THE ATTITUDES OF TYPICALLY DEVELOPING ADOLESCENTS TOWARDS THEIR SIBLINGS WITH AUTISM SPECTRUM DISORDER

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Abstract

Sibling relationships are amongst the most influential relationships in one's life. Bringing autism spectrum disorder (ASD) into these interactional dynamics has a marked influence on these relationships for both the sibling with ASD and the typically developing siblings. The main aim of this study was to investigate how typically developing adolescents describe their present attitudes towards their sibling with ASD, compared to their attitudes when they were younger. Thirty typically developing adolescents who have siblings with ASD were selected to complete the survey instrument, namely the Modified Lifespan Sibling Relationship Scale (MLSRS). The survey instrument operated on the conceptualisation of attitudes as consisting of three components: affective, cognitive and behavioural. The results indicated that the majority of adolescents have very strong positive feelings towards their sibling (affective component), both at the time of the research and when they were younger. Their beliefs about their siblings and their relationship with them (cognitive component) have become more positive as they became older. Their actual interaction (behavioural component) was, however, found to be significantly lower than their feelings towards their siblings (both as adolescents and as younger children) and their beliefs about their relationships as adolescents. This study highlighted the need for children who develop typically to be taught how to interact effectively with their sibling with ASD and the need for siblings to be provided with age appropriate information about their sibling's disorder. The results also indicate that although most of the children seemed to be coping well with the extra demands placed on them they would nevertheless still be able to benefit from support groups for siblings of children with ASD.

KEY WORDS

- Adolescence
- Attitudes
- Autism spectrum disorder (ASD)
- Intervention
- Relationships
- Siblings
- Typically Developing Children

OPSOMMING

Die verhoudings tussen sibbe is van die belangrikste verhoudings in 'n mens se lewe. Wanneer outisme spektrum versteuring (OSV) tot hierdie interaksionele dinamika toetree, het dit 'n beduidende effek op hierdie verhoudings, vir beide die sibbe met OSV en vir die sibbe wat tipies ontwikkel. Die doel van hierdie studie was om ondersoek in te stel na die wyse waarop tipies-ontwikkelende adolessente hulle huidige houding teenoor hul sibbe met OSV beskryf, in vergelyking met hoe hulle hul houding teenoor hul sibbe onthou toe hulle jonger was. Dertig tipies-ontwikkelende adolessente is geselekteer om die "Modified Lifespan Sibling Relationship Scale (MLSRS)" te voltooi. Hierdie data-insamelingsinstrument konseptualiseer houdings as bestaande uit drie komponente: affektiewe, gedrags- en kognitiewe komponente. Die resultate toon dat die meederheid adolessente sterk positiewe gevoelens (affektiewe komponent) teenor hulle sibbe met OSV het, sowel in die hede as in die verlede (hoe hulle onthou dat hul teenoor hul sibbe gevoel het toe hulle jonger was). Die kognititiewe komponent (hoe hulle dink oor hul verhouding met hul sibbe) het meer positief geraak wanneer hulle huidige denke vergelyk word met hoe hulle onthou dat hul daaroor gedink het toe hulle jonger was. Hulle gedrag (gedragskomponent) teenoor hule sibbe met OSV het aansienlik laer waardes getoon as hul gevoelens teenoor hulle sibbe (beide in die hede en soos wat hulle dit onthou van toe hulle jonger was). Hierdie studie het uitgelig hoe nodig dit is om tipies-ontwikkelende adolessente te leer hoe om effektiewe interaksie met hulle sibbe te fassiliteer, asook hoe belangrik dit is om vir hulle ouderdomtoepaslike inligting oor hul sibbe se versteuring te gee. Die resultate dui ook daarop dat, alhoewel baie van hierdie adolessente goed reageer op die addisionele eise wat aan hulle gestel word, ondersteuningsgroepe vir sibbe van kinders met OSV vir hulle voordelig sal wees.

SLEUTEL WOORDE

- Houdings
- Adolessensie
- Outisme spektrum versteuring
- Sibbe
- Intervensie
- Tipies-ontwikkelende kinders
- Verhoudings

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Chapter 1

Introduction to the study

1.1 Introduction

This chapter presents a brief overview of the study. The subject of the study is introduced and a rationale for pursuing this line of research is provided. It also includes outlines of the content of each chapter, a definition of relevant concepts and a list of abbreviations that are used throughout this dissertation.

1.2 Problem statement and rationale

Research to date has indicated that the presence of autism spectrum disorder (ASD) has far-reaching effects on families (Macks & Reeve, 2007; Meadon, Stoner, & Angell, 2009; Smith & Elder, 2010; Twoy, Connolly, & Novak, 2007). Since the majority of the studies have tended to focus on the parents' relationship with their child with ASD, the current study aims to increase understanding of the relationship between siblings. There are three main reasons why these relationships are the focus of this study.

Firstly, very little attention has been paid to the empirical study of sibling relationships, even though these are life-long and very influential relationships. The literature that has emerged on these relationships offers contradictory findings on the impact of ASD on siblings. Amidst the increasing prevalence of ASD, the complexity of its presentation and its impact on family systems seems to necessitate a closer look at its effect on siblings and to intervene when necessary (Smith & Elder, 2010).

Secondly, from the empirical studies that have been conducted, it appears that there is a large need for support for these siblings. Benderix and Sivberg (2007) qualitative study on the experiences of 14 siblings from five families indicated that these siblings tended to experience (among others feelings) a strong sense of precocious responsibility. It must be kept in mind that, although people with ASD have different levels of functioning, most have a normal lifespan. This means that their siblings will probably have to take over responsibility for their special needs beyond their parents' lifetime (Davys, Mitchell, & Haigh, 2010; Smith & Elder, 2010).

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Thirdly, from the literature review, it has become apparent that siblings are valuable resources for assisting children with ASD to learn various skills. Not only do they serve as excellent role models for a child with ASD, but there are some indications that when typically developing children were involved in helping to manage and teach siblings with developmental problems, it resulted in fewer behavioural problems in the siblings who develop typically (Smith & Elder, 2010).

Family systems and the interactions that sustain them are very complex; therefore this study focuses specifically on the attitudes of adolescents towards their siblings. Attitudes are important, since they have a significant influence on behaviour. The more positive adolescents are towards his/her sibling with ASD, the more likely they will be to engage with such a sibling. This will benefit the children who develop typically—since they will experience their relationship more positively. Furthermore, the child with ASD will benefit by being exposed to a better role model for a variety of life skills.

The group being studied was narrowed down to adolescents, firstly because one of the flaws that was pointed out in previous studies as a possible contributor to the contradictory findings, was the inclusion of participants at different stages of life. Secondly, adolescence tends to be a very interesting life stage due to the emotional turmoil experienced by many adolescents as they search for personal identity, which could possibly complicate the affect ASD may have on family interactions (Opperman & Alant, 2003).

Although this study covers a very small aspect of relationships, it is hoped that the outcomes will help pave the way for evidence-based intervention strategies that will help children cope with the stress of having a sibling with ASD. At the same time it may provide them with the skills to become purposeful agents in the intervention process aimed at their sibling with ASD.

1.3   Chapter outlines

Chapter 1 provides an introduction to the study, the problem statement and an outline of the chapters to follow. Important terms are explained and a list of abbreviations used in the study is provided.

Chapter 2 provides a detailed discussion of the theoretical background to the study. It reviews current knowledge of autism spectrum disorder and the effect it has on family relationships. It also expands on what the concept attitudes entails and on

the meaning of adolescence as a phase of life. Relevant research on these concepts are critically discussed and pertinent issues in the current literature are highlighted.

Chapter 3 presents the research methodology that was used in the study. The aims of the study are described as well as the research design, participant selection, participants, development of material, data collection procedures, results of the pilot study, data analysis procedures and ethical considerations.

Chapter 4 presents the results of the study in relation to the sub aims stated in Chapter 3 as well as a critical discussion of these results.

Chapter 5 provides a summary of the study and also contains a critical evaluation of the study. Furthermore, the strengths and weaknesses of the study are discussed. Recommendations for future research conclude this study.

1.4   Definition of terms used in the study

Adolescence

According the American Psychological Association (APA) (Campbell & Gentry, 2002), adolescence refers to the period following the onset of puberty and before young people reach adulthood. This period may start from as early as 10 years of age and is normally completed between the ages of 18 and 20. For the purpose of this study, individuals from 13 to 20 were used. This was to ensure that the participants have reached puberty. Since the study measures the attitudes adolescents' as well as the attitudes that they remembered to have had before they reached puberty, it was important that they were old enough for there to be a significant difference in development between these two life phases.

Attitudes

According to Oppenheim (1998), attitudes reflect a readiness or tendency to respond to a given stimuli in a certain way. Underlying these tendencies are beliefs (the cognitive component) that often elicit very strong feelings (affective component). Together, these result in specific actions being taken (behavioural component) (Oppenheim, 1998). For the purpose of this study, 'attitude' refers to the attitudes held by neurotypical adolescents towards their sibling with autism spectrum disorder. This study also specifically aimed to look at how these attitudes might have changed from those held when they were younger.

Autism spectrum disorder

Autism spectrum disorder is a pervasive developmental disorder with certain key features, namely: social impairments, communication difficulties and repetitive, rigid behaviours or interests (RRBI's). These are often referred to as the triad of impairments (American Psychiatric Association, 2013). For the diagnosis of ASD to be made these symptoms need to be present from early childhood and have a significant impact on the individual's ability to function in everyday situations (American Psychiatric Association, 2013). This research aimed to explore the effects that these characteristics of ASD would have on family relationships, specifically on sibling interactions.

Siblings

Siblings refer to the brothers and sisters within a family system. Generally, these would be the people with whom one would share the closest genetic, family, and social status; and constitutes one of the most enduring relationships most people have (Bemister, 2012). It is also one of the most influential relationships and generally allows for more interactions than that which children have with their parents (Bemister, 2012). This study focuses on sibling interactions due to the influential nature of these relationships. Although siblings generally spend a great deal of time together, there is much variability in the extent to which brothers and sisters get along with each other. Additional stressors in a family may influence family dynamics either positively or negatively (Bemister, 2012; Tremaine, 2011). The focus of this study is to explore how ASD would influence adolescent attitudes towards their sibling relationships in order to help improve these relationships to the benefit of both the sibling who is developing typically, and the sibling with ASD.

Typically development

Children, who reach their developmental milestones within the parameters and norms as determined through the use of developmental checklists or formal measuring instruments, are referred to as children who develop typically (Owens, 2000). For the purpose of this study, this would refer to siblings who have not been diagnosed as being on the autism spectrum.

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1.5   Abbreviations

AA	Adult affect
AB	Adult behaviour
AC	Adult cognition
AAC	Alternative and augmentative communication
ASD	Autism spectrum disorder
CA	Child affect
CB	Child behaviour
CC	Child cognition
DSM	*Diagnostic and Statistical Manual of Mental Disorders*
DSP	Developmental social-pragmatic
GDE	Gauteng Department of Education
LSRS	Lifespan Sibling Relationship Scale
MLSRS	Modified Lifespan Sibling Relationship Scale
RRBI	Rigid and repetitive behaviours or interests
WCED	Western Cape Education Department

1.6   Summary

This chapter presents a summary of the rationale for this study. It provides a list of relevant definitions pertaining to the study. A brief outline of the structure and content of the chapters in the dissertation is presented.

Chapter 2

Literature review

2.1 Introduction

This chapter provides an overview of the literature that is relevant to the attitudes that adolescents who develop typically hold towards their sibling with ASD. The focus of the literature review is on the dynamics of the sibling relationship within the family system and the impact autism has on these relationships. To explore these aspects, an overview of the dynamics of autism as a developmental disorder is presented and its impact on family dynamic is explored. The role siblings may have in intervention strategies are investigated and the effects of attitudes and lifespan on sibling interactions are discussed.

2.2 Introduction to the research topic

Throughout one's lifetime, many opportunities arise for developing various relationships. One's family cannot be chosen, yet family relationships could have the most far-reaching influence on how one develops as a person. Notable amongst these, are the relationships between siblings. These relationships form a very complex sub system of the family system and this relationship is normally the second strongest bond a child forms after that with their parents (Kösea & Demirizb, 2009, Opperman, & Alant, 2003). Not only can it be a lifelong relationship, but it also plays an important role in child development and provides a rich resource for developing effective social skills, which may subsequently be transferred outside the family system (Aksoy & Yilidrim, 2008; Baker, 2000; Brody, 2004; Kim & Horn, 2010; Knott, Lewis, & Williams, 2007; Mandleco, Olsen, Dyches, & Marshall, 2003; Riggio, 2000; Tsao & Odom, 2006).

The addition of a child with a disability, especially a child with ASD, into the family system has a definite impact on the structure and functioning of the family. It can be expected to influence not only the childhood experience, but also the development of the individual siblings (Aksoy & Yilidrim, 2008; Higgins, Bailey & Pearce, 2005; Kaminsky & Dewey, 2003; Kim & Horn, 2010; Linnell, 2012; Orsmond & Selzer, 2007; Mandleco, et al, 2003; Recchia & Howe, 2009; Rivers & Stoneman, 2008). Significant adjustments will necessarily, have to be made in the

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family system in order for the family to cope and continue to function adequately (Altiere & Von Kluge, 2009, Beck & Dennis, 1996).

Quintero and McIntyre (2010) discussed how the roles of children within a family system changed with the introduction of a sibling with ASD. The siblings who develop typically usually receive less attention, often have greater responsibility placed on them and their parents may have higher expectations from them. Yet, at the same time, they have to deal with this in a context where parents are experiencing greater amounts of stress and depression. Added to this is the anticipation that the siblings will probably have to take over their parents' caregiving role at some point in the future. The expectation, therefore, is that they would have severe adjustment problems although the literature seems to indicate the contrary (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009; Quintero & McIntyre, 2010; Tanaka, Uchiyama, & Endo, 2011).

2.3   Background to ASD

To understand the impact of ASD on a family system fully, it is important to have a comprehensive understanding of the difficulties presented by autism. The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines autism as a pervasive developmental disorder with certain key features, namely: social impairments, communication difficulties and repetitive, rigid behaviours or interests (RRBI's). Besides this triad of impairments that are central to diagnosis, individuals with ASD may experience many other difficulties. For example, increasing research has been conducted on difficulties in the sensory processing experienced by individuals with ASD (Kern, Garvey, Carmody, Andres, Mehta & Trivedi, 2008; Hochhauser & Engel-Yeger, 2010). The disruptions caused by sensory behaviours often lead to families being less able to participate in family or leisure activities (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). This is often complicated by the fact that it is not always externally obvious that someone has autism. People have less patience with a 13-year old throwing a tantrum in a shopping centre due to sensory overload than they would with a 2-year-old (Higgins, Bailey & Pearce, 2005).

