and take a photo of them."* This showed that she had a need to be seen. Another participant said that, if she had a wish, she would *"wish that she could do something that everyone will remember".*

Some parents reported that they did sometimes forget to praise siblings and that they let them *"do their own thing because they are so much more independent"* than their brothers with ASD. However, this is not deliberate. One parent reported: *"I sometimes forget to praise her, but I really try to do it."* Another parent reported: *"I am often not there for her as I know she would like me to be."* Thus, parents are aware that they do not always spend enough time with siblings. A parent reported: *"I do take her for granted because she is so responsible."* Parents also *"struggle to cope"* at times, but they still try to make special time for the siblings.

4.3.6 Relationships with Peers

Characteristics of ASD, such as impairment in social interaction (see section 2.3.6.1), cause children with ASD to have difficulties in relationships with peers. This was expressed as of great concern for siblings (see section 4.3.2.2 on Worries). Parents reported that this becomes a problem when the family visits family friends with children, as the other children do not want to play with the child with ASD. Most of the participants in this study were between the ages of 7 and 11 years. According to Erikson and Piaget (Wait *et al.*, 2003), children of these ages are in the developmental stage of middle childhood. This is a stage during which children become aware of social norms and are sensitive to peer pressure (Wait *et al.*, 2003). Around the age of 10, children become very aware of what their friends think of them and they might try various methods (some to personal disadvantage) in attempting to be socially acceptable (Wait *et al.*, 2003). Relationships with peers therefore are very important at this stage of development.

4.3.6.1 Bullying

The impairment in social interaction of a child with ASD can sometimes cause problems in relationships with peers and even lead to bullying. For example, one participant reported why her friend's brother "hates" her brother. She said:

"because [her brother's name] always plays with [the boy's] stuff in his room and [the boy] doesn't like him to touch it. And he [her brother] doesn't ask and sometimes when he asks and the boy says no, he still touches it. And he interrupts our games."

Another participant said "... he just takes someone's cool drink and drinks it".

One sibling expressed her concern about her brother becoming the victim of bullying because he often does not understand social situations. She said:

"I'm scared that somebody's going to do something to [brother's name], like maybe he does something wrong ... in high school for example ... and then that person will think 'Hey that person is hitting on my girlfriend' when he actually just meant to say 'Hello, my name is X, what's your name?' He [brother] just thinks, look there's a person, maybe she'll be my friend and then the dude thinks he's hitting on my girlfriend and he might get angry at my brother and then he might do something and then nobody will understand. Everyone will just think he's a rude person and they don't understand that he's actually just with autism. He just wants to be friends with

everyone ... Although sometimes he finds it hard to talk to people, he just wants to be friendly."

Bullying was a theme that came to the fore in most of the interviews. It seems that children with ASD often are the victims of bullying. This can be linked to section 4.3.1.3, A need for others to understand ASD. One participant mentioned how "*the children in the street [where they lived] almost threw him [brother with ASD] with rocks and then a boy was rude to [brother's name]*". Another participant talked about how his brother with ASD was bullied when they visited friends or at school; he stated: "*[F]or example, when we visit friends and he has to come with or at school, then there are a lot of friends and then there are always bullies too and then they bully him.*"

As discussed in section 2.3.6.2, children with ASD experience communication difficulties which make it difficult for them to distinguish between joking, teasing and bullying. As a result, they often become the victims of bullies (Welton, 2004).

This is upsetting to siblings. In response to a question regarding the feelings of her brother with ASD about being bullied, a participant said that "*it hurts his feelings, but it hurts my feelings the most*". A parent reported that the sibling was "*torn*" when his friends came to visit and they ignored his brother with ASD. It was difficult for him because he wanted to play with his friends but he also loved his brother. The parent reported: "*He felt torn in terms of where his loyalties were supposed to lie.*"

The result of bullying is often that siblings get involved in fights as well. One participant said "*and then the fighting starts*". Furthermore she said that she often caused fights because she "*doesn't want [her brother] to get hurt*". Thus, she "*can't just say, yes take it*"; she will "*run in and hit in the same way they hit [her brother] and more*". This section is linked to section 4.3.3.2, The sibling as protector.

On the other hand, one participant said: "*My friends don't make fun of him and stuff.*" This participant came from a higher socio-economic background and was well informed about ASD, thus it might be possible that bullying occurred less in this specific area, because the children in this area were better informed about disabilities.

4.3.6.2 Siblings as advocates

Advocacy refers to siblings standing up and speaking out for their brothers with ASD. According to Conway and Meyer (2008), siblings can help to dignify the lives of a brother or

sister with a disability (see section 2.4.2). Siblings reported standing up for their brothers with ASD when they were being bullied. One participant said:

"and then I said, you don't push someone who is not like you. Then he [bully] said: 'someone who is disabled/retarded'. Then I said he is not disabled/retarded. Then he said: 'yes he is'. And then I said you don't know anything about my family."

Another participant explained how he always ensures that people know what really happened. He described two different scenarios:

"[T]hey teased him [brother with ASD] and then they hurt him, one threw him with a block of wood over his head. Then I told his mom and he had to apologise to my brother". "My younger brother and [brother with ASD] are big enemies, because [younger brother] always teases him and then he gets hysterical and hits him, then [younger brother] tells my mom and then my mom wants to punish [brother with ASD]. But then I explain the truth about what happened."

4.3.7 Support

4.3.7.1 How siblings currently deal with difficulties

Most participants mentioned that they currently deal with difficulties regarding their brothers with ASD by going to a quiet place or "*hiding*" and waiting for things to calm down or until they feel better. Participants made the following statements:

- *"I go to my room, close the door and ignore him."*
- *"I prefer being on my own, I'll hide somewhere and when I feel better I'll come out."*
- *"I don't tell anyone. I run to my room, I slam the door and I hide somewhere. Then I sit there for hours and hours and then I fall asleep. Then I forget all about it, especially when I cry, then I'll fall asleep."*

Two participants mentioned that they try to "*control their anger*" but that it is not always easy to get it right. As the one participant said: *"I don't have it completely, that thing that will stop you from shouting."* Ways they have invented to try and "*control the anger*" are:

- *"I really try not to do anything. I just carry on until (brother's name) has calmed down and I just go to my room, you know like hit the pillow."*

- *"I just forget what makes me angry and think what makes me happy. Because my mean thoughts actually make me angry. So I just forget about them and think of what makes me happy then I'm all better."*

4.3.7.2 Current availability of support

Most participants said that they could talk to their parents when they are upset. In response to the question 'Who do you go to for support?' one participant said: *"Probably my mom, because I can talk to her about stuff."* Another participant said:

"I usually go to my mom, but when my mom can't say stuff like when we have a big fight and she feels awkward saying stuff to me then my dad will come and talk to me. So I'm sort of pretty close to both."

One participant said she found it *"easier to talk to her teachers"*. Another participant was supported by extended family. She had the best relationship with her *"grandma"* and *"visits her during school holidays"*. Although most of the participants had close relationships with their grandparents, this was not always the case. Contrary to the above-mentioned, one participant's family was not supported by extended family. This participant said: *"We used to stay at grandmas but that didn't work out, she kept on hitting my brother.* Thus, grandparents should also become informed about ASD.

Some participants invented different types of support for themselves. Two participants found a lot of comfort in their pets. One of them said: *"I get lots of support from my dog."* Another participant found support in a teddy bear. She said:

"I used to have a teddy bear, a huge teddy bear. I used to like talk to it (laugh) it's kind of weird actually but I used to talk to it and I used to pretend like it was actually real, I actually felt like it was real. She (the teddy) used to be like a support type of thing."

Parents reported that the siblings usually come to them for support. One parent reported that their family *"have a good support system within their extended family"*. Another parent reported that the sibling *"usually tries to handle difficulties himself or he will come to me [mom]."* Parents did not seem to be aware of the different ways in which siblings attempted to support themselves and the researcher did not find any literature on alternative means developed by siblings to support themselves.

4.3.7.3 A need for more support

Most participants mentioned a need for more support. One participant mentioned that "*there are times that I feel I need more support*". Another participant said: "*[W]ell I think I get enough support sometimes but sometimes I would like more support.*" Another participant said the following in response to the question "Who do you go to for support?"

"I don't really have anyone, because my mom usually goes to him [brother with ASD] and sits with him and talks to him and my dad's usually at work. So usually [the cat's name] or [other cat's name] is around so I just sit with them or usually I lay on my bed and you know, let it go over, and they usually come and sit on my bed. So it is calming in a way but I don't really have a person to turn to."

Most parents also reported that they think the siblings need more support. One parent reported: "*She [sibling] usually comes to me for support, but I am not always available, physically and emotionally.*"

Previous studies have indicated that support plays an important role in helping families of children with ASD to cope with stresses they might experience (Pilowsky *et al.*, 2004). According to Schuntermann (2007), siblings report more positive behaviour when they are provided with social support (see section 2.4.5 for further discussion on support). As discussed in section 1.2, however, no support groups are available to siblings of children with ASD in the Western Cape, which might contribute to siblings' need for more support.