The combination of these factors results in behaviour that may be very stressful on a family (Altiere & Von Kluge, 2009; Higgins, et al., 2005). Disturbed sleeping patterns, tantrums, self-injury, difficulties with toilet training, fussy eating,

wandering, epileptic seizures and lack of emotional reciprocity, are all behaviours that are commonly observed in children with ASD (Cappe, Wolff, Bobet, & Adrien, 2011; Higgins, et al., 2005). These behaviours call for more input and support from parents, which in turn leads to less time being available for their siblings (Higgins, et al., 2005). Added to this, role reversal is also a common occurrence, with younger siblings who develop typically often having to take on what would traditionally be seen as the responsibilities of older siblings (Higgins, et al., 2005).

Originally, ASD was estimated to occur in 4 to 5 children per 10 000, but the incidence of autism has now escalated dramatically to one in 88, according to the latest statistics in the United States (Baio, 2012) and in 1 in 64 in the United Kingdom (Ratajczak, 2011). Recently, the first comprehensive prevalence study on ASD was conducted in South Korea. The international team inferred an incidence of 1 in 38 (Kim et al, 2011). Although there is no clear published statistics for South Africa, Autism Western Cape estimates that a prevalence rate of 1 in 110 is a safe assumption (Autism Western Cape, 2013). Most of these cases are male, since ASD has 4:1 (male:female) ratio (Ratajczak, 2011).

On the continuum of ASD there is a wide variety of severity of symptoms. For example, the one end of the spectrum represents individuals who are nonverbal with significant co-morbid disorders, while the other represents individuals who are relatively autonomous with remarkable splinter skills (Cappe, et al., 2011).

In addition to the stressful symptoms that autism spectrum disorders present, the entire process of having a child diagnosed and receiving appropriate help and support tends to be a lengthy and stressful affair for the entire family system (Lancaster, 2005; Rutter, 2011). Parents often find this time of struggling for an official diagnosis very confusing (Altiere & Von Kluge, 2009). Even though it has been almost 70 years since Kanner (1943) originally described autism, there is still much debate about the aetiology of the disorder (Cappe, et al., 2011; Lancaster, 2005; Rutter, 2011). Since there still is no reliable bio marker for autism, physicians often find it difficult to detect the often subtle signs of autism and to differentiate these from other mental health diagnoses such as selective mutism, attention-deficit hyperactivity disorder, severe intellectual disability, stereotyped movement disorder, etc. (Lancaster, 2005; Ratajczak, 2011).

Once the diagnosis is made, parents have to deal not only with the reality of the severity and pervasiveness of the disorder (for example, it was estimated by

Ratajczak, (2011) that 75% of individuals with ASD are unable to live independently as adults or are institutionalised). Additionally, the parents also have to make complicated decisions surrounding issues such as appropriate treatment plans and finding placement in schools catering to the complex needs that children with ASD have (Altiere & Von Kluge, 2009). Unfortunately, there still are not many autism-specific services available in South Africa and therefore a long time may elapse before assitance is available. This is particularly tragic if one considers the positive impact that early intervention has proven to have on the developmental outcomes of children with autism (Rutter, 2011). Higgins, et al. (2005), cited the lack of support from health care providers and other social services as one of the top three aspects that place stress on a family when raising a child with autism. The remaining two are the permanency of the condition and the societal attitudes towards autistic behaviour.

2.4   Aspects of ASD

2.4.1   Communication in ASD

As mentioned above, communication impairment is one of the defining features of autism and is considered by many to be one of the most debilitating sets of symptoms in ASD (Chiang, 2009; Matson, Kozlowski, & Matson, 2012). When one sibling has autism, there is a good chance of troubled interactions because their difficulties in communication often lead them to use aggressive behaviour to achieve the goals that are normally achieved through speech (Barry & Singer, 2001). In fact, research has shown that communication deficits have a strong impact on relationships among family members (Chiang, 2009).

At varying levels, delayed development of functional speech and language is present in all people with autism (Halle & Meadan, 2007). According to Carr and Felce (2007), up to 80% of children with ASD are estimated to enter the educational system (age 5 years or younger) with very limited functional language. About 33% to 50% of people with ASD never develop speech (Halle & Meadan, 2007; Tincani, 2004; Preston & Carter, 2009). Although some individuals have no speech at all; others will talk almost non-stop, but their speech is either self-stimulatory or echolalic, serving no function in regular communication (Carr & Felce, 2007, Preston & Carter, 2009).

Communication plays a pivotal role in enhancing social engagement and overall adjustment. Additionally, deficiencies in communication have also been

linked to other problems such as aggression (Hattier & Matson, 2012; Matson, et al., 2012). As mentioned earlier, it has been suggested that the challenging behaviour that individuals with ASD display is due to a breakdown in communication. Often individuals with ASD will use unconventional and idiosyncratic nonverbal behaviour for requesting or rejecting objects and/or actions when their expressive language is limited. These messages tend to be difficult to understand, leading to increased frustration and lack of understanding (Halle & Meadon, 2007).

Language disorders associated with autism include echolalia, the inversion of pronouns and idiosyncratic vocal expressions (Blanc, Roux & Barthélémy, 2005). Individuals with this disorder generally seem to have difficulty conforming to the rules that govern conversations and seem to lack the understanding that communication should not always be taken literally. Communication is rather about intended meaning. This difficulty in higher functioning autism to understand non-literal speech such as metaphors or jokes leads to very concrete and rigid language use (Noens & van Berckelaer-Onnes, 2004). Such persons often tend to become preoccupied with severely restricted topics and will talk in excessive detail, not allowing appropriate turn taking. They will often perseverate on preferred topics, finding it hard to disengage once started (Lam & Yeung, 2012).

Some studies have indicated that it is more often difficulties in receptive language rather than in expressive language that lead to aberrant behaviour (Noens & van Berckelaer-Onnes, 2004). Since receptive language is often overestimated in children with autism, they are often expected to understand instructions out of a familiar context and are consequently at a loss as to what is expected of them (Noens & Van Berckelaer-Onnes, 2004).

It has been suggested that the differences in communication problems experienced by high functioning and low functioning autism are not only quantitative but also qualitative in nature. With Asperger's syndrome or high functioning autism, language problems are of a more qualitative nature (Matson, et al., 2012). In fact, individuals with Asperger's syndrome may have very little impairment in the structures of speech, whereas reciprocal speech, appropriate turn taking, politeness, discussing relevant topics in context with others and understanding figures of speech are frequently tripped over (Matson, et al., 2012). It has, however, been suggested that regardless of the level of functioning, both qualitative and quantitative deficits

that underlie communication are problems with joint attention and symbol formation (Halle & Meadan, 2007).

2.4.2. Social interaction in ASD

In addition to the above, communication difficulties, impairments in social interaction and imagination result in children with autism generally not interacting very well with either their siblings or peers and not easily initiating play (Baker, 2000; Kim & Horn, 2010; Yang, Wolfberg, Wu, & Hwu, 2003). Rutter (2011) identified the following three social impairments as being the most explicit in ASD: difficulties in playing cooperatively, inability to recognise the feelings of others and failure to form friendships. These difficulties are perpetuated by the pervasive symptoms of ASD such as poor eye contact, the presence of odd mannerisms and speech, as well as difficulties to orientate themselves to social stimuli (Matson, Matson, & Rivet, 2007; Weiss & Harris, 2001).

Often children with ASD have a desire for social interaction but lack the ability to do so. In a study by Humphrey and Symes (2011) they found that students with high functioning autism were more solitary than their peers. They spent less time in social interaction, showed fewer positive interaction behaviours such as smiling or making eye contact, engaged in less rough play and reacted more aggressively to their peers. Because of these isolating behaviours, the children do not have many opportunities to develop the skills they need to improve their communication and social abilities (Humphrey & Symes, 2011).

2.5   Intervention strategies in ASD

2.5.1   Theories about the causes of ASD and approaches to treatment

Although the causes of ASD are still unclear, there are several theories as to the underlying neurobiology of the symptoms. The three most widely researched are theory of mind, executive functioning, and central coherence (Noens & Van Berckelaer-Onnes, 2004). Since no one theory seems to be able to explain all the features of ASD, more research is now being conducted to see how these theories may work together (South, Ozonoff, & McMahon, 2007). Increasing our understanding of how the core behaviours of autism that are necessary for diagnosis are related to

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secondary symptoms such as sensory difficulties, may assist in formulating a comprehensive theory in this regard (South, et al. 2007).

Of the three theories mentioned above, the 'theory of mind' is the most researched (Lam & Yeung, 2012). 'Theory of mind' refers to one's ability to infer the mental states of other people. If one does not have the ability to understand that other people have a mind separate from your own, it becomes difficult to structure a conversation (Beaumont & Newcombe, 2006; Hale & Tager-Flusberg, 2005). Problems with theory of mind would explain people with ASD's difficulty in understanding the concept of communication as well as the very candid or tactless comments often associated with people with autism (Lam & Yeung, 2012; Noens & Van Berckelaer-Onnes, 2004).

Although not as widely researched as theory of mind, other studies have looked at the effect of impairments in executive functioning that are evident in people with ASD. Aspects of executive functioning that seems to have the most influence on a child's ability to participate in society include the ability to resist impulsivity, the ability to stop behaviour when inappropriate and the ability to regulate emotional responses (Zingerevich & LaVesser, 2009). Lam and Yeung (2012) mentioned that the ability to plan, to inhibit behaviours and cognitive flexibility (which is dependent on executive functioning) are essential for a grasp on the pragmatics of communication.

The last theory that attempts to explain many of the ASD symptoms is that people with this disorder have weak central coherence. This theory hypothesises that neurotypical individuals have a drive to integrate details into a coherent whole enabling information to be processed within the context. Individuals with autism, on the other hand, become so absorbed by details that they often miss the bigger picture or context (Beaumont & Newcombe, 2006; Hoy, Hatton, & Hare, 2004; Lam & Yeung, 2012). Consequently they tend to focus on parts of objects, obsess over minor details and are extremely sensitive towards changes in the environment due to this inability to process information into a global entity (Beaumont & Newcombe, 2006; Hoy, Hatton, & Hare, 2004; South, et al., 2007)

As stated above, none of these theories explain all the features of autism (Beaumont & Newcombe, 2006; Hoy, Hatton, & Hare, 2004; South, et al., 2007). Thus although, for example, theory of mind explains the triad of impairments, it does not explain their scattered IQ profiles, perseveration, repetitive behaviours,

preoccupation with details and circumscribed interests (Beaumont & Newcombe, 2006). Executive functioning and central coherence, on the other hand, provide hypotheses that would predict repetitive behaviours (Hoy, et al., 2004; South, et al., 2007)

The lack of certainty surrounding the biological or neurological aetiology of autism makes choosing a treatment option a complex decision (Lancaster, 2005). Since very little reliable information is available regarding the physiology that results in autistic functioning, a demand for non-pharmaceutically based treatments has come into existence (Lancaster, 2005). These include sensory integration, brushing and a variety of speciality diets. Unfortunately, the need for treatment has created a plethora of treatments on the market, founded on theories that were not validated and often outrageous and unsubstantiated claims (Lancaster, 2005).

Behavioural approaches have traditionally been the most popular, successful and empirically valid treatments available (Chiang, 2009; Lancaster, 2005). A possible reason for its success is that each of the symptoms displayed by the child is conceptualised as individual behaviours. For example, in the areas of social interaction and communication one would look at joint attention and target this ability (Casenheiser, Shanker, & Stieben, 2011). This allows for the implementation of strategies that target the problem behaviours and not allow the lack of understanding of the aetiological source of the behaviour to stand in the way of treatment (Casenheiser, et al., 2011; Lancaster, 2005).

Recently, these more traditional behavioural approaches have made way for more contemporary and social pragmatic approaches often called developmental social pragmatic (DSP) interventions. These interventions seek to firstly teach the functional skills in sequences that fall in line with typical child development and secondly, instead of focusing on the individual behaviours themselves, these approaches aim to teach the skills needed for social communication in pragmatically appropriate social contexts (Casenheiser, et al., 2011). These approaches attempt to elicit communication within everyday contexts, using the child's attempts at initiation to motivate events and activities (Keen, Rodger, Doussin, & Brauthwaite, 2007). The benefit of these approaches in comparison to behavioural approaches are, for example, that children with ASD will often produce unanalysed chunks of communication as part of a cued response. Applying a DSP approach encourages the stimulation of actual communication competence (Noens & Van Berckelaer-Onnes,

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2004). Delprato (in Noens & van Berckelaer-Onnes, 2004) found that pragmatically appropriate training benefitted the generalisation of skills better than the discrete trail training of the behavioural models. He also found that parents preferred these types of training as opposed to discrete trail training. The idea behind intervention would therefore be to keep targeted outcomes as meaningful as possible (Ogletree, 2007).

For lower functioning individuals with autism, especially, these approaches all rely heavily on the use of prompts to encourage the desired behaviours (Chiang, 2009). Developing expressive communication (especially for it to be spontaneous) may be very challenging and much input is needed to facilitate communication development in children with severe autism (Chiang, 2009). Many practitioners feel that for these approaches to be successful, the child's primary social partners should be the primary facilitators of the child's communication and language development (Keen, Rodger, Doussin, & Braithwaite, 2007).

The need to train children with severe ASD to use an augmentative or alternative form of communication (AAC) in order provide them with a functional communication system is well recognised (Carr & Felce, 2007; Matson, et al., 2012; Bondy & Frost, 2001; Tincani, 2004). Higher functioning children, however, often need the support of social stories or scripts to support their social for interaction. For children who develop little or no speech, the two most promising AAC systems are sign systems such as Makaton and the Picture Exchange Communication System (PECS) (Bondy & Frost, 2001; Tincani, 2004; Travis & Geiger, 2010; Yoder & Lieberman, 2010). Since many children with autism will not initiate communication, whether spoken or augmentative, it is of importance that, whichever approach is chosen, that system be taught in such a way that prompt dependency is avoided and spontaneous communication is promoted (Carr & Felce, 2007; Matson, et al., 2012).

2.5.2   Siblings as role players in intervention

Various studies indicated that peer-mediated approaches are one of the most effective interventions for developing both social interaction and communication (Jones & Schwartz, 2004; Locke, Rotheram-Fuller & Kasari, 2012; Oppenheim-Leaf, Leaf, Dozier, Sheldon, & Sherman, 2012). Jones and Schwartz (2004) however, point out that although peer modelling is effective, it is not always possible to include children with ASD in a mainstream setting. This is especially true of children who are lower

functioning. The efficiency of this model is also questioned, since it may be very labour intensive to train peers to be effective models, because adult intervention is often necessary to drive this process (Jones and Schwartz, 2004)

The suggestion is therefore that siblings would make effective models since such a setup would allow for many interactions in the home environment over a long period of time (Jones & Schwartz, 2004). Siblings are also more familiar with a sibling with ASD, which seems to be one of the factors implicit in a good peer model. The nature of the relationship is, however, very important. If the individual does not harbour positive feelings towards their sibling with ASD, he/she will not be an effective model. In the same study by Jones and Schwartz (2004), they also reported that siblings were not necessarily more effective models than peers, but they definitely formed stronger models than adults did. Tsao and Odom (2006) found that when siblings were trained to engage their sibling with ASD, it resulted in positive changes in joint attention and social behaviour. They have also indicated that siblings provide a valuable resource for teaching functional skills in real world settings (Tsao & Odom, 2006). Some researchers argue that older siblings would be the most influential in their sibling with ASD's language and social development by providing a model for these skills. Studies point to a difference in younger versus older sibling relationships. It seems that older female siblings made the most effective instructors (Brewton, Nowell, Lasala, & Goin-Kochel, 2012).

Early social development usually starts with sibling interaction (Baker, 2000). These interactions play an important role in a child's social life, whether they have autism or not and are deemed to be a pivotal source for developing relationship skills. Through their interactions with each other they learn many social skills such as sharing and compromise (Jones & Schwartz, 2004; Kresak, Gallagher, & Rhodes, 2009). Siblings often have the ability to elicit positive behaviours that others are not able to do (Kresak, et al., 2009). There is some indication that sibling interaction can provide a rich source of experience that helps build a theory of mind in children with autism (Perner, Ruffman & Leekman, 1994).

Siblings may be a valuable resource in improving the communication skills referred to above. Social understanding increases with exposure to a variety of social experiences; peer reciprocity is an essential part of developing social relationships, serving a variety of social functions (Weiss & Harris, 2001). For children to engage in reciprocal social exchange they need to exchange social interactions; their actions

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need to support each other and their actions need to become similar to each other's (Weiss & Harris, 2001). It is therefore very important that children with autism learn to use these skills and generalise them to other contexts (Weiss & Harris, 2001). However, without intervention children with autism are at risk of exclusion from their peer group and full participation in society (Yang, et al., 2003). Encouraging social interaction between siblings may provide a rich resource for teaching these skills (Baker, 2000; Brewton, et al., 2012; Brody, 2004; Kim & Horn, 2010; Knott, et al., 2007; Tsao & Odom, 2006). An added bonus may be that social skills are more likely to be generalised to social interactions with peers than adult intervention would be (Oppenheimen-Leaf, et al., 2012).

Unfortunately, the difficulties that are present in ASD may result in frustration for siblings who develop typically, since their attempts at interaction may fail regularly, leading to reduced positive daily learning opportunities (Baker, 2000). However, deficits in social interaction present such a challenge in intervention for children with autism, that these aspects cannot be ignored. The consensus is that social interaction should be central to any treatment programme for a child with autism. Although progress is being made with much research having been done in the last decade, there is still much to be learned to guide evidence-based remediation for social interaction (Matson, et al., 2007; Weiss & Harris, 2001).

As mentioned earlier, the inability to communicate makes it difficult to learn how to engage appropriately during social interaction (Hattier & Matson, 2012). In turn, problems with socialisation tend to isolate children, which may be detrimental to an individual's quality of life (Hattier & Matson, 2012). Early language difficulties have been linked to difficulties with social interaction and the formation of peer relationships of quality in adolescence (Laws, Bates, Feuerstein, Mason-Apps, & White, 2012). An interesting observation made in a study by Law et al. (2012) is that children's rejection by their peers correlated to their communication abilities as rated by familiar adults.

2.6   The effect of ASD on sibling relationships

The family is an important part of any child's environment and plays a vital role in their developmental outcomes (Altiere & Von Kluge, 2009). Families with a child with autism get pulled into a vicious circle. The family benefits from support through interaction with family members and friends, yet in spite of this, due to the

stresses a child with autism places on a family, these families tend to withdraw from or lack the time for engagement in these supportive social activities. The siblings that develop typically are also affected, in that they tend to have far less opportunity for extra-mural activities than their age related peers (Altiere & Von Kluge, 2009). Interestingly, and probably because of this, Altiere and Von Kluge (2009) found that families with an enmeshed interaction style were better able to cope in these stressful situations than those families with other cohesion styles. It would seem that disengaged families find it harder to develop positive coping strategies.

Endeavouring to involve siblings who develop typically in the intervention process would require knowledge of the impact of ASD on them. From a family systems point of view, all members are affected by having a child with a disability as a member of the family (Mandleco et al., 2003). Typical sibling relationships will therefore differ when disability is introduced into the family system. For example, siblings are often expected to take on roles as caregiver or helper to the child. Interestingly, literature indicates that families enduring these kinds of stressors often adapt successfully, indicating that such stressors need not be seen as detrimental to family functioning. Factors that may influence the ability to cope with extra demands being placed on a family are family cohesion, locus of control, and the marital and family conflict (Mandleco et al., 2003).

The Resiliency Model of Family Stress, Adjustment, and Adaptation looks at how families of children with chronic illness or disability adapt in these situations and may explain the positive adaption shown in many of these studies (Mandleco et al., 2003).

> *"The model highlights strengths and abilities that influence resilience and is based on the assumptions that families raising a child with special needs or disabilities (a) face hardships, (b) develop basic strengths and capabilities that foster growth and development and protect individuals and families from disruptions, and (c) benefit from and contribute to relationships and resources within the community. Specifically, the model examines the relationships among (a) appraisal, schema and meanings, (b) problem solving and coping, (c) family types and patterns of family functioning, and (d) resources and social support in the adjustment and adaptation to family stress over time* (Mandleco et al., 2003, p 367).

Other factors that appear to influence how ASD is experienced include perceived parental attitudes, the family structure, gender of the siblings, socioeconomic status, the type and severity of the sibling's disability and the children's individual personalities (Aksoy & Yilidrim, 2008; Tanaka, Uchiyama, & Endo, 2011). Knowledge and understanding of the disorder and social support (which decreases parental stress and in turn has an effect on the attitudes of the siblings) also has an influence (Opperman & Alant, 2003; Tanaka, Uchiyama, & Endo, 2011). The literature indicates that the better informed children are, the better they are at developing coping processes (Opperman & Alant, 2003). The type and severity of the disability also has a major effect, though disability type seems to determine more than the severity of the disability (Aksoy & Yilidrim, 2008). The more visible and easier to understand the disorder is, the closer the relationships between siblings tend to be.

Due to the complexity of ASD and the related behaviours, its effect cannot be compared to other disabilities (Petalas, et al., 2009; Quintero & McIntyre, 2010; Tanaka, et al., 2011). Studies indicate that, when compared to other disabilities, autism seems to pose more challenges to the development of positive sibling relationships (Petalas, et al., 2009; Quintero & McIntyre, 2010; Tanaka, et al., 2011). With most disabilities children report playing more with their sibling with disability than with typically developing siblings; however, in autism, the reverse has often found to be true with children spending less time interacting with their sibling with autism than those children who have typical siblings or siblings with Down syndrome (Stoneman, 2001). Some studies have also shown higher levels of depression in siblings of children with autism (Petalas, et al., 2009; Quintero & McIntyre, 2010).

On the other hand, many researchers have not found any increased risk for negative adjustment for these siblings (Petalas et al. 2009; Quintero & McIntyre, 2010). In fact, some studies on the sibling interaction between children with ASD and children who develop neurotypically seems to indicate that sibling relationships can be mutually beneficial and positive (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Kaminsky & Dewey, 2003).

Benson and Karlof (2008) suggested that these mixed results may be explained by the genetic vulnerability of siblings with autism that has not always been taken into account. This is often referred as the broader autism phenotype (Rutter, 2011). If the siblings have sub-threshold autism characteristics, they might find it harder to cope with the stress of having a child with autism in the household. Many of the studies

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also did not focus on a specific developmental age, but included children in a variety of life stages (Orsmond & Selzer, 2007; Orsmond, Kuo & Selzer, 2009).

Huff (2006) also noted that, generally, it is the older studies that account for the more negative reports concerning self-concept specifically in siblings of children with disabilities. The more recent research tend to report more positive self-concepts when compared to siblings who develop typically. This could be due to a society that is more aware and accepting of disabilities. In autism especially, much research has been done to understand autism and how best to intervene; increased knowledge and improvement in service delivery could make it easier for parents to move through diagnosis to an appropriate treatment programme faster than they would have a decade ago (Huff, 2006).

The amount of knowledge the siblings had about autism and support might have influenced the results as well. Aksoy and Yilidrin (2008) posited that it was the invisibility of autism that seemed to make it harder for siblings to understand what they were dealing with, to explain it to others and to come up with effective coping strategies. Added to the fact that autism is particularly difficult to explain in concrete terms, the siblings also have to deal with unexpected behaviour at all times (Aksoy & Yilidrim, 2008).

Studies have shown that social skills taught to children with ASD in a preschool setting were generalised to interaction with their siblings at home. The increase in skills leads to better sibling interaction (Cassidy, Fineberg, Brown, & Perkins, 2005). Interventions targeted at teaching the sibling interaction also helped increase sibling interaction and communication. Early positive interaction seems to be predictive of closer, more supportive relationships in adulthood. Early intervention when sibling relationships are troubled may help promote more positive lifelong relationships (Barry & Singer, 2001). The siblings who developed typically and participated in this study reported decreased frustration and increased comfort in interacting with their siblings after learning how to use initiation strategies, prompts and praise in their interactions with their siblings (Cassidy, Fineberg, Brown, & Perkins, 2005).

2.7 The effect of attitudes on sibling relationships

To develop effective intervention strategies, a clear idea of the influence of ASD on interaction in the sibling subsystem is needed. There are so many facets to interaction that this study focuses specifically on the attitudes of children towards their sibling with autism. Attitudes are postulated to drive behaviour and the literature indicates that many obstacles that people with disabilities face are due to societal attitudes (Beck, Thompson, Kosuwan, & Prochnow, 2010; Findler, Vilchinsky, & Werner, 2007; Seitz, Lord, & Taylor, 2007). Research has indicated that if children have a positive attitude towards children with disabilities they are more likely to interact with these children (Dyson, 2005; Findler, et al., 2007; Chew, Jenson, Rosén, 2009; Law, Sinclair, & Fraser, 2007). These studies also indicate that an understanding of children's knowledge of and attitude towards other children with disabilities are important if interaction is to be encouraged. Assessing children's attitudes towards their sibling with autism may therefore provide important information in designing interventions that are aimed at improving attitudes and behaviour towards children with autism, as well as encouraging positive relationships that may be mutually beneficial (Lobst, Nabors, Rosenzweig, Srivorakiat, Champlin, Campbell, & Segall, 2009). It is hoped that this may pave the way for designing effective strategies to promote the well-being of the family system as a whole and will help siblings to adjust and develop optimal social relationships (Opperman & Alant, 2003).

Attitudes are said to comprise a range of feelings, either favourable or unfavourable, toward an object, a person, an issue or behaviour. These are learnt either through direct experience or through received information (Walker & Heere, 2010). Although there is still no universally accepted definition, most researchers agree that attitudes may be described as consisting of three components: affective, cognitive and behavioural (Beck, et al., 2010; Findler, et al., 2007; Kline, 1993; Malhotra, 2004; Seitz, Lord, & Taylor, 2007; Walker & Heere, 2010). Both the affective and cognitive components of attitude have been demonstrated to be cross-culturally applicable and therefore applicable in a South African context (Cervellon & Dubé, 2002).

The affective component refers to the feelings and emotions that a person has in relation to the attitude object. The cognitive component involves the beliefs that a person holds in terms of the positive or negative attributes of the attitude object.

These lead to the behavioural component that refers to the actions or intentions to act towards the attitude object (Seitz, et al., 2007). Behaviour can be seen as a person's displayed attitude (Friedkin, 2010).

Some researchers have found however, that there may be discrepancies between people's attitudes and their behaviour. Factors that might influence this include people's situations, their dispositions and their motivation behind certain behaviour. The strength of the relationship between attitude and behaviour is increased when there is a match between the affective and cognitive component of a person's attitude towards a specific object. Generally, people try to be consistent in their attitudes and their behaviour (Beck, et al., 2010).

Considering that people tend to interact with people with similar attitudes, similar behaviours are usually reinforced socially. From the studies mentioned above, the conclusion has been drawn that a person's attitude towards an individual will largely determine their actions towards the other individual. These will further be reinforced if the person belongs to a group that holds similar attitudes (Beck, et al., 2010).

Results of research on attitudes towards peers with communication impairments are similar to those of research on physical and intellectual disabilities—in short, not as positive as one would hope (Beck, et al., 2010). Children with ASD who have limited spoken language abilities, will often use a variety of AAC techniques to communicate, the most popular of which are picture exchange systems such as PECS (Bondy & Frost, 2001 Sulzer-Azaroff, Hoffman, Horton, Bondy, & Frost, 2009; Yoder & Lieberman, 2010). Although these may decrease a great deal of the frustration experienced by children with ASD, at the same time negative social reactions towards individuals using AAC techniques have been found to affect socialization opportunities, employment opportunities and the ability to develop a sense of psychological well-being (Beck, et al., 2010). In studies with children in Grades 1-6 it seemed that the type of AAC technique did not really influence attitudes as much as internal variables such as gender, familiarity with disabilities and age. A study by Lilienfield and Alant (2002) did however indicate that attitudes were more favourable towards AAC devices with voice output.

It has been reported that the negative attitudes of elementary and middle school students towards unfamiliar children with autism may be mediated by providing information on autism. The more informed students were about autism, the

more favourable cognitive attitudes were towards an unfamiliar student showing autism-like behaviours (Campbell, 2007). Explanatory information was more instrumental in favourable cognitive attitudes than descriptive information was. If the student already had some prior knowledge of autism, the type of explanation had no effect (Campbell, 2007).