4.3.7.4 How siblings would like to be supported

Although most siblings felt that they needed more support, only three of the eight participants said that they would like to go to support groups if there were support groups for siblings. The reasons for not wanting to go to these groups were: the possibility of being excluded; not wanting to talk about their brothers (see section 4.3.7.5 for further statements on Privacy); and because they were not sure that other children would understand because everyone's experiences are unique. A participant made the following statement about the possibility of support groups:

- *"I am not someone who talks about my feelings easily."*
- *"For some people it would be a little bit too intruding in their lives."*
- *"I don't think it would be bad, but a lot would be different, how Autism is and how the family is."*

Parents reported the following concerns regarding support groups:

- *"Bad advice or negative feedbacks"*
- *"Being forced to be part of a group"*
- *"A bad thing could be if they have moved on and become traumatised by other children's experiences"*
- *"Building up negativity"*
- *"That he might start to feel sorry for himself"*
- *"It might be a constant reminder of the whole 'Autism Business'"*
- *"It may be a bit overwhelming"*

The participants did, however, like the idea of knowing that there are other children who also have brothers and sisters with ASD and who might understand what they are experiencing. Seven of the eight participants did not know anyone else who had a brother or sister with ASD. One participant said:

"I've never met anyone else who has a sibling with autism. I've met lots of children who have autism, obviously they're at my brother's school, but I've never met a sibling that has autism so I know that there are other people but my brain is like telling me that there isn't a lot of people so it feels like I'm the only one here with the brother with Autism and that nobody else understands because my friends, they don't have siblings with autism."

Another participant said: *"I think it would be nice to hear that other people are also experiencing what I am going through and it's not just me."*

Most parents also reported that an advantage of a support group might be that siblings will realise that they are not alone. One parent reported: *"It would be good to share experiences and just to know someone that knows what you're going through."* Another parent reported: *"She [sibling] could then see that she is not alone, she is not the only one with a weird brother."*

Furthermore, parents reported that the advantage would be to be able to share their experiences, to *"realise that some negative feelings they sometimes have are acceptable"* and *"to learn techniques to cope"*. Two parents reported that they would like the siblings to

join support groups. One parent reported: "*I think a sibling support group will be so much more helpful and relevant to some challenges that may pop up.*" One parent suggested that it should rather be a fun group for siblings. She reported:

"What I think would work best is if the sibs could go out and have fun together. Play, art, swim, movie, whatever. After a few meetings they will warm up and chat about their feelings and experiences – or not!"

Previous research supports the development of support groups for siblings of children with ASD (Lock & Finstein, 2009). In previous overseas studies, siblings also showed interest in opportunities to learn from others with similar experiences to their own, but articulated less enthusiasm for support groups (Lock & Finstein, 2009). Lock and Finstein (2009) ascribed the lack of enthusiasm for support groups to low interest; lack of experience (uncertainty as to what a support group is); anxiety about the implications thereof; and the location of the group meetings.

Participants mentioned the following ways in which they would like to be supported:

- Three participants said it would be nice to go to a support group where they can learn more about ASD and share experiences with people who understand what they are going through.
- They would like to be included more in family activities. One participant said: "*Well I think I'd like it if they go shopping to ask 'come we're going shopping, come with us'.*"
- Participants would want their parents to spend some special time with them (see section 4.3.5.2 and 4.3.5.3).
- Participants would like their parents to "*put them first*" sometimes. One participant said that her mom usually supported her brother when he had had a tantrum, but she also needed support then. She said: "*Then my mom usually goes and gives him a pep talk or something.*" (Refer to section 4.3.5.3)
- They would like their parents to acknowledge their accomplishments. (See section 4.3.5.3)
- As mentioned in section 4.3.1, participants have a need for advice and information and they would also like other people to understand their brothers with ASD.

Schuntermann (2007) found that, when social support was provided in families, positive behaviour was reinforced. According to Conway and Meyer (2008) it is important to support siblings from an early age, rather than to wait for problems to arise.

4.3.7.5 Privacy

Some participants expressed a need for privacy and most mentioned that they did not like talking about the brother's ASD. Two of the participants started crying while talking about difficulties regarding ASD. Participants expressed their feelings around talking about their brother with ASD in the following statements:

- "*I just don't like talking about it ... I keep most of it to myself ... I am not someone who easily talk [sic] about how I feel.*"
- "*I don't really like talking about my brother with other children, I don't actually want to talk about my brother like that.*"
- "*And I don't want to broadcast it everywhere that he has Autism but I just want them to understand.*"

4.3.8 Siblings' perceptions of their lives being different from their friends' lives

All the siblings said that their lives were different from their friends' lives. However, only two of these siblings thought that their lives were different because of ASD. One participant said:

"Well I guess my life is different from my other friends at school because some of my friends are like only child or they have siblings but they are just like normal siblings who can do what they want but [brother's name] usually needs help ... So they don't really have brothers like [brother's name] or sisters with Autism so I guess sometimes I have to explain to them why he's doing something and their brothers and sisters don't need so much help as [brother's name] does sometimes."

Another participant thought that ASD has financial implications which made her life different from her friends' lives. She said: *"I think so, financially. I guess you can't say there would have been more, but you could say that. Autistic children cost more money than normal children ... there are more expenses."*

The other reasons participants gave for their lives being different from their friends' lives were that their friends' parents were divorced, or that they had sisters and not brothers, or that they were only children, etc.

4.4 CONCLUSION

The data obtained through this study enables others to hear the voices of eight siblings of children with ASD in the Western Cape in South Africa. Although parents seemed to be aware of many of the siblings' experiences, perceptions and feelings, some inconsistencies between parent and sibling reports were also revealed. For example, one sibling told how she "*got involved in fights and secretly drove behind her brother in order to protect him*", while her parents' perception was that "*she bullies him, because she sometimes scolds him when he is too slow*". This emphasises the importance of hearing the siblings' voices. Furthermore, all the participants seemed to enjoy a chance to be the centre of attention and to have someone to listen just to them. One participant said: "*It was really nice talking to you.*" This shows that siblings have a need for someone to listen to them, someone to understand what they are experiencing and someone who can provide information about ASD. Another participant experienced bullying at school, but his parents did not seem to be aware of this.

The implications of the issues raised in these themes are discussed in the next chapter.

CHAPTER 5

DISCUSSION AND CONCLUSIONS

5.1 INTRODUCTION

This chapter focuses on answering the research questions, and discussing and interpreting the themes that emerged in the study. This is followed by a review of the strengths and limitations of this study. Recommendations are made for possible future studies and a reflection by the researcher is followed with a brief conclusion. This chapter can also serve as a guideline for parents and professionals. It will give them insight into the siblings' experiences and how they would like to be supported.

5.2 DISCUSSION AND INTERPRETATION

The study was aimed at exploring the experiences of siblings who live with children with ASD. The following research questions were developed to gain insight into siblings' experiences, with the main question being:

What are the experiences of siblings of children with ASD?

Several secondary questions were also included and they were:

1. What are the siblings' perceptions of ASD and does it affect how they deal with the situation?
2. What are the siblings' responsibilities and do these responsibilities add extra pressure on siblings?
3. What are siblings' experiences of their relationships with others (brothers with ASD, parents, peers) and what role does ASD play in these experiences?
4. What support is currently available to the siblings and do they have a need for more support? If so, what kind of support would they like?
5. How do the siblings' lives differ from their friends' lives?
6. What are the parents' perceptions of siblings' experiences?

Throughout this discussion, it is essential to remember that each sibling's experience is unique. Their experiences are influenced by their personality, their age, their level of understanding, their context and the amount of support available to them. As mentioned in section 2.2, the bio-ecological model emphasises the "interaction between an individual's development and the systems within the social context" (Swart & Pettipher, 2011, p. 10). Thus, the individual's temperament and context (which are at the centre of the model) influence all other systems. It will influence how the sibling experiences relationships with others, pressure, worries, etc. While one participant enjoyed being responsible for his brother and taking care of him, another felt that it placed considerable pressure on her. The findings of this study also revealed the interrelatedness of the different systems as described by the ecosystemic perspective in section 2.2.

As mentioned in section 2.4.1, Vermoter (2003) found that siblings had a great need for information. Now, eight years later, siblings in the Western Cape expressed a similar need. All the participants expressed a need for information. It became evident that the siblings had a broad idea of what ASD is, but there were still many uncertainties as to why brothers with ASD act in certain ways and what the future holds for their brothers with ASD. Often, this lack of information was a cause of distress for siblings. One participant described the time of not knowing what was going on as traumatic. Siblings also wanted to know how to deal with difficult situations (e.g. tantrums) and how they could help their brothers. The siblings did not just express a need for information for themselves, but also that others would be more informed and aware of ASD. Participants mentioned that their friends and the people in their neighbourhoods did not know what ASD is. Thus, the need for information stretches across all the systems within the social context. Firstly, within the microsystem (parents and friends), parents often have many uncertainties themselves, which makes it difficult for them to explain the different characteristics of ASD to the siblings. The siblings, however, depend on their parents to inform them as a direct result of their lack of information. Although many participants mentioned that they did not like talking about their brother with ASD, they did think that it would be easier if their friends understood their brothers. Informing school-going children about ASD might also lessen the occurrence of bullying and marginalisation (see section 4.3.6.1).

Within the exosystem, extended family (such as grandparents) and family friends should become informed about ASD. Extended family can provide support for families with children with ASD. Most of the participants were supported by their grandparents, but if grandparents do not understand the behaviour of the child with ASD it might cause distress (see section

4.3.7.2 for an example). If family friends do not understand ASD, it might also lead to exclusion of the family living with a child with ASD.

Autism is a non-visible disability.⁴ In the literature on non-visible disabilities, Girli (cited in Aksoy & Bercinyildirim, 2008) mentioned that it is more difficult for siblings to understand disabilities that are difficult to see (see section 2.4.1). One could thus assume that it is also more difficult for others (for example, friends of the family) to understand ASD. Although awareness of ASD is much greater now than some years ago, many people's knowledge of ASD is restricted and misperceptions or stereotypical ideas occur.

Some participants experienced feelings of guilt. One participant felt guilty about becoming angry with her brother, another blamed herself for her brother's tantrums and yet another participant felt guilty because his brother got ASD but he did not (refer to section 4.3.1.4). These feelings of guilt often are the result of misperceptions or a lack of understanding. Nevertheless, extreme feelings of guilt over misperceptions are reason for concern and parents should be aware of these feelings and provide clarification, if necessary. Again, provision of information might relieve feelings of guilt (Vermoter, 2003). Refer to section 4.3.1 for a discussion on siblings' need for information.