In Reiter and Vitani's study (2007) peers who develop typically showed less burn-out, more positive attitudes and improved quality of mediation after a specially designed intervention programme. Teaching peers to make comments to children with autism instead of making request or asking questions resulted in a marked increase in social behaviour (Reiter & Vitani, 2007). In young children participation in integrated playgroups has also resulted in positive changes in the attitudes of peers who develop typically (Wolfberg & Schuler, 1999). Initially seeing themselves as helpers working with children with disabilities, their attitudes changed as they came to develop more balanced and reciprocal relationships. Many of these developed into friendship that continued beyond the setting of the playgroup (Wolfberg & Schuler, 1999).

As mentioned before, gender seems to be one of the strongest characteristics in determining attitudes towards individuals with disabilities. Females tend to hold more positive attitudes than their male counterparts do. In a study done specifically on autism (Campbell, 2007), no initial difference was found between the attitudes of girls and boys towards an unfamiliar child with autism. Once explanatory information was provided, however, the girls reported more favourable attitudes than the boys.

2.8   The effect of life stage on sibling relationships

To control for the effect of different life stages, this study focuses on the adolescent's experience of their sibling with autism. Adolescence is a very interesting life stage characterised by emotional turmoil and a search for personal identity and autonomy, which may further complicate the effect autism already has on a family system (Opperman & Alant, 2003). It tends to be a very stressful time, marked with conflict as the child develops his/her individuality. Conflict usually centres on petty issues such as clothes, pocket money, etc. with the underlying desire for the adolescent to differentiate themselves from other family members. Providing the adolescent with opportunities to express their individuality within a context of closeness and parental support, allows them explore their own ways of coping with

life's dilemmas (Opperman & Alant, 2003). This is also true when taking in consideration the impact of having a sibling with ASD, which has been linked with feelings of shame, stigma and concern for their sibling's future as reported in the literature (Opperman & Alant, 2003).

There is a paucity of research on adolescent attitudes towards children with disabilities in comparison with research on children and adults (Beck, et al., 2010; Lilienfeld & Alant, 2002). Since adolescence marks a time of many transitions for children, not only the change from primary to high school but also the many changes associated with the onset of puberty, one would expect this to have implications for their attitudes towards their siblings.

Gaining a greater understanding of adolescent's attitudes towards their siblings with ASD may help lay the foundation for designing effective evidence-based strategies in dealing with the effects of autism in both the adolescent themselves and the people around them. By encouraging positive attitudes towards their sibling with ASD, social interaction may be increased. Through the enhancement of these sibling interactions, the child with autism may learn valuable skills in communication and social interaction, which may lessen many of the social effects of autism such as temper tantrums or withdrawal. This in turn may relieve some of the stress associated with autism, thereby promoting the well-being of the whole family system.

2.10   Summary

The aim of this chapter was to discuss literature relevant to the attitudes of adolescents who develop typically towards their sibling with ASD. This entailed a discussion on family relationships with special focus on sibling relationships. It provides a brief overview of ASD and the effects it may have on family dynamics.

The potential for siblings to be part of the intervention process was explored. The effects that attitudes and life stage have on sibling interaction were also discussed.

Chapter 3

Research method

3.1 Introduction

This chapter describes the method used to conduct the research necessary to address the main aim of the study, namely, to investigate how adolescents who develop typically describe their present attitudes towards their sibling with ASD, compared to their attitudes when they were younger. The main aim and the sub aims are presented first. This is followed by a discussion of the research design and an overview of the research process. The development of material is described next. This includes a rationale for the choice of survey instrument and a description of any modifications that were made to ensure relevance to the target population. The pilot study is subsequently presented, including an overview of the process that was followed, a description of the participants and all modifications that were made to the procedures and/or material. The procedures used for the main data collection is then discussed in detail, including a rationale for the selection criteria that were set. The chapter includes a summary of the descriptive information of the participants and detail of the procedures used for data analysis.

3.2 Aim of the study

3.2.1 Main aim

This study aims to investigate how typically developing adolescents describe their present attitudes towards their sibling with ASD, compared to their attitudes when they were younger.

3.2.2 Sub aims

The following sub-aims were formulated to work towards addressing the main aim:

(i) To describe the results obtained from the Modified Lifespan Sibling Relationship Scale (MLSRS) as it pertains to the components of attitudes (affective, behavioural and cognitive) of typically developing adolescents.

(ii) To compare their present attitudes in regards to their relationship with their sibling with ASD to their attitudes when they were younger.

3.3   Research design

A non-experimental, prospective, survey design within the quantitative framework was used to address the research aim (McMillan & Schumacher, 2006). Quantitative research uses numerical representation to measure and describe phenomena as objectively as possible (Lawshe, 1975; McMillan & Schumacher, 2006). The structure of the survey used, namely The MLSRS, allowed the researcher to describe and draw comparisons between the different components of attitudes (affective, behavioural and cognitive); and between their present attitudes as adolescents and a reflection on the attitudes they held as a younger child.

The design is non-experimental, since the study aims to describe the attitudes of children who develop typically, towards their sibling with ASD without manipulating any of the conditions that are experienced by the participants (McMillan & Schumacher, 2006). More specifically, it is descriptive in that this study provides a summary of the attitudes held by the participants as they are, without any interference from the researcher (McMillan & Schumacher, 2006).

Only one uniform source of data collection, a survey, was used for this study, namely The Lifespan Sibling Relationship Scale (Riggio, 2000). A survey is one of the most widely used techniques for gathering data (Litwin, 1995; McMillan & Schumacher, 2006). It was chosen for this study because it readily translates information about a participant's beliefs, opinions and behaviour into a quantitative form (McMillan & Schumacher, 2006).

There are several potential disadvantages to using a self-report, self-administered questionnaire for this research study (McMillan & Schumacher 2006). These include factors such as the complexity of sibling relationships not being fully reflected as participants are limited to answering specific questions; a tendency for a relatively low response rate and the fact that the researcher has very little or no control over the conditions under which the survey would be completed. It was therefore decided to have a "Sibling Day", where the participants could fill in the survey under supervision of the researcher, to attempt to standardize conditions in which the survey was completed.

A purposive sampling method was used to select each participant as being the sibling of a child with ASD who attended a school specialised in the education of children with ASD. Since it would be impractical to study a phenomenon in its entirety, a sample is usually selected from a larger group of people. Purposive

sampling was used to select participants that the researcher would have access to who would reflect, in essence, the same characteristics the larger population would (McMillan & Schumacher, 2006).

3.4 Overview of the research process

The research process proceeded on a linear model. Once ethical clearance was obtained (Appendix A), the target population for the survey was defined. A survey instrument was selected and modified so that it would be suitable for addressing the aims of the study. The survey instrument was subsequently piloted on a similar population and the necessary modifications were made. As soon as this was completed, the main data was collected, analysed and discussed. Figure 3.1 provides a schematic presentation of the different steps of the research.

STEP1:
Obtained ethical clearance from the University of Pretoria

STEP 2:
Survey population defined

STEP 4:
Pilot study

STEP 3:
Selection of survey instrument and development of material

Necessary modifications made to format

STEP 5:
Data collection for main study

Two points of data collection
1. Data collected as part of 'Sibling Day'
2. Data collected from surveys completed at home

STEP 6:
Data analysis and discussion of results

Figure 3.1: A visual representation of the research process

3.5   Material

The material used comprised four different items. Each will be discussed in more detail below.

     3.5.1   The MLSRS (Appendix B)

     3.5.2   Letters requesting consent

          3.5.2.1 Letters requesting consent from principals (Appendix C)

          3.5.2.2 Letters requesting consent by parents (Appendix D)

     3.5.3   Flyer for the "Sibling Day" (Appendix E).

     3.5.4   A "Sibling Day" programme

3.5.1   The Lifespan Sibling Relationship Scale

In order to select a scale that would be able to answer the research question a thorough search was done on three journal platforms (SpringerLink, ScienceDirect and GoogleScholar). This particular scale was chosen for the ability to identify differences in attitudes that might occur over time as the siblings develops and because it has been well validated for its psychometric properties (Riggio, 2000). It is a self-report survey developed out of recognition of the importance of sibling relationships throughout the lifespan. It is grounded in basic research on attitude structure and its psychometric properties have been thoroughly tested (Riggio, 2000). The scale has been developed to measure three dimensions of the sibling relationship in both adulthood and in childhood, namely "the frequency and positivity of behavior toward the sibling, affect toward the sibling and beliefs about the sibling and the sibling relationship" (Riggio, 2000, p. 707). It is based on the conceptualisation of attitudes as consisting of affective, cognitive and behavioural components.

The scale differs from other scales that measure sibling relationships in that it not only measures present attitudes of the individual as an adult, but also assesses the memory of attitudes held towards the sibling relationship in childhood. Since sibling relationships start at childhood and continue through the entire lifespan, reflective attitudes would add insight into present attitudes.

The scale consists of 48 items divided into six sub scales. Child affect (CA) and adult affect (AA) measure emotions towards the sibling. Child cognition (CC) and adult cognition (AC) assess beliefs about their sibling and their sibling relationship in the respective developmental phases. The measurement of how

positive behavioural interactions were, or are, falls under child behaviour (CB) and adult behaviour (AB).

The LSRS has been found to be psychometrically sound and high internal consistency has been shown for all six subscales and the instrument as a whole (Riggio, 2000). There is also evidence of a coherent factor structure and stability of responses over time (Riggio, 2000).

Table 3.1 provides a summary of the reliability and validity tests run on the LSRS. The scale was completed by 711 students with a mean age of 23.5 years (Riggio, 2000; pp712-720).

Table 3.1

Reliability and validity of the LSRS

Tests	Overall score	Result
Means and standard deviations	Mean: 164.8 Range: 186 (high 237, low 51)	This indicates that the LSRS is able to capture a wide variation of attitudes
Reliability: Internal consistencies	Coefficient Alpha: 0.96	Demonstrates high internal consistency
Reliability: Test-retest reliability	All correlations were greater than 0.80 Total score 0.91	30 individuals completed the test one month apart. The results indicated that the responses are stable over time
Reliability: intercorrelations among LSRS scales	All 6 of the LSRS scale and total scores were moderately to highly positively correlated with each other ($p < 0.001$)	Indicates intercorrelations are statistically significant. However, the adult scales seem to be more strongly correlated with each other than with the three child scales, and so too the three child scales with each other.
Discriminability of the LSRS: One way analysis of variance (ANOVA) on the total score using the positive/negative grouping variable	Means = 178.5 similarly, (SD = 31.6) and 140.3 (SD = 35.6), respectively, $F_{(1, 106)} = 43.75$, $p < 0.001$	Indicates that the LSRS does discriminate between the most positive and the most negative relationships
Discriminability of the LSRS: Multivariate analysis if variance (MANOVA)	$F_{(6, 101)} = 6.36$, $p < 0.001$	Indicates significant multivariate differences between the two groups on the LSRS subscales
Convergent and discriminant validity	Sample 1: Eysenck Personality questionnaire	Significant correlations (Higher scores on Eysenck Personality questionnaire neuroticism and Eysenck Personality questionnaire psychoticism were related to a more negative experience of sibling relationships.)
	Sample 2:five semantic differential items that indicating	High correlation

	overall satisfaction with their sibling relationships	
	Sample 3: Inventory of socially supportive Behaviours	High correlation
	Sample 4: Marlow-Crowne Social Desirability Scale	"The lack of correlation indicates that social desirability as a response bias was not associated with reports of sibling relationship attitudes"
	Sample 5: Rand Well-Being Scale	Significant correlations
	Sample 6: Adult Sibling Relationship Questionnaire	Significant positive correlations

Since the LSRS was originally designed to measure adult attitudes, it was necessary to modify it slightly in order to answer the main aim, which is to investigate adolescent attitudes.

The Modified LSRS comprised five sections:

(i)   A cover page where the participants could indicate assent

(ii)   A section for biographical information

(iii)   Instructions on how to complete the survey instrument

(iv)   Three trial items

(v)   The survey instrument itself

Table 3.2 provides a rationale for the choice of questions included in the demographic section of the survey instrument.

Table 3.2

Development of Demographic Questionnaire

Question	Question area	Type of question	Reasons for inclusion	Theoretical justification
1	Diagnosis	Yes/no option	To ensure that participant does have a sibling with ASD	Literature indicates that developmental phase as well as gender of sibling has an effect on sibling relationships (Brewton, Nowell, Lasala & Goin-Kochel, 2012, Orsmond & Seltzer, 2007).
2	Age	Open ended	To determine the average age of the participants.	
3	Age Relationship to participant	Open-ended	To determine the average age of the siblings and to determine family structure (whether sibling is younger or older)	
4	Gender	Yes/No option	To determine gender of participants	
5	Gender	Yes/No option	To determine gender of siblings	
6	Living in the same home	Yes/No option	To determine family structure	If they are living in the same home the relationship will have greater impact (Mandleco et al, 2003)
7	Other siblings	Yes/No option	To determine family structure	Family structure may influence relationship (Mandleco et al., 2003, Petalas et al., 2009)
8	Number of siblings	Open-ended	To determine family structure	Family structure may influence relationship (Mandleco et al., 2003)
9	Marital status of parents	Yes/No option	To determine family structure	Families' ability to deal with stressors have impact on sibling relationships (Mandleco et al., 2003)

The instructions included a directive that if the participant had more than one sibling with autism, he/she was asked to complete the questionnaire with only one younger sibling relationship in mind (Riggio, 2000). The items were answered on a 5-point Likert Scale indicating the extent to which they either agreed or disagreed with the statement as reflective of their sibling relationship (Riggio, 2000). 1= Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 =

Strongly agree. The following items are negatively worded and are therefore reverse scored: 6, 13, 19, 25, 27, 28, and 38. These items were scored as follows: 1 = Strongly agree, 2 = Agree, 3 = Neither agree nor disagree, 4 = Disagree and 5 = Strongly disagree.

For the purposes of the current study, certain modifications were required. Twenty-one questions on the three subscales dealing with attitudes held as children had to be reworded slightly. Therefore, in questions 25 to 43 and 45 to 47, for example, 'I enjoyed spending time with my sibling as a child' would become 'I enjoyed spending time with my sibling when we were younger' (See Appendix A). During the modification phase item 42 in the Child Cognition subscale was accidentally omitted. However, this did not influence the results, since the total per subscale was not calculated, but rather the mean over the items within each subscale (See Table 4.2 for the Cronbach Alpha values for each of these subscales, indicating their reliability).