To answer the first of the secondary research questions (What are siblings' perceptions of ASD and does it affect how they deal with the situation?), the researcher concludes that siblings have a great need for information regarding ASD. By informing siblings, the siblings will gain a better understanding of the characteristics of ASD, which might lead to a more positive experience of having a brother with ASD. Vermoter (2003) reported that providing information to siblings might relieve feelings of guilt and anger. Additionally, it might result in less distress and frustration, and an even better relationship with a brother with ASD. Siblings do not only have a need to be informed themselves; they also want others (especially their friends) to be informed about ASD. As the prevalence of ASD is increasing, providing information about ASD to all children has become something that could be addressed in schools.

Concerns that were expressed by many siblings were worries about the future, firstly with regard to ASD (e.g. what his behaviour will be like in the future and whether he will 'get better'). Secondly, with regard to care, siblings worried about the ability of their brothers with ASD to take care of themselves and therefore also about who would take care of them one day. In parents' perceptions of siblings' worries, the same worries were reported. A study by Krauss and Seltzer (2010) has shown how these worries about the future affect siblings' life

⁴ Non-visible disability infers that there are no physical signs of disability.

choices (see section 2.4.4). This might place much pressure on siblings and they should therefore receive support to deal with these worries. Most siblings who participated in this study were still young, but worrying about who will care for their sibling might increase as they grow older. Some siblings also reported that they are worried that something bad will happen to their brothers in the future. One sibling was worried that her brother might hurt himself (see section 4.3.2.1). According to Wing (cited in Attwood, 2000), there is a risk of depression in adults with Asperger's Syndrome. Wolf (cited in Attwood, 2000) reported a genuine risk of suicide. Thus, the participant's concern should not be ignored. Depression in people with Asperger's Syndrome is usually a result of wanting to be like others and making friends, but not knowing how, and being teased and ridiculed (Attwood, 2000). By informing siblings, they can be helped to be advocates for their brothers and other people with ASD (see sections 4.3.6.2). Siblings also expressed that they are worried about their brothers' social abilities. Previous studies have found that siblings of children with ASD experience various negative effects such as stress and depression (Conger *et al.*, 2009; Dyson, 2010; Ross & Cuskelly, 2006; Schuntermann, 2007). The provision of support might prevent the worries expressed by siblings from escalating to such negative results at a later stage. Refer to section 2.6 for more examples of possible negative effects that siblings may experience according to previous studies.

At times, the worries that siblings experience are related to a lack of information. For example, one participant was extremely worried that his brother might die when he is operated to take the Autism out of his brain. It would relieve a lot of stress if this participant were to be better informed regarding treatment for ASD. Siblings should be informed that ASD is not curable, but that different treatments can show remarkable improvement in their skills and behaviours (Koudstaal, 2011; Mash & Wolfe, 2005). This will help siblings to have a realistic view of the future, without discouraging them.

With regard to the second secondary research question (What are the sibling's responsibilities and does this add extra pressure on siblings?) it became evident throughout the study that siblings took on care-giving roles with regard to their brothers with ASD; even those siblings who were younger than their brothers with ASD. The roles of siblings as identified in the literature are discussed in section 2.4.4. Previous studies have also found that siblings often take on the parental role of care giving. This, it was pointed out in the literature, is sometimes done excessively, which could lead to those siblings maturing prematurely (Abrams, 2009; Aronson, 2009). Although parents participating in the current study mentioned that the siblings were very "*independent*" and often had to "*carry on on their own*", these parents did not place excessive pressure on siblings to take care of their

brothers and siblings were not punished if they did not take care of their brothers. Extra responsibility rather was requested from parents. However, parents should remain aware of the sibling's age and the need to play and act as children. It was mentioned in the literature that girls have a tendency to show and report more affection and intimacy in their relationships with siblings than boys would usually exhibit (Akiyama, Elliot & Antonucci; Kim, McHale & Wayne Osgood cited in Orsmond & Seltzer, 2007). In this study, however, it was revealed that both girls and boys took on care-giving roles; thus, gender did not play a significant role.

The role of their brothers' protectors was also experienced by siblings as one of their responsibilities. In order to protect their brothers, siblings sometimes became involved in fights themselves. This section is linked to section 4.3.6 on relationships with peers (including bullying and siblings as advocates). The impairment in social interaction of children with ASD therefore also affects siblings' relationships with peers. It seems that parents are not aware of the bullying that goes on at times. Siblings should be supported in this regard and they should be better equipped to deal with bullies in a constructive and non-aggressive manner. Furthermore, siblings should be encouraged and empowered to inform their peers about ASD, as this will serve further as a tool for avoiding misconceptions and confrontational situations.

Some siblings mentioned that part of their responsibility was to be an example and to teach their brothers with ASD social and every day skills, e.g. appropriate and acceptable behaviour when in the company of others. As discussed in section 2.4.4, teaching a brother with ASD or peer tutoring can be an enriching experience for both parties involved. Children with ASD learn valuable skills from their siblings, while siblings develop various characteristics, e.g. self-confidence, responsibility and acknowledgement of diversity (Jones, 2007). From an ecosystemic perspective, the sibling and his/her brother with ASD are interdependent as they both learn from each other (see section 4.3.4.5 for examples of what siblings have learned from their brothers with ASD). The encouragement of sibling/peer tutoring could have positive effects within families. Firstly, the existing literature has shown that peer tutoring has been successful in teaching social skills to children with ASD (Rogers, 2000). This might subsequently also improve the social skills of children with ASD, which will evidently relieve the siblings' worries about their brothers' "*fitting in with friends*". Secondly, siblings might experience a sense of accomplishment (Jones, 2007). However, parents should provide praise and acknowledgement for the siblings' efforts in teaching their brothers. Peer tutoring might contribute to siblings becoming advocates for Autism. This can be linked with section 4.3.6.2.

The amount of pressure these responsibilities place on siblings depends on the personality of the sibling; it is a subjective experience. While some felt pressured to protect their brothers because "*something bad might happen*" if they did not, others did not feel added pressure from being responsible for and needing to protect their brothers. Parents should be aware of the personality of siblings and assure them that they appreciate all efforts to protect their brothers, but make it clear that they are not solely responsible for them. Parents and siblings can be seen as a team that work together to create the best possible environment for the family as a whole.

The participants mentioned that they had very close relationships with their brothers with ASD. Some of the data correlated with the literature on sibling relationships; see section 2.4.2 for a discussion of this. There also were, inconsistencies, however. In contrast with what was reported in the literature, all the siblings seemed to spend a fair amount of time with their brothers with ASD. They never mentioned that their brothers embarrassed them and they expressed genuine love for their brothers regardless of circumstances. One has to bear in mind that most of the siblings participating in this study were still young and that feelings of embarrassment may surface as they get older. According to the literature, the age of siblings play a role in their experiences and emotions. This was discussed in section 2.4.3. Also refer to section 2.4 for a discussion on developmental stages. Interestingly, all the participants' parents were married and they seemed to have close relationships in the family, which formed a tightly knit unit. According to Schuntermann (2007), siblings reported more positive behaviour towards their Autistic siblings when there was less marital stress and when social support was provided within the family. Thus the family relationships and marital status of parents may contribute to the resilience of siblings. Resilience is discussed further in section 2.4.6.

Although the siblings reported close relationships with their brothers with ASD, they also reported that the characteristics of ASD challenged their relationships with their brothers at times. As discussed in section 2.3.6.3, restricted repetitive and stereotyped patterns of behaviour, interests, and activities are characteristic behaviours of ASD (American Psychiatric Association, 2000). This includes stereotyped and restricted patterns of interest; non-functional routines or rituals; repetitive motor mannerisms such as hand flapping; and preoccupation with parts of objects. These behaviours (especially tantrums), together with impairment in social interaction (which is another characteristic of ASD and is discussed in section 2.3.6.1), mostly cause these frustrations and difficulties. The data revealed that siblings reported this behaviour as causing distress and one participant even described it as traumatic. Siblings were also concerned about and confused by their brothers' anger.

According to the literature, outbursts and being difficult are often secondary consequences of ASD (e.g. because of difficulties with communicating or sensory problems) rather than main features (Koudstaal, 2011). The distress siblings feel in the above-mentioned situations may be alleviated through the provision of information that explains the causes of such behaviour and simultaneously address the fears and concerns that siblings may be experiencing.

Five out of the eight participants mentioned that their relationships improved over time. This correlates with the literature, which described how changes over time may be the result of the changes in the behaviour of children with ASD when they learn skills and techniques to compensate for their deficits and family members adapt to the situation (Aronson, 2009; Carr, 2006). It also correlates with the theoretical framework of the study. The chronosystem, which is one of the systems identified in Bronfenbrenner's model of child development, refers to the interaction of all other systems over time (see section 2.2).

Siblings who are older than their brothers with ASD mentioned the valuable lessons they have learned from their brothers, e.g. embracing diversity and endurance. On the other hand, siblings who are younger than their brothers with ASD did not think that their brothers have taught them anything. In this case, the ages of siblings may have influenced their responses and insight into their situation.