To ensure that the participants would easily understand the Modified LSRS's various readability, scores were obtained on the questions. On the Flesch-Kincaid grade-level computer analysis in Microsoft Word (English U.S.), the items scored 76.40 (McClure, 1987). Scores on the Flesch-Kincaid Reading Ease go from 0 to 100 with a higher score indicating easier readability. This was then converted to render a grade-level based on the United States of America's education system. A grade-level indicates the number of years of education a person has. According to this grade-level, the MLSRS is readable on a 5.60 grade-level. To ensure that the participants have the required reading ability, the study will focus on adolescents who are attending high school, or have successfully completed high school. In South Africa high school includes grade 8 to 12.

3.5.2   Letters requesting consent

3.5.2.1   Letters requesting consent by principals

The principals of the schools that were involved in the study, were e-mailed information letters providing an overview of the study, information on the data collection process as well as implications for the participants' time. Attached to these e mails were copies of the approval letters obtained from the relevant education

departments (Appendices H and I). The principals were requested to provide the researcher with written confirmation of their consent to participate in the study.

3.5.2.2 Letters requesting consent by parents

Parents were provided with an information letter explaining the purpose of the study. This letter included a page where they could sign if they granted consent, as well as a selection criteria checklist. The selection criteria checklist was included to ensure that only those parents whose children who conformed to the selection criteria would respond. Both the signed consent form and the completed in selection checklist were sent back to the researcher.

3.5.3 Sibling Day flyer

To broaden the field of available potential participants, a flyer was designed to inform parents of the sibling days that were held in Cape Town and Pretoria. These flyers provided a brief overview of the purpose of the day and information on dates, times and selection criteria for participants. The researcher's e-mail address and telephone number were also provided. Parents were asked to contact the researcher if they were interested in allowing their child to participate and to ask any questions that they may have. These flyers were distributed through the networks of Autism Western Cape and Autism SA.

3.5.4 Programme for 'Sibling Day'

It was decided to have the participants complete the survey instrument as part of a 'Sibling Day' in order that they may answer the questions under the supervision of the researcher. This would also allow the participants to debrief and share their experiences with other adolescents who also have a sibling with ASD, once the MLSRS was completed (Guzman, 2007; Huff, 2006). There were a few parents who contacted the researcher asking whether their child could attend the day even if they were younger than the required age for the purpose of meeting other particpants who are sharing their experience of having a sibling with ASD. It was decided to allow them to attend, to participate in the activities, but not to use their data for analysis purpouses.
The program proceeded as follows:

11:00: Participants arrive

During this time various activities were presented so that the adolescents could find something to keep busy while people were still arriving. This included arts and crafts equipment. The researcher and three assistants chatted informally with the children and tried to avoid letting the discussions centre around autism until the survey instrument had been completed in order to control for the Hawthorne effect (McMillan & Schumacher, 2006).

11:30: Icebreakers

These were included to help the adolescents learn each others' names and to create a more relaxed atmosphere:

(i) Participants stood in a circle with the researcher and the research assistants. Each person said his/her name. Once all names had been provided, each person had to shout the name of the person he/she was going to throw a ball to, and then throw. This allowed for more exposure to each others' names.

(ii) Caterpillar race: Participants were divided into three teams. The teams stood in a line with their hands on the shoulders of the person in front of them. The teams could only move forward by jumping forward with both legs together. Only one person in the team can jump forward at a time, which necessitates the teams to work together to get to the end point as quickly as possible.

12:15 Completing of questionnaires

the practice items were completed together after which the participants could complete the survey at their own pace.

12:30 Lunch

13:00 Video and discussion

A 10-minute video on the experiences of children with a sibling with autism was shown to the participants (Autism Council of Utah Resources and Services Committee, 2009) . The video covered at the following aspects: The children's understanding of what autism is, the different expectations their parents have of them compared to their sibling with ASD, their experience of having a sibling with ASD (both the positive and negative aspects), and what their hopes, dreams and fears are for their sibling's future.

The discussions centred around the issues mentioned above, which most of the participants seemed to identify with. These discussions were not used as data, but rather to provide an opportunity for the participants to debrief. Feedback from the participants and from the parents was very positive and several families asked whether similar events would be held again in the future.

3. 6   The pilot study

3.6.1   The aim of the pilot study

To find out whether changes made to the survey instrument would be applicable, a pilot study was conducted (Litwin, 1995). The pilot study also aimed to determine whether the survey format and the coding procedures were appropriate (Litwin, 1995). Attention was given to question formulation, format and required response modes.

Some of the selection criteria needed to be changed during the preparation for the pilot study. Initially, the selection criteria included that the participant be the older sibling of a child with ASD, since the literature indicates that there is a difference between relationships due to birth order. Children who were born after a child with autism are affected differently than children born before (Petalas, et al., 2009). It became evident that this would narrow the field of available participants too much so this selection criterion had to be left out.

3.6.2   The pilot study process

The pilot study was conducted as follows:

i.   A school for special needs that specialised in the education of learners with ASD was selected as a pilot site by the researcher. Class teachers were asked to identify children who fit the selection criteria.

ii.   Letters were sent home with these children, briefly explaining the purpose of the study, the selection criteria for the study, a parental consent form and the programme and invitation to the 'Sibling Day'. The parents who indicated that their children conformed to the selection criteria and were willing to participate were e-mailed, providing further details.

iii.   The parents subsequently brought their children to the school on the arranged date. The programme followed the same steps as suggested for the main study in the section on material.

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3.6.3 Participants in the pilot study

Fourteen children arrived for the 'Sibling Day', but eight of them did not meet the selection criteria. These eight children joined in on the activities but did not complete the questionnaire. Data was therefore only collected from six participants (n = 6). Table 3.3 describes the pilot participants according to the information obtained from the demographic questionnaire.

Table 3.3

Description of Participants for the Pilot Study (n=6)

Category	P 1	P 2	P 3	P 4	P 5	P 6
Age of participant	17	15	17	17	13	19
Age of sibling	7	17	15	14	7	17
Gender of participant	Female	Male	Female	Female	Male	Female
Gender of sibling	Male	Male	Female	Male	Male	Male
Live in the same house	Yes	Yes	Yes	Yes	Yes	Yes
Number of siblings	4	3	3	3	4	3
Parents married	Yes	Yes	Yes	Yes	Yes	Yes

Note: P = Participant

The average age of the participants was 16 years and of the average age of their siblings was 13 years. Five out of the six siblings with ASD were younger than the participants were. Of the participants, four of them were female and two male. Only one of the siblings with ASD was female, which is consistent with the published figures, which indicates that only 1 out of 4 people with ASD are female (Ratajczak, 2011). All of the participants were still living on the same house with their sibling and their parents were married. Four of the participants come from families with three children and two of them from families with four children.

The specific aims of the pilot study, the materials and methods used, results and all changes made after the pilot study are shown in Table 3.2.

Table 3.4

Procedures, results and recommendations from the pilot study

Aims	Materials	Methods	Results	Recommendations
1. To determine whether the instructions are understandable	Instructions section Trial items Feedback session	Participants were asked to read the instruction sheet before completing the demographic form and the trial items. The participants were asked whether they found the instructions clear and understandable.	The participants found the instructions clear and understandable.	No modifications were made to the written instructions for the rest of the data collection process.
2. To evaluate whether the language used in the items are easily understood by adolescents attending high school (i.e. grades 8-12)	MLSRS items Feedback session	Participants were asked to provide feedback on whether the questions were clear. The Scale was measured to be readable at a grade 6 level	Trial answers were answered appropriately. The participants also reported that they understood all the questions.	No modifications were made to the questions.
3. To determine whether the format and the layout of the scale is clear	Feedback session Trial items		The participants used the whole range of the five response items The participants reported that the format was clear and understandable. Shading of alternate items was used to make sure that no questions were missed.	Format to remain as is.
4. To ensure that the administrative and coding procedures suggested for the main data collection is efficient	Column for official use MS Excel spreadsheet	Scores were transferred into the column for official use and entered on an MS Excel spread sheet	Realised during coding that lower scores indicated better results, which was confusing. Otherwise, the coding procedure proved efficient.	The recommendation for main study to change order of Likert scale categories so that higher scores equal attitudes that were more positive. Reverse scoring of items occurred at the data capturing stage.

3.7   Main study

3.7.1   Data collection

Before any fieldwork was conducted, permission to conduct the research was obtained from the University of Pretoria's Ethics Committee (appendix A), the Western Cape Education Department (appendix F) and the Gauteng Department of Education (appendix G). The individual principals of the schools where the studies were conducted and the parents provided consent.

The target population for the survey was defined as being adolescent siblings of children who were diagnosed as being on the autism spectrum. A suitable survey instrument to address the aims of the research was selected and then modified. Since the chosen instrument was originally developed for use with adults, it was necessary to change the wording of some of the items to render them suitable for use with adolescents, as discussed in section 3.5.1

The MLSRS was piloted on six participants who met the criteria for the main study. The purpose of the pilot study was to determine if the measuring instrument was effective in attaining the aim of the study and to ensure that the data collection procedures were effective.

Since no significant modifications were necessary after the pilot study for either the survey content or the data collection procedure, the main data collection proceeded in a similar manner as for the pilot study. Data was collected at two venues, one in Cape Town and another in Pretoria as part of a 'Sibling Day'. A flyer was distributed through the networks of Autism Western Cape and AutismSA. Letters were also sent to schools specialising in the education of children with ASD in both Cape Town and Pretoria.

There were 17 families who indicated a willingness to participate but who, for a variety of reasons, were unable to attend either of the 'Sibling Days'. These participants were sent a copy of the survey either via e-mail or via the school, depending on their personal preference. The survey was completed at home and sent back to the researcher, either via e-mail, or by returning it to the school.

To ensure that the participants and their parents were fully informed on all aspects of the research, parents were provided with information about the study and implications for their time (Leedy & Ormond, 2005). The letter included a section that the parents could keep for future reference, as well as a reply slip that was

returned to the researcher as proof of written consent. (Please refer to appendix B for a copy of these documents.)

Both the participants who attended the 'Sibling Day' and those who completed the questionnaire at home were informed of their right to withdraw at any time if they no longer wished to participate. They were also assured that all personal information would be treated as confidential by documenting the survey with a respondent number and removing all identifying details that were irrelevant to data processing before statistical processing commenced (McMillan & Schumacher, 2006). They were then asked to indicate their assent to participate on the cover letter of the survey (Appendix E).

3.7.2   Selection criteria for participants

Table 3.5 provides a summary of the selection criteria that were set. The necessary information was obtained from information provided by the parents and confirmed by the demographic questionnaire completed by the participants (See appendix A)

Table 3.5

Selection criteria

Criteria	Justification	Method
Between the ages of 13-20	The study is aimed at adolescent attitudes since the research indicates that there is a change in attitudes over the developmental stages (Beck & Dennis, 1996). According to the American Psychological Association (APA) adolescence is defined as a developmental period starting with the onset of puberty (which can start as early as the age of 10 years in girls and 11/12 in boys) and continues until maturity. It was decided to use children from the age of 13 years only, because this is the age when most children should have started puberty. Adolescence ends with adulthood, which can range between the ages of 18 and 21 years.	Parents were asked
Attending an English or dual medium school	Survey instrument is in English and should be easily understood to ensure reliability of responses and results (Maxwell & Satake, 2006)	Parents were asked
Have a sibling diagnosed with ASD	The study aims to look at the attitudes of adolescents who have a sibling with ASD.	Participants were contacted through ASD schools and networks
Attend High School (grade 8 - 12) to ensure reading ability at a grade 6 level	Participants had to be able to read the scale items independently. The readability of the scale scores at an average of Grade 6 level.	Parents were asked whether the participant is at high school (grades 8-12). This implies that the participants should be able to read at Grade 7 level.

3.7.3 Descriptive information of the participants

As part of the demographic questionnaire, participants disclosed their age, their sibling age and their gender. They were also asked how many siblings they were altogether, whether they lived in the same home and if their parents were married. The following tables provide summaries of the information obtained from the demographic section of the survey instrument.

Table 3.6 provides a summary of the age range of the participants. The age range fell between 13 and 20 years, and the average age was 16 years.

Table 3.6

Age of Participants (n = 30)

	Age of participants (in years)							
	13	14	15	16	17	18	19	20
Number of participants	2	8	5	3	6	1	4	1

An equal number of boys and girls completed the MLSRS (15 boys and 15 girls)

3.7.4 Descriptive information of the siblings with ASD

The age range of the siblings with ASD is provided in Table 3.7 below. As can be seen in this table the sibling ages ranges between 7 and 21 years, with the highest number of siblings being 10 years old (n = 6).

Table 3 7

Age of the Siblings with ASD (n=30)

	Age of sibling with ASD (in years)											
	7	8	9	10	11	12	13	14	15	16	17	21
Number of siblings for the participants	2	3	2	6	1	3	2	3	1	3	3	1

The majority of the siblings were male (90%), while only 10% were female. This is significantly higher than the 4:1 gender ratio (male:female) of the general

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autism population (Ratajczak, 2011). It is interesting to note the difference in gender ratios between the participants and in the siblings with ASD.

The majority of the participants were living in the same house as their sibling at the time of data collection (90%). Only ten percent (10%) of the siblings with ASD were staying in care facilities, this would imply that they were living in a different home to the family home where the participants lived.

Ninety percent (90%) of the parents were married at the time of data collection. Only three of the participants had parents who were separated (10%). This was interesting, since the literature indicated that the stress of having a child with ASD is higher than with any other childhood disability, which raises the likelihood of divorce (Stoneman, 2001). The type of sampling used could possibly have skewed the data, in that it would be easier.

The majority of siblings with ASD (90%) were younger than the adolescent who acted as the participant for this study. Only three siblings (10%) were older than the corresponding participant.

Because data was collected in two different ways (at home versus at one of the sibling days), demographic variables were compared in order to ensure the functional equivalence of the two groups. Seventeen of the questionnaires were completed at home (Group 1), whilst 13 were completed as part of the 'Sibling Day' (Group 2). These two groups were compared regarding the age of participants, age of sibling, gender of participants, number of siblings at home and birth order.

A Wilcoxon two-sample test (Steyn, Smit, & du Toit, 1998) was conducted to compare the two groups in terms the age of participants and the age of siblings. As can be seen from the results in Table 3.8, the p-values indicate that there was no significant difference between these two groups based on the age of participants and the age of their sibling with ASD.