According to the bio-ecological model, proximal interactions, which are close, face-to-face and usually long-term relationships with parents, play the most important role in shaping lasting aspects of development (Donald *et al.*, 2006). Parents thus play a vital role in siblings' development and in providing support to siblings. In the literature, as well as in reports from siblings, it was clear that the daily lives of families are often planned around the needs of the child with ASD (Tsibidaki & Tsamparli, 2009). This results in siblings experiencing treatment by parents as unfair. Siblings reported that they often feel left out during family activities. This, in turn, might influence siblings' relationships with friends. Some siblings also felt excluded from friends and others feared the possibility of exclusion. This correlated with the ecosystemic perspective which emphasises the interrelatedness between different systems (Donald *et al.*, 2006). Siblings also reported that they would like some more attention and acknowledgement from parents. As children with ASD have so many difficulties, there usually is a big celebration when they succeed. Siblings, on the other hand, are just expected to accomplish certain things and they usually do that without much effort. Parents sometimes forget to celebrate their accomplishments with the same enthusiasm as their brothers'. Parents reported that they are aware that they sometimes take siblings for granted, forget to praise them and do not spend as much time with them as

the siblings would like. The aim of the study was not to place blame on parents, as the researcher is aware of the difficulties parents have to cope with on a daily basis. The study, instead, aimed to provide parents and professionals with insight into the siblings' experiences and how they would like to be supported. Parents and professionals could use the study as a guideline to provide adequate support for siblings. Even though siblings felt left out and treated unfairly at times, they also reported close relationships with their parents and indicated that they saw their parents as their support system. Thus, if parents could use this study as a guideline and meet the needs of siblings, it might strengthen their relationships even more. Siblings and parents could then help each other to cope with daily difficulties. Siblings can help parents by teaching and caring for their brothers and parents can help siblings by providing support and sufficient attention. This could result in a positive and enriching experience for both the siblings and the parents. Parents should, however, be careful not to place too much responsibility on siblings, which might cause them to mature prematurely (see section 2.4.4).

Within the microsystem, siblings' relationships with peers are influenced due to the characteristics of ASD. According to Carr (2006), impairment in social interaction manifests as a failure to develop age-appropriate peer relationships. Children with ASD do not understand the rules of games or the concept of turn taking and they are often not "tuned in" to others (Welton, 2004. p. 19), therefore, even if children with ASD want to interact with others, they often do not know how to play with their peers (Robinson, 2007).

The theme of bullying occurred often during the interviews with the siblings. Usually their brothers with ASD were victims of bullying, teasing or exclusion. Previous studies attributed deficits in social interaction and lack of understanding of the behaviour of others as a root cause of bullying and victimisation of adolescents with ASD (Frith & Hill cited in Van Roekel, Scholte & Didden, 2010). This is upsetting for siblings and a great cause of concern for them.

Secondly, it often causes siblings to get involved in fights as well, as siblings usually act as the protectors of their brothers. (See sections 4.3.3.2 and 4.3.6 for discussions on peer relationships and siblings as protectors).

Thirdly, siblings become advocates for their brothers with ASD. According to Scorgie and Sobsey (cited in Bayat, 2007, p. 703), people often undergo "transformations" or "life changing experiences" when they live with a child with a disability. One of these "transformations" is to speak out and advocate for people with disabilities. In order to address the issue of bullying, siblings should be informed about bullying as well as taught

appropriate ways to deal with it. Advocacy cannot be the sole responsibility of siblings and should therefore be addressed within various systems. The issue of ASD and bullying could, for instance, be addressed in schools and by providing information to parents. Siblings did report having some good friends who did not tease their brothers.

It is unclear what role the siblings' context plays in bullying. Although one participant from a higher socio-economic background did not report bullying, another participant from such an environment did. Thus, it appears that bullying occurs in all contexts.

According to the literature, siblings of children with disabilities share most of the experiences usually described by parents, for instance isolation, a need for information, guilt, concerns about the future, care-giving demands and sleep deprivation (Doherty; Powell & Gallagher; Seligman in Conway & Meyer, 2008). Some of these concerns were also raised in this study. Siblings should be provided with support in the same manner as parents. Participants' thoughts and feelings on current support available to siblings, as well as how they would like to be supported, are discussed in section 4.3.7. Through sibling responses it became evident that siblings do not particularly want to attend support groups for siblings. They did, however, mention that they have a need for more support. Furthermore, it seemed that parents can play an important role in providing support for siblings. This was also found in a study by Schuntermann (2007) that showed that siblings displayed more positive behaviour when social support was provided within the family. Siblings mentioned how they would like to be supported. This included the following:

- They need opportunities to share their experiences.
- They would like to be included in activities at home and they want their parents to "put them first" at times and spend special time with them.
- Siblings want more acknowledgement of their abilities and performance.
- Siblings want more information about ASD and they would also like others to understand ASD.

The need for information is discussed in section 4.3.1. Parents can support siblings by listening to them and making time for them specifically. Parents should also be aware of siblings' emotions and feelings. Although most participants said that they could talk to their parents if something bothered them, it was not clear whether siblings do talk about it when they are upset or ask for support when they need it. Most siblings mentioned that they hide somewhere until they feel better when they get upset. A build-up of unresolved emotions can

become overwhelming at times. Some participants became very tearful when asked about things about their brothers that upset them, which elicited the researcher's concern for those siblings. Parents should therefore make a deliberate attempt to sit down with siblings and provide them with a platform to express their fears and concerns. Parents should also attempt to provide siblings with as much information as possible about ASD and to ensure that there are no misperceptions which might cause distress and develop feelings of guilt in siblings.

All the participants reported that their lives were different from their friends' lives, but only two participants ascribed this difference to ASD. Other participants mentioned the number of siblings their friends have or how they were so much luckier than their friends because their friends' parents were divorced, etc. One could deduce that, although ASD presents some challenges for siblings, the participants did not see ASD as an entirely negative aspect of their lives.

In summary, the experiences voiced by the siblings of children with ASD in general were shared experiences, fears and concerns, with a lack of information about ASD surfacing as the most outstanding theme emerging from this study.

5.3 STRENGTHS AND LIMITATIONS OF THE STUDY

One of the strengths of this study was that the specific group of siblings were given the opportunity to let others hear their voices. The data collected through this study provided valuable insight into siblings' experiences, as well as their needs. Secondly, parents and other professionals could be made aware of siblings' experiences and needs through the study, and could use this study as a guideline for providing support to siblings.

A limitation to this study is that a small sample limited to the Western Cape was used, which might not provide a good enough representation of the experiences of other siblings of children with ASD. Another limitation concerned the age of participants. Most participants were very young (between the ages of 7 and 11). Although the participants provided valuable information, their reflections on specific experiences were limited at times. The study also only gained information from children in a specific stage of development.

All the children with ASD were boys. According to the literature, boys are affected more frequently, whereas girls are usually more severely affected by ASD. All the participants' brothers had received some form of intervention. Some of them were, or had been, in special schools and others were enrolled in programmes such as REACH or SNAP. The

experiences of siblings may have been different if there had been no intervention or if the child with ASD had been a girl.

Time constraints governed the completion of this thesis. This was a limitation of the study. If more time had been available, the researcher would have liked to conduct follow-up interviews with siblings, or conduct a focus group interview.

5.4 RECOMMENDATIONS

There is scope for further investigation in this field:

- Further research could explore the experiences of adolescent siblings of children with ASD. As adolescence is a different stage of development which usually goes hand in hand with different types of relationships with peers and parents, an investigation of the adolescent experience of having a brother/sister with ASD and the effect thereof on relationships might be very interesting.
- The experience of having a brother/sister with ASD when living in a single-parent family, or a family with some degree of marital stress could also be investigated.
- Research could also be undertaken to explore the experiences of siblings of a brother/sister who has not received any form of intervention, as siblings reported that their experiences changed over time (thus with intervention).
- A similar study could be focused on a larger group of siblings.
- Research could be undertaken to further explore the impact of socio-economic and cultural differences on siblings' experiences.
- Although many siblings reported that they would not like to go to a support group, support groups could be initiated for those siblings who would like to make use of this kind of support.
- Parents and other professionals could use this study as a guideline to provide sufficient support to siblings. Parents should be aware of the distress, guilt and worries experienced by siblings and provide support in order to prevent the possibility of eventual negative outcomes such as depression and anxiety.

5.5 REFLECTION

During this research process, the researcher gained valuable insight into the siblings' experiences. Some participants started to cry during the interviews. This was of great concern to the researcher, because it led to the realisation that having a brother with ASD does cause much distress and made her aware of the fact that siblings currently are not supported sufficiently. Also of concern were the feelings of guilt felt by siblings, usually as a result of misperceptions or a lack of information. Such strong emotions, coupled with the worries that siblings' experience and the daily pressures on them, could lead to symptoms of depression. It appeared that siblings enjoyed the opportunity to speak about their experiences within a psychologically safe environment. It was a positive experience for the researcher to provide siblings with acknowledgement and a safe space to express their thoughts and feelings. At the same time, the researcher gained admiration for the strength and compassion that siblings exhibited. Although siblings felt left out by their parents, they still loved their brothers with ASD dearly and always put them first. This is a very mature characteristic, especially in such young children.

5.6 CONCLUSION

In contrast with the tremendous increase in the prevalence of ASD and the amount of research conducted on this topic, little is known about the experiences of siblings and, of more importance, little support is currently available to these siblings. Although siblings do not view the experience of having a brother with ASD as negative, they deal with a variety of challenges on a daily basis. Often siblings deal with these difficulties by hiding away and waiting for negative feelings to pass. However, if support is not provided, a build-up of worries, the pressure of responsibilities, feelings of exclusion and feelings of guilt may result in problems with stress and depression at a later stage. Provision of support and information to siblings might relieve many negative feelings induced by frustration, guilt and worry.

Awareness of ASD is another important factor that needs to be addressed. A better understanding of the condition and the challenges that accompany it might have several positive outcomes. Exclusion, victimisation, bullying and other negative aspects might be minimised if people became better informed about the intricacies of ASD.

The manner in which siblings interviewed in this study have adapted to tremendously challenging circumstances is astonishing. Their tenacity and strength belie their age and they deserve society's admiration.