Table 3.8

Comparison of Group 1 and Group 2, based on age of participants and sibling

	GROUP 1 (n = 17)		GROUP 2 (n = 13)		
	Mean	Standard deviation	Mean	Standard deviation	Wilcoxon test p-value
Age of participant	16.00	2.15	15.77	1.877	0.8659
Age of sibling	11.71	3.04	12.85	4.18	0.4796

To compare the groups in terms of gender a Fischer's test (Steyn et al., 1998) was run with a p-value of 0.9999 indicating that there was no significant difference between the two groups in terms of gender. Table 3.9 provides a comparison of gender between the two groups.

Table 3.9

Comparison of Group 1 and Group 2 based on gender of participants

	GROUP 1 (n = 17)		GROUP 2 (n = 13)		
	Percentage	Frequency	Percentage	Frequency	p-value
Male	47.06%	8	53.85%	7	0.9999
Female	52.94%	9	46.15%	6	

The two groups were also compared based on the number of siblings in the household. A Fischer test was run on the data, which obtained a p-value of 0.2608.

Table 3.10

Comparison of Group 1 and Group 2 based on number of siblings in the household

	GROUP 1		GROUP 2		
	Percentage	Frequency	Percentage	Frequency	p-value
2 siblings	47.06%	8	30.77%	4	0.2608
3 siblings	47.06%	8	38.46%	5	
4-5 siblings	5.88%	1	30.77%	4	

Because these tests indicated that there were no significant differences between the two groups, based on the demographic variables, the data from both groups were analysed together, as one data set (n = 30).

3.8 Analysis of data

The collected data was analysed using descriptive statistics in accordance with the selected research design (McMillan & Schumacher, 2001). The answers from both the demographic questionnaire and the MLSRS were assigned variables, which were coded on an MS Excel spread sheet. Frequencies, means and percentages were calculated from this data. Inferential statistics were applied to the data to compare the different components of attitudes and differences across lifestages. The following tests were run on the data: Pearson's paired t-test, Friedman two-way analysis of variance, the Wilcoxon two-sample test and the Fischer tests. The reliability of the MLSRS was tested by means of Cronbach alphas (Maxwell & Satake, 2006; Steyn et al., 1998).

3.9 Summary

This chapter discussed and validated the method that was selected in order to address the aims of the study. The steps followed for in the pilot study and for the main data collection were described in detail. The procedures for analysing the collected data in accordance with the selected research design were subsequently described.

Chapter 4

Results and discussion

4.1   Introduction

This chapter focuses on a discussion of the results obtained from the Modified Lifespan Sibling Relationship Scale (MLSRS). The reliability of the obtained responses is discussed in the light of the overall reliability of the survey instrument. This is followed by a description and analysis of the data within the three components of attitudes, namely, affect, behaviour and cognition. A comparison of the adolescents' present attitudes and their attitudes at an earlier life stage is presented. Figure 4.1 provides a visual outline of this chapter.

4.1 Introduction

4.2 Reliability

4.3 Description of results
- 4.3.1 Adolescent affect
- 4.3.2 Adolescent behavior
- 4.3.3 Adolescent cognition
- 4.3.4 Child affect
- 4.3.5 Child behavior
- 4.3.6 Child cognition

4.4 Overview of the components of attitudes

4.5 Comparison of the components of attitudes
- 4.5.1 Comparison of attitudes according to lifestage
- 4.5.2 Comparison of attitudes components within each lifestage
- 4.5.3 Implication for typically developing siblings
- 4.5.4 Implications for sibling with ASD
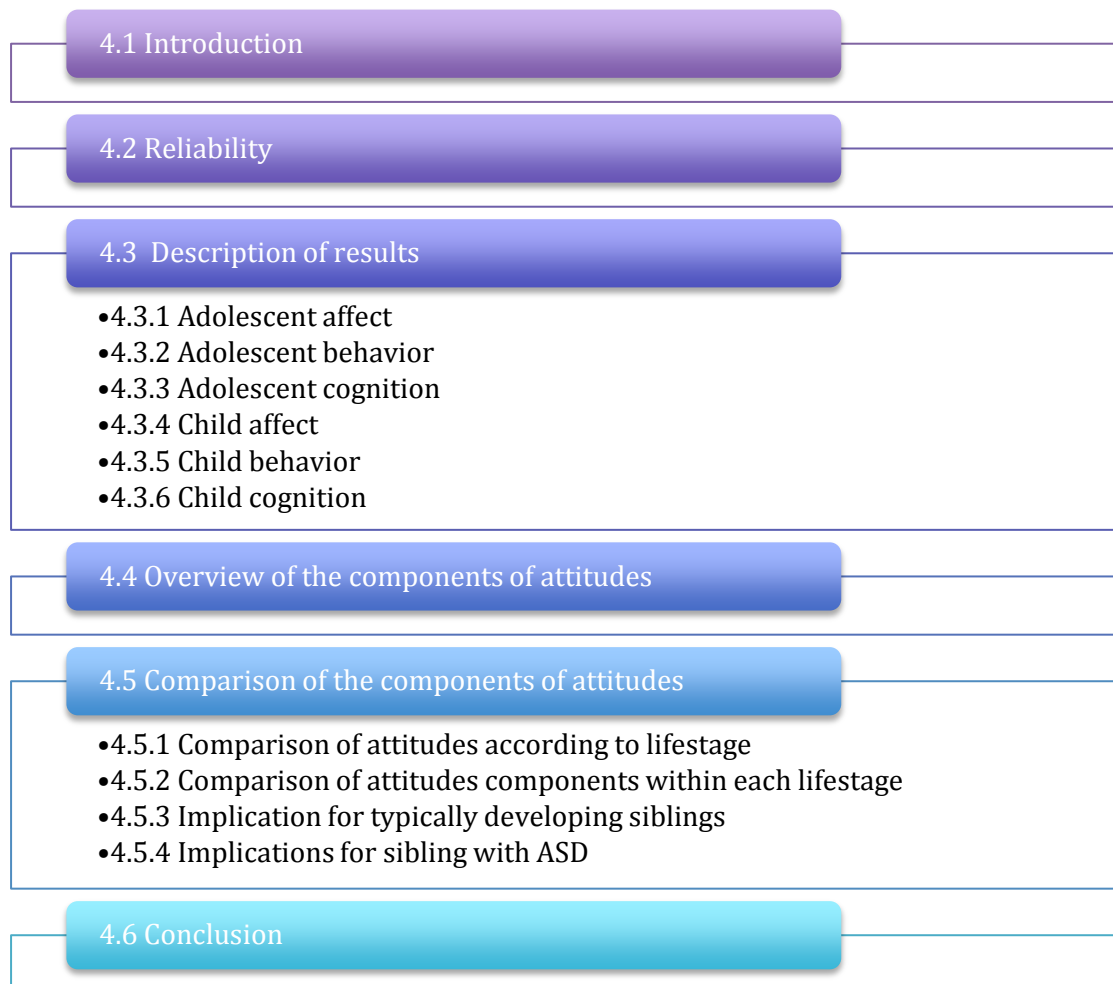
4.6 Conclusion

Figure 4.1. Visual representation of the content of chapter 4

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4.2   Reliability

The survey instrument (MLSRS) that was used in this study was based on an existing scale, the Lifespan Sibling Relationship Scale, which has been extensively tested for both validity and reliability, as discussed in Chapter 3 (Riggio, 2000). The scale consists of 48 items divided into 6 sub scales. Child affect (CA) measures emotions towards their sibling and their relationship as younger children, while the participants' affective component of attitude as adolescents is measured under adolescent affect (AA). Child cognition (CC) and adolescent cognition (AC) assess beliefs about the sibling and the sibling relationships in the respective developmental phase. The measurement of how positive behavioural interactions were or are, falls under child behaviour (CB) and adolescent behaviour (AB) respectively.

A pilot study was conducted to ensure reliability in the current study's context. Three trial items precede the scale so that the participants may demonstrate whether they understand how they should answer using the 5– point Likert scale. It was noted with the six survey instruments completed in the pilot study and at the sibling days for the main data collection that the participants did not need any additional explanation on completing the questionnaire.

In order to test whether the MLSRS retained its reliability with the modifications made, Cronbach's alphas were obtained for each of the 6 subscales (Steyn et al., 1998). All the CA values were higher than 0.7 and may therefore be regarded as satisfactory, as can be seen in Table 4.1.

Table 4.1

Cronbach Alpha Values for the MLSRS

Subscale	Cronbach's alpha values
Adolescent Affective component of attitude (AA)	0.92
Adolescent Behavioural component of attitude (AB)	0.80
Adolescent Cognitive component of attitude (AC)	0.86
Child Affective component of attitude (CA)	0.91
Child Behavioural component of attitude (CB)	0.79
Child Cognitive component of attitude (CC)	0.71

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4.3   Description of results

Descriptive statistics were used to calculate data from the study. Percentages were calculated for each of the 30 responses on each item (McMillan & Schumacher, 2006). These will be discussed in detail and represented visually in the form of bar graphs. All items that needed to be reverse scored were done at the data capturing stage. These bar graphs therefore reflect negatively worded items as already reverse scored.

4.3.1   Adolescent Affect

The MLSRS contained 8 response items that were aimed at measuring adult or, for the purpose of this study adolescent affect. The percentages obtained are represented in Figure 4.2.
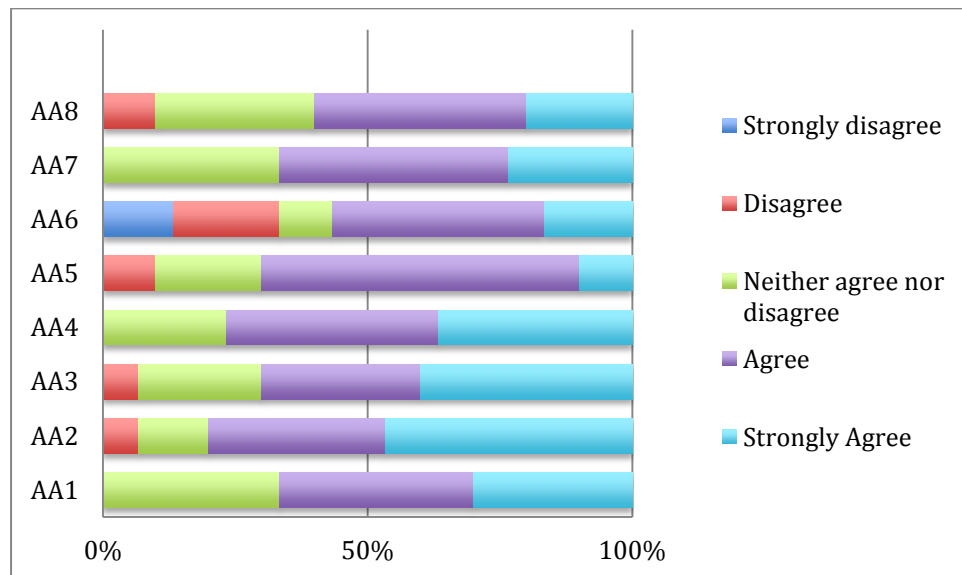
Figure 4.2. Adolescent Affect

The highest number of positive responses were given on AA2 (*My sibling's feelings are important to me*), with 80% responding either with '*Agree*' or '*Strongly Agree*'. Only 7% of the respondents answered negatively on this item. AA1 (*My sibling makes me happy*), AA4 (*I am proud of my sibling*) and AA7 (*I admire my sibling*) received no negative ratings at all. When asked whether their sibling frequently made them angry (AA6), a third of the participants responded with '*Agree*' or '*Strongly Agree*', making this the item the one with the highest percentage of negative responses. Item AA6 was also the only item that received strong negative responses, with 13% responding negatively. When asked whether they enjoyed their

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relationship with their sibling (AA3) 70% provided a positive response, 7% a negative response disagreed and the remaining 23% was ambivalent. Seventy per cent responded positively to item AA5 (*My sibling and I have a lot of fun together*), 20% were ambivalent and 10% answered with '*Disagree*'. *I like to spend time with my sibling* elicited a positive rating (60%), 30% an ambivalent response and 10% of the respondents responded with '*Disagree*'.

Overall, this section of the MLRS received the highest number of positive responses, indicating that by adolescence, the respondents had stronger positive feelings towards their sibling. This echoes findings by Kaminsky and Dewey (2003), who found that children between eight and 18 years of age reported less conflict and competition with their sibling with ASD and greater admiration for their sibling than those with siblings who developed typically.

4.3.2 Adolescent Behaviour

The MLSRS contained eight response items pertaining to adolescent behaviour. The percentages obtained are captured in the bar graph in Figure 4.3.

Figure 4.3. Adolescent Behaviour

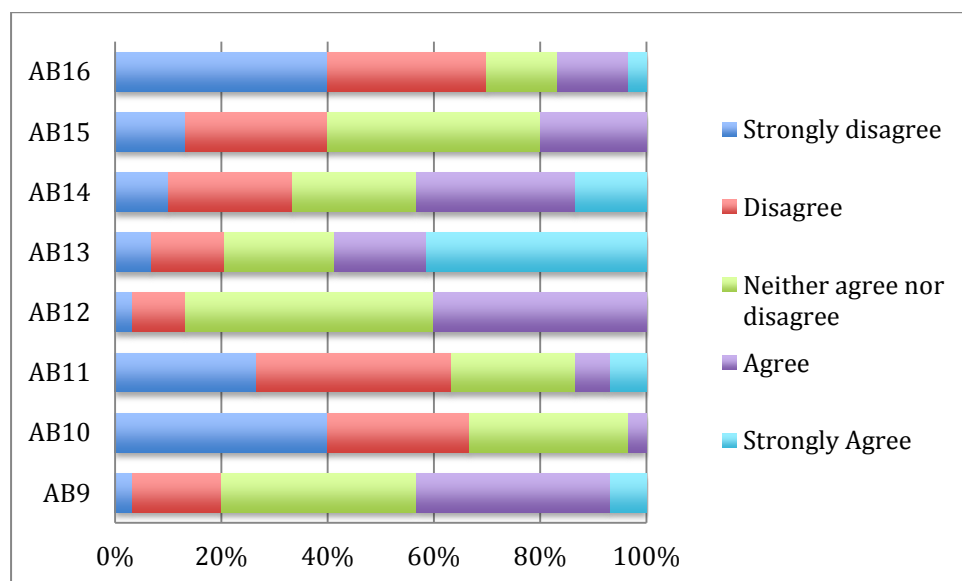Figure 4.2 shows that Adolescent Behaviour received a higher number of negative or ambivalent responses than Adolescent Affect. When asked whether they call their sibling on the phone (AB10) only one participant responded positively. Thirty percent (30%) were ambivalent and the other 67% responded negatively. This was the item with the lowest positive score. Item AB13 (*I never talk about my*

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problems to my sibling) received the highest positive rating (this item was reverse scored as it contained negatively worded items), with 57% answering with either '*Agree*' or '*Strongly agree*', 20% were ambivalent and the remaining 23% disagreed with this statement. The second highest positive score was for AB9 (*I presently spend a lot of time with my sibling*) with a 43% positive response, 37% were ambivalent and 20% responded negatively. The lowest negative score, with 45% answering ambivalently and 40% agreeing with the statement for item AB12 where they were asked whether they do a lot of things with their sibling. *My sibling and I share secrets* (AB11) received a negative response of 63%, 23% ambivalent and 23% positive responses. Forty-three percent (43%) responded that they and their sibling borrowed things from each other (AB14), while 33% said that they did not. The remaining 24% were ambivalent in their response. When asked whether they and their sibling '*hang out together',* (AB15) 20% checked '*Agree'*, 40% were ambivalent and the remaining 40% marked either '*Disagree'* or '*Strongly disagree'*. '*My sibling talks to me about personal problems'*(AB16), elicited a very high negative rating with 70% responding either '*Disagree*' or '*Strongly disagree'*. Seventeen percent (17%) responded positively and the remaining 13% were ambivalent.