The following quotes put into words how unique siblings of children with ASD are and how they never fail to surprise:

A few months ago, I took my sons to buy shoes. Nate is 14 and autistic. Joey is 8 and 'typical'. And I'm the parent — most of the time. Before we got to the store, Joey said to me, "If Nate has a tantrum, I can handle him. You just focus on buying shoes. I'm better at handling tantrums than you. Sometimes you just yell and it makes things worse. No offense."

None taken. He's absolutely right.

The 'typically developing' siblings of autistic children are, in fact, the furthest thing from typical. Often, they are wiser and more mature than their age would suggest. And they have to be, given the myriad challenges they face: parental responsibility; a feeling of isolation from the rest of their family; confusion, fear, anger and embarrassment about their autistic sibling. And on top of all of it, guilt for having these feelings (Lennard Goehner, n.d.).

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ADDENDUM A



3 March 2011

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Enquiries: Sidney Engelbrecht
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Reference No. 480/2010

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Ms S Bishop

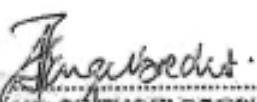
APPLICATION FOR ETHICAL CLEARANCE

With regards to your application, I would like to inform you that the project, *The experience of siblings of individuals with autism*, has been approved on condition that:

1. The researcher/s remain within the procedures and protocols indicated in the proposal;
2. The researcher/s stay within the boundaries of applicable national legislation, institutional guidelines, and applicable standards of scientific rigor that are followed within this field of study and that
3. Any substantive changes to this research project should be brought to the attention of the Ethics Committee with a view to obtain ethical clearance for it.

We wish you success with your research activities.

Best regards


MR. S. ENGELBRECHT

Secretary: Research Ethics Committee: Human Research (Non-Health)



ADDENDUM B



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INVITATION TO TAKE PART IN A RESEARCH STUDY

The experiences of the siblings of children with Autism

Dear Parents

I am an Educational Psychology Master's student at the University of Stellenbosch and I am presently working on my thesis. The main aim of my thesis is to explore the experiences of the siblings of children with Autism. This includes exploring the siblings' personal perceptions of Autism, exploring the relationships within the family and what the non-autistic sibling's role is in the family, exploring how Autism affects their lives and what support they have. In order to do this study, I require participants to be between the ages of 10 and 16 and currently living with a brother or sister with Autism. Parents are also required to fill out a questionnaire.

It is hoped that through this research learners will gain an opportunity to explore their relationship with their sibling with Autism and become aware of the positive aspects thereof, as well as the support they have in place. When one considers the worldwide increase of the prevalence of Autism and the effect it has on the siblings, the importance of educating siblings regarding the above-mentioned issue, enhancing their ability to cope with possible barriers and raising awareness of support becomes essential.

Should the interviewer feel it necessary, she will refer the participant to a counsellor or psychologist to provide support. The following counsellors/psychologists have experience in the field of Autism and can be contacted: Christelle Pentz (cmpentz@gmail.com, 082 758 8702), Carlyn Coetzee (carlyn@snap.org.za, 082 556 8246), Famsa Western Cape (famsa@famsawc.org.za, 021 447 7951), Jana Forrester (janafor@telkomsa.net, 021 683 0596).

Both you and your daughter's/son's participation in this study will be invaluable in helping to generate data that could inform awareness programmes in the near future.

Semi-structured interviews (with the siblings of children with Autism) and questionnaires (completed by the parents) will be utilised in order to explore the above. This is planned to

take place after school time in the first term of 2011. Arrangements will be made regarding the venue of interviews.

Research will be based on ethical principles in order to protect and respect participants. Participants can choose whether they want to take part in the study or not. Before making this decision, all ethical issues, the nature of the study and any risks regarding the study will be discussed to ensure that participants make an informed decision. The researcher will obtain informed consent from the parents, as well as assent from the participants. If they volunteer to be in this study, they may withdraw at any time without consequences of any kind. They may also refuse to answer any questions they don't want to answer and still remain in the study.

Any information that is obtained in connection with this study and that can be identified with a participant will remain confidential and will be disclosed only with their permission or as required by law. Confidentiality will be maintained by using pseudonyms. The names of the participants will not be known. This research aims to contribute to the general well-being of people; participants' rights will not be abused for the purpose of gaining information or knowledge.

Should you be interested in this study, please do not hesitate to contact me at the number provided below or fill in the attached form and leave it at reception for me. I will provide more information about the study, should you agree to it. Please note that both you and your child must be willing to participate in the study.

Thanking you in anticipation.

Yours sincerely,

.....
Sunette Bishop

MEdPsych

University of Stellenbosch

Mobile: 073 218 1855; Email: sunette.bishop@gmail.com

INVITATION TO TAKE PART IN RESEARCH

Please fill in the following form if both you and your child are willing to participate in this study:

Parent(s) / Guardian(s)

I, _____, have a child with Autism and another child (children) without Autism and I am willing to take part in this study. I hereby give Sunette Bishop the permission to contact me with regard to the study.

Sibling:

I, _____, have a sibling with Autism and I am willing to take part in this study. I am ___ years old. I hereby give Sunette Bishop the permission to contact me with regard to the study.

Please fill in your contact details:

Name and Surname:	
Tel / Cell:	
Email:	
Address:	

Please contact me if you have any questions.

Kind Regards

Sunette Bishop

073 218 1855

sunette.bishop@gmail.com

ADDENDUM C

Interview schedule: Siblings of children with Autism

- Personal introduction
- Statement of purpose
- Ethical issues explained
- Ask for questions

Age of participant: _____

Gender of participant: Male *Female* .

Semi-structured individual interview

Opening question: Tell me about yourself.

1. What is Autism? (Personal perception)

1.1 Tell me something bad about Autism

1.2 Tell me something good about Autism

1.3 What would you like to have known about Autism when you were younger (to help understand your brother/sister)?

2. Tell me about your family (relationships within the family)

2.1 What activities do you like doing as a family?

2.2 Who do you have the closest relationship with?

2.3 Tell me about your brother/sister (how do you get along with your brother/sister?)

2.4 What don't you like about your brother/sister? (dislike)

2.5 What do you like about your brother/sister?

2.6 What worries you about your brother/sister?

2.7 What are your wishes for your brother/sister?

2.8 What have you learned from your brother/sister?

2.9 How has your relationship with your brother/sister changed over the years?

3. What are your responsibilities in the house?

3.1 What happens if you don't want to take on those responsibilities?

3.2 What happens if you do chores your parents ask you to do?

4. How is your life different from your friends' lives?

4.1 Do you think your life would be different if you did not have a brother/sister with Autism?
How?

4.2 Do your friends know what Autism is?

4.3 Do you invite friends over to your house? Why/Why not?

4.4 How do they react/what do they say about your brother/sister?

5. What do you do when your brother/sister upsets you?

5.1 Who do you go to for support when you are sad, upset, worried?

5.2 Would you like to have more support?

5.3 What kind of support would you like?

5.4 If there were support groups (explain term) in your environment, would you like to go to one?

5.5 What would be good about a support group? / What would be bad about a support group?

6. What are your wishes for yourself?

Time for questions

Sibling booklet

ADDENDUM D

Questionnaire for Parents

Please answer these questions with regard to the sibling participant.

Age of your child (sibling without Autism): _____

Gender of your child (sibling without Autism): Male Female

1. What do you think your son's/daughter's perception of Autism is?

2. About your family

- 2.1 What activities do you as a family enjoy doing together?

- 2.2 Whom do you think your son/daughter has the closest relationship with?

- 2.3 How do you perceive your son's/daughter's relationship with his/her brother/sister with Autism?

- 2.4 What do you think your son's/daughter's biggest worry/fear is for his/her brother/sister with Autism?

3. What are the roles and responsibilities your son/daughter takes on in the family?

3.1 To what extent has the child taken on family-related responsibilities he or she might not have if a sibling were not disabled?

3.2 Under what conditions were these responsibilities taken on? (That is, how much choice did the child have in the matter?)

3.3 What responsibility gradually shifted onto this child out of convenience or necessity?

3.4 How do you respond to your child when he/she refuses to take on responsibilities?

3.5 What has been your response when the child has been helpful? Has he or she received praise, or have the efforts been taken for granted?

4. How do you think your son's/daughter's life differs from other children his/her age?

4.1 How does your son's/daughter's (without Autism) friends react towards your Autistic son/daughter?

4.2 Does your son/daughter invite friends over to your house? Why do you think this is the case?

5. What support does your son/daughter have?

5.1 Who does he/she usually go to when something upsets him/her?

5.2 Do you think your child receives sufficient support?

5.3 If there were support groups for siblings in your environment, do you think your child would like to go to one?

5.4 What would be good about a support group? / What would be bad about a support group?

6. What are your wishes for your child (without Autism)?

Thank you!!

ADDENDUM E

Example of Transcription

S: en sê vir my, as hulle hier kom speel en * doen iets snaaks, wat doen jou maatjies dan?**

T: hulle lag en dan speel hulle samet hom en dan voel ek so...amper jealous

S: as hulle met hom speel, en nie met jou nie?

T: ja, dan voel ek somme ek wil vir hulle uitskel

S: en wat doen jy dan?

T: dan sit ek daar en kyk hoe lag hulle met *** en dan raak ek so kwaad

S: en dan sê jy nie iets vir hulle nie?

T: ja eenkeer het ek vir hulle geskel toe se ek "julle is mos hier om met my te speel dan hoekom is julle nou samet ***?"

S: En toe, wat het toe gebeur?

T: toe kyk hulle manet en toe gaan hulle huistoe
(rukkie stil)

S: dink jy daar is iets anders wat mens kan doen?

T: ja mens kan vir hulle op 'n mooi manier se "jy kan met my broer ok speel, maar kan jy klein bietjie ok met my speel" of "kan ek saamspeel"

S: mmm, want jy wil ok speel né?

T: mmm

S: so jou maatjies is nooit lelik met * nie?**

T: he-uh

S: Wat doen jy as jy hartseer is of as * jou**

kwaad gemaak het of ontstel het? Vir wie gaan sê jy dan?

T: Ek gaan sê vir niemand nie, ek hardloop na my kamer toe, ek gooi die deur toe en ek steek my êrens weg

S: en voel jy beter dan?

T: nee, dan sit ek daar vir ure en vir ure en dan sit ek daar en dan val ek aan die slaap. Dan vergeet ek alles daarvan, especially as ek huil en dan val ek aan die slaap

ADDENDUM F

Example of Coded Transcript	
	THEMES
<p>And he also...he also gets this tantrum thing you know</p> <p>S: Mmmm</p> <p>Li: And it's not so nice because sometimes...say we just had a fight, now he's in this thing where he goes on and on and on and he won't stop until I say something that will bring him to an end...so, so say we just had a fight and then he stands in the doorway and just like stares at me and he's got this look as if he's about to cry and then he cracks, then he screams and he starts crying and he tries to hit me and he used to bite people</p> <p>S: Mmm is that better now?</p> <p>Li: He doesn't bite anymore but he does punch and it's really sore...he'll do that (show how he punches) and I don't like it because it's not nice seeing someone you love acting all angry and stuff, you'd rather see them looking happy and instead he gets these mood swings and stuff...and yeah</p> <p>S: How...does he get tantrums often or?</p> <p>Li: Only if we usually have disagreements but there are so...there are so many I can't even...I'll give an example, ok...ok here's an example: It happened quite a...just a day or so ago. We watched a movie in my room, I was lying in my bed because I watched it from there and it was finished and he was already standing up, walking around my room, and I was like X would you mind please switching the machine off, he knows how to do that and then he says "Aggg Mooom" and he calls my mom. As in mooom will you switch it off and then I say "X, why are you calling mom when she's all the way over there...why don't you just do it yourself if I ask you for a small favour" and then he breaks out into a...then he goes but mom can do it and then I say "X that's kind of being lazy" and then he says "I'm not lazy Lizzy" and I say "But you were kind of acting lazy". So then my mom</p>	<p>Siblings' experience of difficult behaviour</p>

<p>came in and she switched it off anyway and then I was like "see, she had to do it anyway" and then I want to the bathroom to brush my teeth and then he stands in the doorway...and then he cracks...then he cracks. He starts tearing and crying, he starts ummm shouting at me and then he punches me unnecessarily and then he walks away to his room or something and he slams the door. Then my mom usually goes and gives him a pep talk or something</p> <p>S: And what do you do then?</p> <p>Li: Well if you didn't...say you didn't do much and now you're just minding your own business and then someone breaks into a tantrum and punches you, you get angry don't you?</p> <p>S: Mmmm</p> <p>Li: Now I've had a very long time to try and learn to control my anger, I don't have it completely...that thing that will stop you from shouting. But usually when he did that I'd also break out into shouting and then I'd hit him back. Because I'd be thinking "Why did you just hit me, I didn't do anything". And I was angry because...and it was also late so I was tired and then I, then I hit him back and then he also gets angry again. But I think when I hit him he also gets a bit hurt because I mean he's my brother and he knows that I don't hurt him but then I hit him so he might also, I think he might feel you know like angry at the fact that, that and then we get into a fight. But now I try, I really do, to try and like not do anything. I just carry on until X has calmed down and I just go to my room...you know like...hit the pillow</p> <p>S: Mmmm but it's still upsetting for you</p> <p>Li: So that's why sometimes I just can't help saying "You are such a jerk!!" before I walk into my room and slam the door...I can't help saying something</p> <p>S: Ja...and then, if he upsets you like that, who do you go to for support?</p> <p>Li: I don't really have anyone, because my mom usually goes to him and sits with him and talks to him and my dad's usually</p>	<p>Unfair treatment by parents</p> <p>Experience of difficult behaviour</p> <p>Close relationship with brother</p> <p>Lack of support</p> <p>Create different types of support</p>
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<p>at work...so usually (the cat's name) or (other cat's name) is around so I just sit with them or usually I lay on my bed and you know...let it go over...and they usually come and sit on my bed so it is calming in a way but I don't really have a person to turn to</p> <p>S: Mmm...ja animals can help but it is also nice to have someone to talk to sometimes...umm so do you think you would like to have some more support?</p> <p>Li: Ja in a way...because my mom...I've had quite a few times when I asked my mom "Mom, why is it that, it's like you like X more than me, is that why your paying more attention to him than to me?" Although I know that he's got autism, I tell her "yes, I know he's got autism but that doesn't make him any...a hundred times different than me"</p> <p>S: Mmm</p> <p>Li: you know in a way...in a sense that he deserves more attention than the average person</p> <p>S: Mmm and you know when he has a tantrum it's also upsetting to you so you also need some attention and support then</p> <p>Li: ja</p> <p>S: But ummm, so if you could have more support, what kind of support would you like? What would you like...how would you like to be supported in situations like that?</p> <p>Li: I've never really had a support so I've never really thought of what would I do if there was a person so I wouldn't really know what would I do if I did...because I mean mainly...even if I won't tell because sometimes it's me that started a fight because you heard what I said...I told him he was lazy. And then he..."I'm not lazy, why is she calling me lazy?"</p> <p>S: Mmmm but it's also not a usual reaction to have such a big tantrum over something small like that</p> <p>Li: Mmmm so then...</p> <p>S: So you can't always blame yourself either</p> <p>Li: But sometimes I really DO start a fight and I just don't really know because I've never had a support so I don't know</p>	<p>Would like more support Unfair treatment from parents</p> <p>Lack of support Blames herself for brother's tantrum</p> <p>Creates different types of support</p>
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what will I do if I did. And I used to have a teddy bear, a huge teddy bear...I used to like talk to it (laugh) it's kind of weird actually but I used to talk to it and I...now that I think about it I used to pretend like it was actually real, I actually felt like it was real so whenever I was in bed I'd give it equal part of my pillow because I felt like it also deserves part of my pillow and then I'd...I kept feeling like there was a monster in my cupboard or something...so say your bed's in the middle of the room then you can turn to that side of the room or that side of the room so I'd sleep on the one side and then my teddy bear would sleep on the other so she's watching that side while I'm watching that side and I'd say "Ok you watch that side and I'll watch that side" and then she used to be like a support type of thing

S: Mmmm it's actually a great way of creating your own support, because sometimes it like (sigh) a person can sometimes be almost like a volcano you know...when they build up and they build up and they build up until they just erupt and then all the emotions come out, so it's good to get the emotions out you know even if you talk to the teddy bear you still get those emotions out, or maybe if you want to write them in a diary it's also a good way of getting it out. But tell me...would you like mom to do something else to support you or dad?

Li: Well I'd like her to sometimes maybe put me first

S: Mmmm

Li: So say, I know I'm like old enough but I still like it if she tucks me in

S: Mmmm

Li: So then she goes to X first and then she reads him a story and then she says good night and then she comes to me, she says good night and she goes and watches a movie

S: Mmmm

Li: And then from time to time like once a week type of thing she sits by me and then I just talk to her as in let my emotions out but it's not so often that I get to and it's usually