Overall, responses on items related to behaviour received a higher number of negative responses than cognitive and affective items. This outcome reflects the current thinking about autism, since these items centre largely on social interaction, for example, '*I presently spend a lot of time with my sibling*', '*My sibling and I hang out together*' and '*My sibling and I borrow things from each other*'; also the ability to communicate, for example, '*My sibling talks to me about personal problems*', '*My sibling and I share secrets'* and '*I call my sibling on the phone'*, which are well-known areas of difficulty in ASD (Kanner, 1945, Lantz, 2005, Tremaine, 2011). In a qualitative study done by Mascha and Boucher (2006) on children between the ages of seven and 20, the majority of the children described their sibling with ASD as good-natured and reported having fun playing with their siblings. The activities that they reported engaging most with their sibling with ASD was playing together, watching television and spending time outside. These children, however, also mentioned times when they felt embarrassed by their sibling, incidents of destructive behaviour and concerns for the future of their sibling. Their relationships were also less close when compared to neurotypical sibling dyads (Kaminsky & Dewey, 2003).

4.3.3 Adolescent Cognition

Eight items of the MLSRS endeavoured to determine Adolescent Cognition. The percentages were calculated and represented in Figure 4.4.
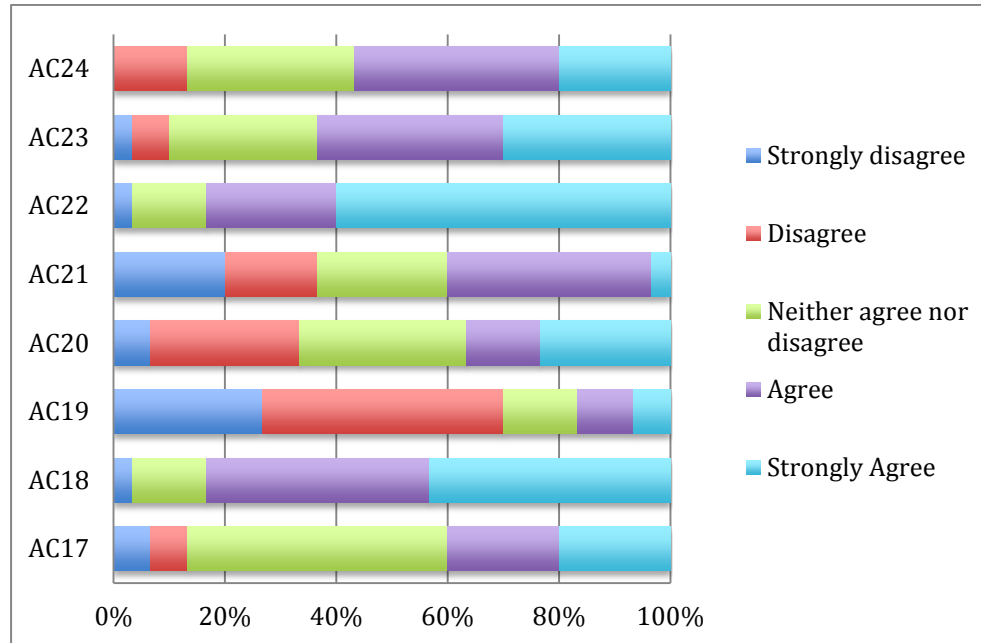
Figure 4.4 Adolescent Cognition

The item with the highest positive rating asked whether the participants believed they were important to their siblings (AC22), with 83% of the respondents responding with either '*Agree*' or '*Strongly agree*'. Only 10% responded negatively and 27% were ambivalent. AC18, which asked whether their sibling was important to *their* life, elicited 83% of positive responses, 10% of negative and 27% ambivalent responses; but a lower ratio answering '*Strongly agree*' compared to AC22. The highest number of negative responses was elicited by item AC19 that asked whether they and their siblings were close, with 70% providing a negative response to this question. Thirteen per cent were ambivalent and 17% provided a positive response. It is possible that this item was problematic for the participants as it is negatively worded. AC 17 asked whether they considered their sibling to be a good friend. To this question, 13% of participants provided a negative response, 47% were ambivalent and 40% were positive in their response to. Thirty-three (33%) responded negatively to '*My sibling is one of my best friends*' (AC20) , 30 % were ambivalent and 37% responded positively. Therefore, AC 20 elicited a very even distribution of responses. Forty percent indicated that they had a lot in common with their sibling (AC21), 23%

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were ambivalent and 37% felt that they did not have a lot in common with their sibling. Sixty-three percent (63%) indicated that they were their sibling's best friend (AC23). Ten per cent (10%) said that they were not and the remaining 17% were ambivalent. Fifty-seven (57%) per cent said they thought that their sibling was proud of them, 30% were unsure and the remaining 13% felt that they were not.

Overall, this section of the research indicated very positive responses from the participants. According to Campbell (2007), peers who develop typically, showed cognitive attitudes towards disabilities that were more positive when they had a clearer understanding of what the disability entailed. After several years of living with their siblings, it seems feasible that siblings would have a much clearer understanding of their siblings, autism and the effects that it has on their sibling, which may be reflected in their positive responses in this sub section (Mascha & Boucher, 2006).

4.3.4 Child Affect

The MLSRS contained eight items that were aimed at measuring child affect (CA). The percentages obtained are represented in Figure 4.6.
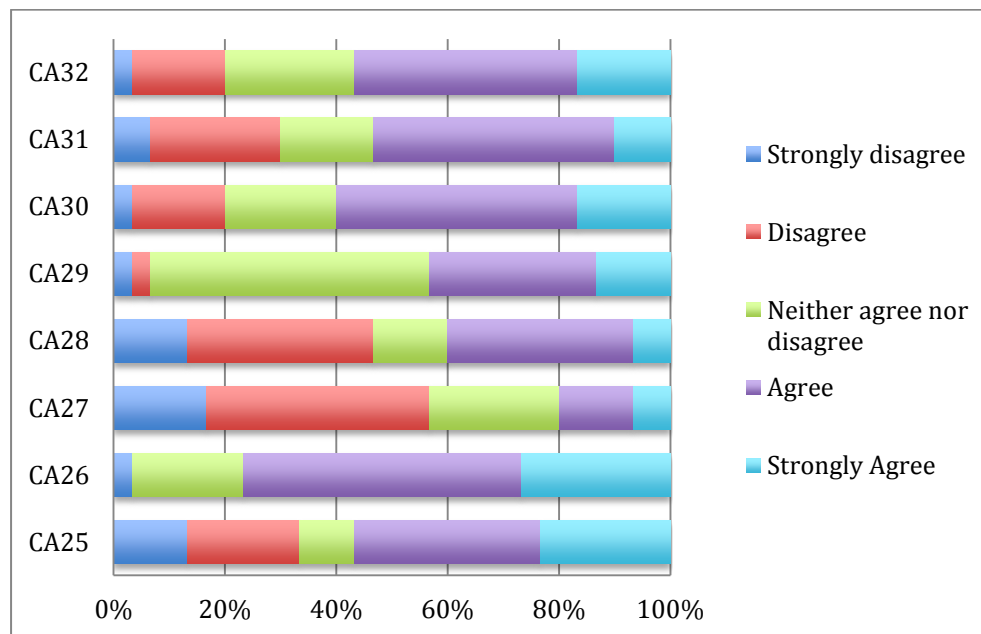

Figure 4.5. Child Affect

The statement '*I remember loving my sibling a lot when we were younger*' received the highest number of positive responses (CA26), with 77% responding with

'*Agree*' or '*Strongly agree*', 20% of the responses were ambivalent, and only 3% was negative. Half of the participants were ambivalent about their responses on item CA29 ('*I was proud of my sibling when I was younger*'), 7% responded negatively and 43% were more positive. The highest number of negative responses were elicited by item CA27, with 57% indicating that their sibling made them feel miserable when they were younger. Of the remaining 43%, the majority (23%) were ambivalent. '*My sibling bothered me a lot when we were younger*' received 57% positive, 33% negative and 10% ambivalent responses (CA25). Forty-seven percent (47%) indicated that their sibling frequently made them angry when they were younger, while 40% did not feel this way(CA28). Sixty per cent (60%) remembered enjoying spending time with their sibling when they were younger (CA30), 20% were ambivalent and another 20% did not remember enjoying time spent with their sibling. More than half the respondents (53%) remembered feeling close to their siblings when they were younger (CA31), 17% were ambivalent and 30% experienced distance. When asked whether they remember having fun with their siblings when they were younger (CA32) 57% agreed with the statement, 20% disagreed and 23% neither agreed nor disagreed.

As with adolescent attitudes, the affective component of attitude received the highest number of positive responses. Although the majority of responses were positive, the items were answered over the full range of the Likert scale, with a fair number of participants answering '*Strongly disagree*' or '*Disagree*' to the questions. As was mentioned in the literature review, studies on the effect of autism on sibling relationships provided contradictory results, with many studies finding higher levels of anxiety and depression, while others found that these children were in fact very resilient at dealing with the additional stress that autism may place on a family (Bemister, 2012; Mandleco et al., 2003; Petalas, et al., 2009). It would seem that the item responses reflect some of this discrepancy.

4.3.5 Child Behaviour

The MLSRS measures child behaviour (CB) with eight items. The results from these were calculated and the percentages obtained are represented in Figure 4.6.
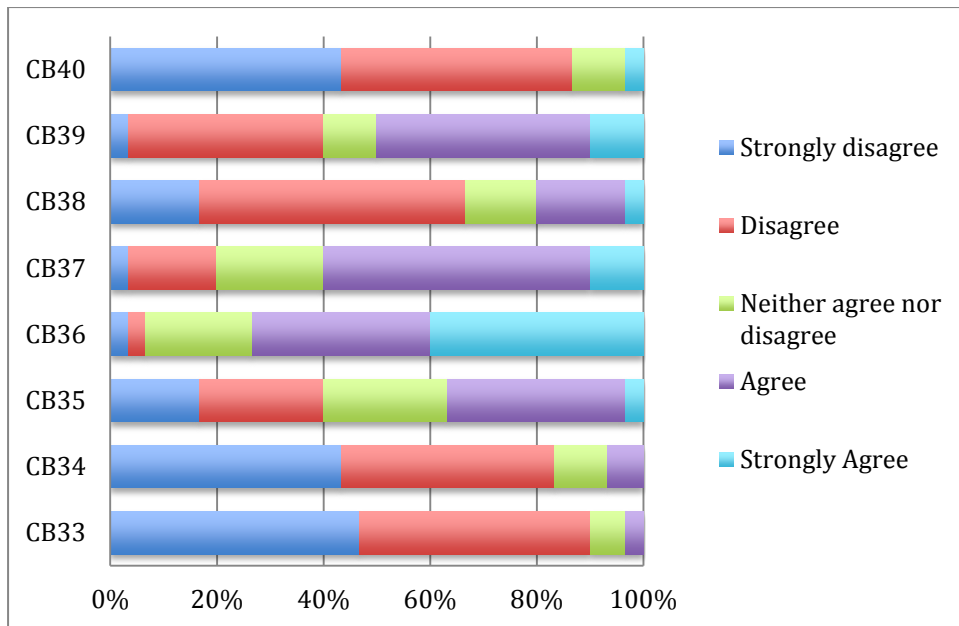
Figure 4.6. Child Behaviour

Seventy-three percent of the participants responded that they looked after their sibling when they were younger (CB36). This was the item for child behaviour that showed had the highest percentage of positive responses. Only a small margin (7%) responded that they were not involved with looking after their sibling, with the final 20% who were ambivalent in their response. The highest number of negative responses was shown for CB33 ('*My sibling and I had the same friends when we were younger*'), 7% were ambivalent and only 3% provided a positive response. The remaining 90% replied negatively. When asked whether they shared secrets when they were younger with their sibling (CB34) 83% answered negatively, 10% were ambivalent and only 7% replied positively. '*My sibling and I played together as children*' (CB35) received a relatively even response at 37% positive responses, 23% ambivalent responses; 40% answered with either '*Disagree'* or '*Strongly disagree'*. At 60%, CB37 ('*My sibling and I often played together as children*') elicited the second highest number of positive responses. A further 20% of the participants responded ambivalently to this item and the remaining 20% responded negatively. Sixty-seven percent reported said that they did not spend a lot of time with their sibling when they were younger (CB38). Twenty percent (20%) indicated that they did; and the remaining 13% was ambivalent. For item CB39, which asked whether the respondents spent time together after school with their sibling, 50% responded that they did (CB40). Ten percent (10%) were ambivalent and the remaining 40% said that they did not. Only 3% indicated that they talked to their sibling about their

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problems when they were younger. Ten percent (10%) of respondent was ambivalent and the remaining 87% responded that they did not remember sharing their problems with their sibling when they were younger.

Once again, behaviour accounted for the highest number of negative responses within the three components of attitudes. Other studies mentioned that, although children had a desire to interact with their sibling, they did not always have the knowledge to engage their sibling with ASD. Even when they did, their sibling's difficulty to communicate and to interact made it very difficult to do so (Hansford, 2011; Rivers & Stoneman, 2003; Tsao, 2004).