How siblings would like to be supported

Unfair treatment from parents

Unfair treatment from parents

<p>X that gets the things first so ummm I'd like it if she'd spend a bit more time with me</p> <p>S: Mmm so maybe if you could make some special time where just the two of you can bond and talk or do something fun or whatever...some special time for you</p> <p>Li: But you see, my dad's usually...it's like a 3 circle, he usually isn't involved with that because he's usually at work or something and then when it's a...something we do together it's usually the three of us and now it can't be the two of us because where does he go?</p> <p>S: ja</p> <p>Li: So it can't always be the two of us it's always the three of us</p> <p>S: Ok...so its X and you and mom</p> <p>Li: Even it it's just like a afternoon, done with my homework, dad's still at work...why don't we go to the park? Ok. Let's go. X goes with as well</p> <p>S: Mmmm but then there are often times when mom and X bonds when she tucks him in and then you're also on your own? So....does X ever go and visit friends?</p> <p>Li: I don't think he's ever visited...all the friends usually come here...I'm not too sure where he goes...he's got a few friends now, apparently he's very popular... I don't know if he's been to a few friends but usually he's best friend comes here</p> <p>S: Ok so maybe while he is playing with his friend...video games or whatever...then you and mom can spend some time together</p> <p>Li: And then there is another problem when school comes in</p> <p>S: Mmmmm</p> <p>Li: I always have homework and she...whenever we get to spend time together she's always at work...and when I say "why don't we do something" then she says "I've just got to finish this CV, it will only take a minute" and like an hour later she's still busy sitting there with work so I decided I'm not going to ask her again because she's just gonna say "Oh just another CV or something" so I just</p>	<p>Unfair treatment by parents</p> <p>Would like a support group / How siblings would like to be supported</p> <p>You are not alone</p>
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<p>read a book...</p> <p>S: Mmm it is difficult because you have to get the work done as well so maybe you must make time on the weekend? If there were maybe a support group for siblings, you know if there were a lot of brothers and sisters of children with autism and they could meet together...do you know what a support group is?</p> <p>Li: Uhhh I think so</p> <p>S: ja sometimes you get a support group for parents, but if there were one for siblings where they could all meet and maybe learn a little bit more about autism or just have fun together and maybe...I don't know...do art activities or whatever and learn about autism and maybe even talk to each other to know that you're not alone, that there are other siblings as well who struggle with the same things as you...would you like to go to a group like that?</p> <p>Li: I guess so because I've never met anyone else who has a sibling with autism. I've met lots of children who have autism, obviously they're at my brother's school, but I've never met a sibling that has autism so I feel...I know that there are other people but my brain is like telling me that there isn't a lot of people so it feels like I'm the only one here with the brother with the autism and that nobody else understands because my friends, they don't have siblings with autism. Yes they have siblings, but they don't have siblings with autism...and when I explain it to them they...I think that they think that he's just some weirdo that...even my best friend, she doesn't fully understand when I talk to her about it because she doesn't experience it every day</p> <p>S: I think what also makes it difficult for other people to understand is because you know when you have someone with a disability like they can't walk you'll have someone sitting in a wheelchair and everyone can see that that person can't walk. But when you have autism you look like everybody else so people struggle to understand that that person also has difficulties with certain things</p>	<p>Need for others to understand ASD</p> <p>Worried about brother being bullied</p> <p>Need for others to understand ASD</p> <p>Privacy</p>
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<p>and it makes it sometimes difficult to live with that person</p> <p>Li: And there's another thing...there's another thing that I'm scared of</p> <p>S: Mmmm?</p> <p>Li: I'm scared that somebody's going to do something to X, like maybe he does something wrong...in high school for example but he still hasn't lost that little bit of something and then that person will think "Hey that person is hitting on my girlfriend" when he actually just meant to say "Hello, my name is X, what's your name?" like he just thinks...look there's a person, maybe she'll be my friend? and then the dude thinks he's hitting on my girlfriend and he might get angry at my brother and then he might do something and then nobody will understand, everyone will just think...hey he's a rude person and they don't understand that he's actually just with autism. And I don't want to broadcast it everywhere that he has autism but I just want them to understand</p> <p>S: It would be nice if... I think these days people know a lot more about autism than before but it would be nice if like you know in school you have a life orientation period where you learn about things like AIDS and stuff...do you learn about that?</p> <p>Li: jip</p> <p>S: So it would be nice if you could also learn about autism so people can also understand it...I think</p> <p>Li: So when I say...so what's wrong with your brother? "he's kind of got autism" "Huh?? What's that?" and when I try to explain to them they think there's something wrong with his brain...as in...so they still don't understand...so</p> <p>S: Hmm so your also a bit worried about the future for him?</p> <p>Li: I really wont know what's going to happen to him when he's older...because, hopefully he'll live a normal life when he's older and he'll be able to do stuff because I think sometimes people with autism become very amazing people. I remember this one person, I think I was watching tv with my</p>	<p>Need for others to understand</p> <p>Worried about the future</p>
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mom, and there was this women, I think she was on this farm and there were these cows and I think they were about to be slaughtered or something but they wouldn't walk into that pen but they couldn't see anything and they didn't know what was about to happen to them and this lady had autism and she went down and she said "they're scared of this" and she showed this little piece of glass or something, they don't want to walk past because they're scared of this. And they took it away and they walked through...and I was wondering but how does she know that? And she wasn't like an expert or anything she just had autism. And I was thinking that maybe X will do something awesome.

ADDENDUM G

Themes							
ANNI	TABITHA	HULK	HANNAH	LILY	ELI	LIZZY	WILLIAM
Introvert	Chance to shine Perception of ASD Upset / emotional Close relationship with brother Need for information Influence on sibling's schooling	Sibling as carer Does NOT get support from grandmother Close relationship with brother	Perception of ASD Advocate Social interaction – cause difficulties in relationships	Close relationship with extended family (grandparents)	Resilience – family size??	Advocate (differentness)	Relationships with peers – bullying (not related to ASD)
Difficult behaviour – makes it difficult to go out					Relationship with brother – spend much time together	Close family relationship	Creates different types of support
Perception of ASD			Need for information Perception of ASD	Little knowledge about ASD		Pressured by responsibility	
Experience of behaviour			Starts crying – need for support Privacy	Difficult behaviour	Close relationship with extended family (grandparents)	Pressure	Close relationship with extended family (grandparents)
Changes over time - better			But quite well informed Influence on daily lives	Close family relationships	(never in lime light)		
Knows brother very well			Knows brother well	Knows brother well	Scared of being excluded by peers	Experience of difficult behaviour	
Experience of difficult behaviour			Brother interferes with peer relationships	Perception of ASD (needs info)	Scared of being excluded by peers	Need for information	
Close relationship with brother			Close relationship with brother but also some difficulties	Relationship with peers – others "hates" brother	Worried – social – not easy to make friends for brother	Close relationship with extended family (grandparents)	Need to understand (don't know what autism is)
Need for knowledge	Guilt Worries – that something will happen to brother (run away)	Worried about the future	Change over time - better	Because of social impairment	Close relationship with brother	Close relationship with brother with ASD	Needs help with homework (needs more attention)
Knowledge about the future	Sibling as Carer	Learned from brother –	Experience of difficult behaviour	Relationship with peers – hurts siblings feelings when others bully brother	Relationship with peers	Lack of information/understanding	Impairment in social interaction and communication make it difficult
Plan to accommodate brother	Knows brother very well Wishes – future – that he will get	Responsibility Sibling as carer	Close relationship with brother	Brother being			

Difficult behaviour – influence on daily routine	better Worries – social interaction – others will bully him because of it	Difficulties with relationship with peers (not related to ASD)	Worries – health	Wishes – fit in with friends	bullied	Lack of information / understanding certain behaviours	Cause frustrations
Close relationship with brother	Bullying Sibling also gets involved in fighting	Need for others to understand	Learned from brother	Doesn't teach me anything	Advocate	Experience of difficult behaviours	
Need for information	Sibling as protector	Support	Changes over time – better	Sibling as protector	Need for others to understand	A need for information	
Worried about the future	Advocate Sibling involved in bullying	Would not like support group	Need for others to understand	Life different from friends' lives (nothing to do with ASD)	misperception – guilt	Perception of ASD	Relationship with brother (good but lots of difficulties – not used to him yet)
Wishes for brother – successful in the future	Sibling as protector	Privacy (introvert)	Close relationship with brother	Friends don't play with brother (relationship with peers)	Need for information	Lack of understanding ASD	Sad not to know what was going on (information)
Learned from brother	Sibling as protector		Responsibility Sibling as teacher (Example for brother)	Experience of behaviour (sad)	Experience of behaviour (sad)	Influence of characteristics of ASD on sibling relationship (social interaction, difficult behaviour)	Knows brother well
Close relationship with brother	Sibling as protector		Dealing with difficulties	Close family relationships	Close family relationships	Siblings experience of difficult behaviour	Changes over time – better
Responsibility Sibling as carer	Responsibility Sibling as teacher		Pressure of responsibility	Sibling as teacher	Unfair treatment from parents	Guilt	
Life different from friends' lives – financial influence of ASD	Changes over time – better Experience of behaviour		Life is different from friends' lives – brother needs a lot of attention	Support	Accommodate brother	Experience of behaviour/characteristics of ASD – frustrations	Close family relationships
Brother needs a lot of attention	Advocate Responsibility Sibling as teacher		Creates different types of support	Wont not like support group	Close relationship with brother	Unfair treatment from parents	Need for information – misperceptions can cause distress
Privacy	Pressure of responsibility		Don't know many others with brother/sister with ASD (you are not alone)	Responsibility (very responsible for such a young girl) –could take self to school – independent	Advocate	Experience of difficult behaviour	Worried – brother might die
Dealing with	Life different than lives of friends'			Worries – brother not being able to be independent	Worries – brother not being able to be independent	Close relationship with brother	
	(not really related)					Lack of support	
						Create different	
							Wishes – that

difficult behaviour	to ASD)			(on his own)	types of support	autism will go away
Support	Does not know many others with a brother or sister with ASD (you are not alone)		Friends don't bully him	Sibling as carer	Would like more support	Support
Need more support	Her close friends knows what ASD is		It's nice to have someone who also has a brother with ASD – understands (You are not alone)	Wishes for brother – weer regkom – make friends	Unfair treatment from parents	Sibling as carer
Would NOT like support group	Feeling left out (peers)			Learned from brother – I teach him	Lack of support	Need for others to understand
Would be nice if other understood ASD	Dealing with difficulties		Experience of difficult behaviour	Sibling as teacher	Blames herself for brother's tantrum	Don't know others with b/s with ASD (you are not alone)
	Support		Dealing with difficult behaviour	Changes over time – better	Creates different types of support	Need for information
	Would like a support group		Support	Responsibility – sibling as carer	How siblings would like to be supported	Fear of exclusion (peers)
	Proud of brother/advocate (close relationship)		Would like more support	No pressure – enjoys being the responsible one – no pressure from parents (if he doesn't do it – mom will look out for them)	Unfair treatment from parents	
	Fear of being excluded by peers		Feeling left out		Unfair treatment from parents	
	Wishes – brother will get better		Unfair treatment from parents		Unfair treatment by parents	
	Financial influence		How would sibling like to be supported – included	Doesn't no others with b/s with ASD	Would like a support group / How siblings would like to be supported	
	Experience of difficult behaviour		Don't feel the need to go to support group	Life is different from friends' lives (not related to ASD)	You are not alone	

			You are not alone					
				Others don't understand – misperceptions?		Need for others to understand ASD		
				Relationships with peers (ignore brother)		Worried about brother being bullied		
				Help hom reg (sibling as teacher)		Need for others to understand ASD		
				Dealing with difficulties		Privacy		
				Would like support group		Need for others to understand		
				Need for others to understand – not tease brother		Worried about the future		
				How would sibling like to be supported – advice to help brother		Sibling as Carer		
				Need for information – misperceptions can lead to feelings of guilt?		Close relationship with brother with ASD		
				Wishes – broer sal regkom		Love for brother		
						Need to understand brother		
						Feeling left out		
						Need for information		
						Worried that his feelings might get		

					<p>Close relationship with brother</p> <p>Attention – parents give equal attention – sibling handles situation very well and enjoys the responsibility of caring for his brother – is it because of his personality or his parents who give equal attention and don't put pressure on him???</p> <p>(Reflection)</p>	<p>hurt/feel bad about himself/hurt himself</p> <p>Close relationship with brother</p> <p>Wishes for brother</p> <p>Social interaction</p> <p>Need for others to understand and accept brother</p> <p>Learned from brother</p> <p>It's ok to be different</p> <p>Close relationship with brother</p> <p>Feels nobody really cares</p> <p>(relationship with peers – gossiping – not related to study???)</p> <p>Changes over time – better</p> <p>Need for others to understand</p> <p>Life different from</p>	
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					<p>friends lives – nothing to do with ASD</p> <p>Close family relationship</p> <p>Knows brother very well</p> <p>Feeling left out</p> <p>Responsibility Sibling as carer</p> <p>Need for information (type of support – learn from other's experience)</p> <p>Would like to go to support group</p> <p>Would like a chance to shine</p> <p>You are not alone</p> <p>Brother gets all the attention</p>		

ADDENDUM H



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

LETTER OF CONSENT

February 2011

Dear

I am an Educational Psychology Master's student at the University of Stellenbosch and I am presently working on my thesis. The main aim of my thesis is to explore the experiences of the siblings of children with Autism. This includes exploring the siblings' personal perceptions of Autism, exploring the relationships within the family and what the non-autistic sibling's role is in the family, exploring how Autism affects their lives and what support they have. Semi-structured interviews (with the siblings of individuals with Autism) and questionnaires (completed by the parents) will be utilised in order to explore the above. This is planned to take place after school time from _____ to _____ on the following dates:

- _____
- _____

Your permission to participate in my research is requested. The identities of all participants will remain confidential in all discussions of findings. All information gathered during interviews and questionnaires that are completed by the parents shall remain confidential and the learners' identities shall be protected. The semi-structured interviews will be taped with permission of the participants; only the researcher will have access to these tapes. After transcribing the interviews the participant will have the right to review transcriptions and tapes will be erased after completion of the examination process of my master's thesis. The information will only be viewed, interpreted and read by me as researcher and my supervisor Mrs. C. Louw (Lecturer and Educational Psychologist at the Department of Educational Psychology at Stellenbosch University). However, this confidentiality is limited in the sense that should I be informed of any potentially risky, harmful or illegal behaviour, it is my obligation to report this. Providing information, resources and methods of empowerment as well as debriefing learners after the semi-structured interviews will also be an important aspect of the process.

The interview and reflecting on experiences might be uncomfortable to parents and siblings. Participants may withdraw from the study at any time without consequences; they also have a choice whether they want to answer the questions. Participants will have time to debrief after the interview. Should the interviewer feel it necessary, she will refer the participant to a counsellor or psychologist. The following counsellors/psychologists have experience in the field of Autism and can be contacted: Christelle Pentz (cmpentz@gmail.com, 082 758 8702), Carlyn Coetzee (carlyn@snap.org.za, 082 556 8246), Famsa Western Cape (famsa@famsawc.org.za, 021 447 7951), Jana Forrester (janafor@telkomsa.net, 021 683 0596).

It is hoped that through this research learners will gain an opportunity to explore their relationship with their sibling with Autism and become aware of the positive aspects thereof, as well as the support they have in place. When one considers the worldwide increase of the prevalence of Autism and the effect it has on the siblings, the importance of educating siblings regarding above-mentioned issue, enhancing their ability to cope with possible barriers and raising awareness of support becomes essential. Your daughter's/son's

participation in this study will be invaluable in helping to generate data that could inform awareness programs in the near future.

Informed consent is requested from both parents/guardians. Should you agree to your own as well as your child's participation in this study, please sign the attached consent form. However, your daughter/son will only participate in the study if she/he is willing to do so. Assent is therefore similarly required from him/her, after I have discussed with him/her the above-mentioned risks and benefits of the study.

You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Mrs Malene Fouché (021 808 4222) at the Unit for Research Development.

Should you have any queries about my study, please do not hesitate to contact me at the number provided below.

Thanking you in anticipation.

Yours sincerely,

.....

Sunette Bishop

MEdPsych

University of Stellenbosch

Mobile: 073 218 1855

Email: sunette.bishop@gmail.com

CONSENT FORM

Consent from both parents is kindly requested in order for yourself and your daughter/son to participate in this study.

I, mother/father/legal guardian of hereby verify that I have read the attached letter and having fully understood its contents give my permission for my daughter/son to participate in Miss S. Bishop's research, as part of her master's thesis. I am also willing to complete the questionnaire.

.....
Signature of parent/guardian

.....
Date

I, mother/father/ legal guardian of hereby verify that I have read the attached letter and having fully understood its contents give my permission for my daughter/son to participate in Miss S. Bishop's research, as part of her master's thesis. I am also willing to complete the questionnaire.

.....
Signature of parent/guardian

.....
Date

ASSENT FORM

Assent from siblings of children with autism is kindly requested in order for siblings and parents to participate in this study.

Dear

Thank you for returning the consent forms from your parents to me. As you are aware, both your parents/guardians have agreed to your participation in my study on the experiences of the siblings of children with Autism. However, you can only participate in the study if you also agree to it.

Please indicate your willingness to participate in this study or decision not to participate by ticking one of the boxes below. Please make certain that you write your age and full name where it is required below.

If at any time you change your mind about your participation you will be free to withdraw from the study without any consequence.

Thank you once again for your time.

Kind regards,

Miss S. Bishop

Please tick the box of your choice below.

Name: Age:



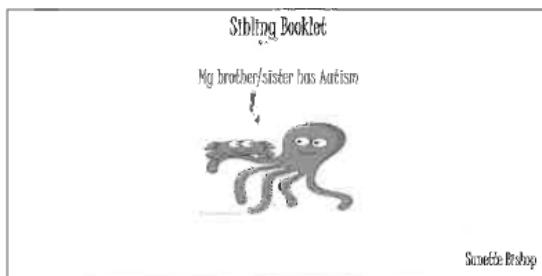
I would like to participate in this study and I know that I can withdraw at any time.



I would prefer not to take part in this study.

ADDENDUM I

Sibling Booklet



Advice from adult siblings to teenage siblings

(Aut;talk (Edition 15) – April 2010)

Do whatever you can to promote good experiences with your brother/sister with Autism. It is not always easy; sometimes it is difficult to "connect" with them.

Keep it in perspective. No blame to anyone. Take care of yourself and your needs as to stay strong and CLEARLY realistic for your sibling and those around you.

Join a peer support group. Learn everything you can about the disorder.

Understand that autistic individuals have a hard time relating to other people.

LAUGH!! Because if you focus only on the negative, you will never respect/understand your sibling.

Have open communication. If not with your family, then with professionals. Talking about fears, anxieties, etc. helps, rather than retreating into embarrassment or denial.

Don't take things too serious. Try to be positive about things and involved in things as do other people...

Develop your own peer group and pursue your own interests. Find a way to express your feelings, especially if your family cannot cope with your needs on top of your autistic sibling. Plan for an adult life where you can be an advocate and support person for your sibling without sacrificing your well-being.

Aim of this booklet

You can use this booklet as a resource to find out more about Autism and to show your friends more about Autism. There are a lot of stories and websites you can watch to help you understand Autism. This booklet will also provide support for you!! If you need to talk to someone you can contact one of the counsellors/psychologists. You can also read stories and look at websites and see that there are many other children with brothers/sisters with Autism.

YOU ARE NOT ALONE!!

Books to read

Brotherly Feelings: Me, My Emotions, and My Brother with Asperger's Syndrome – Sam Fender & Robin Schiffmiller

Can I tell you about Asperger Syndrome: A guide for friends and family – Jude Welton

House Rules – Jodi Picoult

The Complete Guide to Asperger's Syndrome – Tony Attwood

The Way I See It: A Personal Look at Autism and Asperger's – Temple Grandin

Look me in the eye: My life with Asperger's – John Elder Robinson

Born on a blue day – Daniel Tammet

The curious incident of the dog in the night – Mark Haddon

The Way Things Look To Me – Roopa Farooki (Pan Books, 2009)

I'm a Teenager, Get Me Out of Here!: A survival guide for teenage siblings of young people with autism! – C. Brock

I have autism – what's that? K. Dorothy, P. McNally & E. Sherrad

More on: [http://www.autism.org.uk/about-autism/autism-library/magazines-articles-and-reports/...](http://www.autism.org.uk/about-autism/autism-library/magazines-articles-and-reports/)

The following counsellors/psychologists have experience in the field of Autism and can be contacted:

Christelle Duckitt (christelle.duckitt@gmail.com, 082 758 8702)

Carlyn Coetzee (082 556 8246)

Famsa Western Cape (famsa@famsawc.org.za, 021 447 7951)

Jana Forrester (janafor@telkomsa.net, 021 683 0596).

Websites

www.autismsouthafrica.org/autism%20south%20africa%20brochure.shtm

Autism South Africa (Support groups etc)

The National Autism Society: www.nas.org.uk

The Autism Research Institute: www.autism.com

www.autismspeaks.org ; www.autismsiblings.org ;
www.aspergerfoundation.org.uk ; www.autism-society.org ;
www.lifewithautism.co.uk

<http://www.strengthforcaring.com/daily-care/caring-for-someone-with-autism/Reflections-from-adult-siblings-who-have-a-brother-or-sister-with-an-autism-spectrum-disorder/>

www.nas.org.uk/nas/lsp/polopoly_lsp?d+235&a=10631