4.3.6 Child Cognition

Seven of the items were aimed at child cognition in the MLRS. The percentages obtained are presented in Figure 4.7.
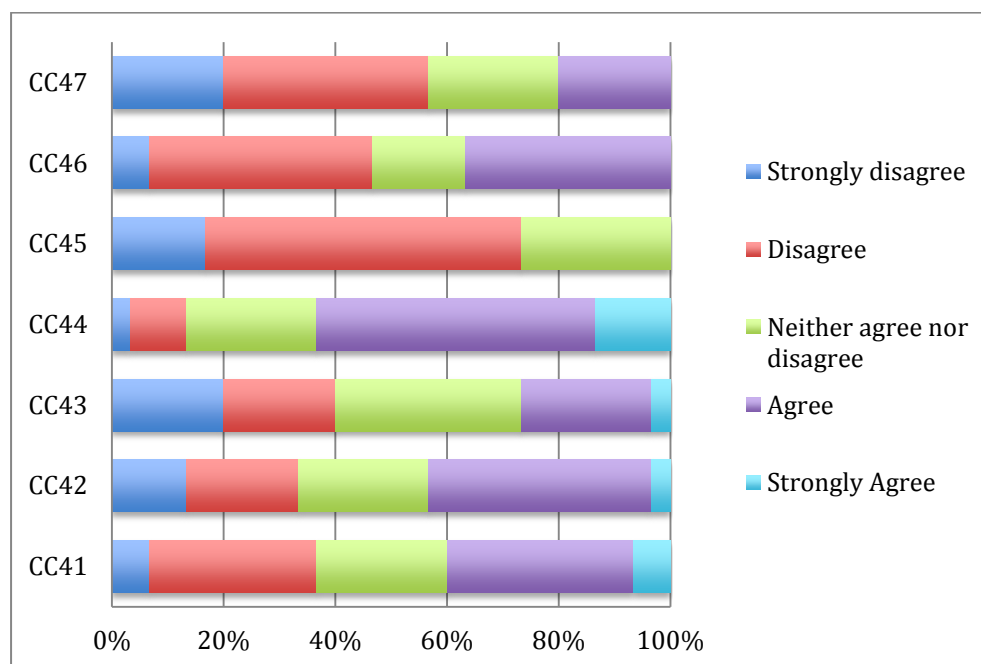
Figure 4.7. Child Cognition

The item that probed whether their sibling had an important and positive effect on their childhood (CC44), elicited the highest percentage of positive responses (63%) for the section dealing with child cognition. Twenty three (23%) perent of participants was ambivalent and the remaining 13% responded negatively. On the opposite side, item CC45 ('*My sibling knew everything about me when we were younger*') received no "agree" responses, 27% were ambivalent and the majority

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(63%) replied negatively. CC41 asked whether the participants perceived themselves to be 'buddies' with their sibling when they were younger. To this question, 40% responded positively, 37% negatively and 23% neither agreed nor disagreed. Fort-three per cent indicated that they were closer with their sibling when they were younger (CC42), 23 % were ambivalent and 33% disagreed or strongly disagreed. Twenty-seven percent (27%) indicated that they and their sibling were important to each other when they were younger (CC43), 40% did not agree with this statement and the remaining 33% were ambivalent. Item CC46, which asked whether they liked the same things as their sibling when they were younger, received a 37% positive response, 17% ambivalence and a 47% negative response. '*My sibling and I had a lot in common*' was answered positively 20%, 23% was ambivalent on this item (CC46) and 57% responded negatively.

Child cognition received a higher percentage of negative responses than did adolescent cognition, indicating that their beliefs about their relationship improved as they grew older. According to Piaget's theory of development, children at the formal operational stage would be better able to understand what autism is and how it will influence their relationship with their sibling (Ferraioli & Harris, 2009; Glasberg, 1998; Piaget, 1929). It is possible that their increased understanding of this matter would influence their beliefs about their relationships. It is, however, interesting to note that studies have found that children's understanding of ASD tends to be lower than what their tested cognitive level indicated them to be functioning at. This will be discussed in more detail in the next section.

4.4 Overview of the components of attitudes

The main aim of this study was to determine the attitudes of adolescents who develop typically towards their sibling with ASD. One of the most widely cited models for attitudes postulates that attitudes are the products of beliefs (the cognitive component) that often elicit strong feelings (affective component) and may lead to specific actions (behavioural component) (Oppenheim, 1998). The Lifespan Sibling Relationship Scale (Riggio, 2000) was therefore chosen and adapted for its ability to tap into the three underlying components of attitudes. In addition, it also has the ability to differentiate between present attitudes and those held by the participants at a younger age. It was of particular interest to the researcher to determine whether attitudes changed when siblings transition from one life stage to another.

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In order to gain an overview of the participants' (n=30) present attitudes and those that they remember having had at a younger age, the means procedure was employed during the statistical analysis of the data. The means for adolescent attitudes combining all three subscales were compared to the attitudes the respondents remembered to have held when they were children, using the t-test procedure. See Table 4.2 for a comparison.

Table 4.2

Comparison of adolescent and child attitudes (n=30)

	Mean	Standard deviation	Median	p-value
Adolescent attitudes	3.35	0.69	3.48	0.0072*
Child attitudes	3.00	0.59	3.13	

* Value significant at a 5% level (p ≤ 0.05)

With a p-value of 0.0072 there is a significant difference at the 5% level, indicating that there is a difference between the participants present attitudes (mean = 3.35, SD = 0.69) and the attitudes they remembered having when they were younger (mean = 3.00, SD = 0.59). As can be seen in Table 4.2, from the higher value, the participants' present attitudes were recorded as more positive. Further tests were subsequently run on the data to see, more precisely, where this difference lies within the components of attitudes. These results will be discussed in the following sections, which address the sub aims of this study.

Overall, the results from the MLSRS reflected the same trends as previous studies conducted on sibling relationships in families where ASD is present. In other words, there was a large majority of participants who responded to the challenges associated with ASD in a largely positive way, with a smaller minority who find it more difficult to deal with (Bemister, 2012; Mandleco et al., 2003; Petalas, et al., 2009). One hypothesis for this phenomenon is that the siblings who find it harder to cope, are part of the Broader Autism Phenotype, which would make adaptation harder for these children (Rutter, 2011). Families that include such children might also struggle to teach coping skills, either because they themselves lack the skills or because they are too preoccupied dealing with the child who is on the autism spectrum to respond to their typically developing child's needs as well (Petalas et al., 2009).

Bloch and Weinstein (2009) discuss the almost phenomenal ability that family members have to develop personal strengths and skills to cope with the extra stress of having a family member with a disability. These siblings often choose a career path associated with caretaking that requires empathy and compassion, but it has also been hypothesised that these children's extra helpfulness is born out of their own feelings of guilt for being healthy (Bloch & Weinstein, 2009).

4.5   Comparison of the components of attitudes

4.5.1   Comparison of attitudes according to life stage

To allow for a more comprehensive discussion of the results, further analyses were performed on the data. Firstly, the means and medians were calculated for each of the six subscales of the MLSRS, i.e. for AA, AB, AC, CA, CB and CC. In order to compare the components of attitudes held presently to those the respondents held previously, a paired t-test was run on the data (Steyn et al., 1998). In other words, child affect was compared to adolescent affect; child behaviour to adolescent behaviour; and child cognition to adolescent cognition. The results of the means procedure and the paired t-test are summarised in Table 4.3.

Table 4.3

Comparison between adolescent and child components of attitudes (n=30)

Components of attitudes	Adolescent			Child			Difference			
	Mean	*SD*	Median	Mean	SD	Median	Mean	*SD*	t-value	p-value
Affect	3.80	0.75	3.88	3.38	0.881	3.50	0.42	0.89	2.59	0.0148*
Behaviour	2.62	0.69	2.88	2.79	0.64	2.75	-0.18	0.68	-1.40	0.1710
Cognition	3.65	0.79	3.81	2.81	0.62	2.93	0.84	0.82	5.59	<0.0001*

Note: * Significant at the 5% level (p ≤ 0.05); *SD* = Standard deviation

There is a significant difference at a 5% level between adolescent affect and child affect (p= 0.0148) and between adolescent cognition and child cognition (p < 0.0001). For this group of participants, there seems to be no significant difference between adolescent behaviour and child behaviour (p = 0.1710). Overall, the responses were more positive in the section dealing with adolescent attitudes, as reflected by the higher mean values.

As shown in Table 4.3, the means for adolescent affect were higher than the means for child affect (mean = 0.42, SD = 0.89). The average adolescent may exhibit a range of mature to childlike reactions to situations (Hockenberry et al., 2005). As they become older, they learn to develop control over their emotions, which generally translates into more mature thinking about and feeling towards their siblings (Vliem, 2012).

Besides an increase in maturity, Bloch and Weinstein (2009) mentioned several reasons that could explain why individuals might experience their relationship with their sibling with ASD more positively as they become older. Younger children may be more affected by their parents' response to the diagnosis, which can be a very stressful process for the whole family. Since ASD is normally only diagnosed after two years of age, the grieving time in which the parents need to adjust to this new reality is delayed (Orsmond et al., 2009; Renty & Roeyers, 2006). Initially, siblings might feel very isolated, since as parents might not have the extra energy to deal with the needs of their children who develop typically, while they are going through this process and coming to terms with autism and its effect.

As the children become older, both they and their families may have more energy available to put better coping mechanisms in place (Vliem, 2011). This may help parents to be able to make decisions that benefit all members of the family as far as this may be possible (Bloch & Weinstein, 2009). In families with typically developing children parents would normally be concerned with clarifying their expectations of the roles they expect from their children in such a way that the maximum positive interactions are encouraged. Papacek (2012) however, found that when one of the children is diagnosed with ASD, parents become more focused on discussing the needs of the child with ASD. Normal division of familial roles will have to be adjusted to include this change in parents' expectations of their different children. Although this may help everyone to adjust to the new situation, it may have both negative and positive results. The parents' ability to navigate this minefield can have a significant impact on the relationships between the siblings (Papacek, 2012).

Another factor that might influence attitudes to become more positive is the adolescents' increased understanding of autism and its effects (Bloch & Weinstein, 2009; Glasberg, 2000; Vliem, 2011). Petalas et al. (2009) found that the better an individual's understanding of autism is, the more favourable their attitudes will be.

As children develop cognitively, they become better at problem solving, thinking ahead, at grasping abstract concepts and at controlling their emotions (Vliem, 2011). These are valuable skills to have when trying to understand the conceptual aspects of ASD (Aksoy & Yilidrim, 2003). The increase in positive attitudes may therefore be linked to an increase in understanding of ASD and its presenting characteristics (Petalas et al., 2009; Vliem, 2011).

There are studies that report that the understanding of ASD by their typically developing siblings tends to be very superficial (Huff, 2006; Glasberg, 1998, 2000). Glasberg (1998) also found that parents generally overestimated their children's understanding of autism. Usually, a person's understanding would depend on his or her cognitive level. Based on this, adolescents should be able to grasp more abstract concepts, which is necessary when trying to comprehend ASD and its characteristics; it is, however, not always obvious what the challenges are and what is driving the visible behaviour (Ferraioli & Harris, 2009). Studies have shown that children's understanding of less concrete disabilities like diabetes or autism is often lower than their tested level of cognitive understanding. It is therefore important for parents to note that, when it comes to autism, telling does not necessarily equal understanding (Glasberg, 1998, 2000). One reasons for the above may be that the emotionally laden nature of these disabilities might affect cognitive processing (Piaget, 1929). According to Piaget (1929), an individual's affective state will have an influence on how information will be processed. Some studies have found that these siblings were, however, able to recognise the long-term implication, such as that they will probably assume a caregiving role as well as the possibility that their own children might have similar problems (Huff, 2006; Glasberg, 1998, 2000).

Howlin and Yates (1990) also mentioned that children who have siblings with autism often develop into very compassionate and empathic adults with positive self-concepts shaped by their experiences with their siblings. In fact, their experience of growing up with a sibling with ASD often has an effect on their career choices (Martins, 2007). Vliem (2011) observed that, when there was a sibling with disabilities, adolescents found it very difficult to start separating themselves from their family to form their own individual identity as part of normal development. These adolescents will often decide to spend more time at home and choose tertiary education options or work opportunities that are closer to home, because of feelings of guilt or responsibility for their disabled sibling. This same thinking might possibly

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translate into responses that are more positive, since the participants may want to overcompensate for their sibling's disability by being more loving or caring (Vliem 2011).

A second notable difference reflected in the data is that the means for the behavioural components were the lowest reported means of the MLSRS. As mentioned earlier, it is possible that this is due to the fact that, no matter how positive their feelings towards their sibling are and how well they understand autism, they still need to deal with the obstacles associated with autism, for example, the impact a lack of communication and social skills will have on relationships (Glasberg, 1998). Thus, even though they would love to 'share their secrets with their sibling', they might not be able to do this if their sibling has limited understanding of language. Vliem (2011) mentions that one of the main stressors that children with a sibling with ASD report, is their frustration of their sibling not reacting to their attempts at interaction. Stoneman (2001) found that children who have a sibling with ASD spent, on average, less time with their sibling than those who have siblings with a different disability. Other negative aspects that stand out in the literature that would affect their responses towards their siblings are incidents of aggression from their sibling with ASD (Altiere & Von Kluge, 2009; Barry& Singer, 2001; Brewton et al., 2012)

Some researchers have also found that there may be discrepancies between people's attitudes and their behaviour. Factors that might influence this include people's situations, their dispositions and their motivation for behaviour. The strength of the relationship between attitude and behaviour is increased when there is a match between the affective and cognitive component of a person's attitude towards a specific object. Generally, people do try to be consistent in their attitudes and their behaviour (Beck, Thompson, et al., 2010).

Failure to acknowledge the difference between the adolescent's affect and cognition compared to their behaviour may possibly account for the mixed results reported in previous studies. Many of the previous sibling studies were based on parental reports on the sibling relationship (Farber, 2010). They would therefore place more weight on the behaviour that they can see, without necessarily accessing the internal processes of their children's feelings (affect) and beliefs (cognition) towards their sibling with ASD.

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4.5.2 Comparison of attitude components within each lifestage

In order to gain a better understanding of the three components of attitudes, a Friedman two-way analysis of variance (Steyn et al., 1998) was conducted to explore how the components of attitudes (affective, behavioural and cognitive) differed within each life stage. Table 4.4 provides a summary of these findings.

Table 4.4

Comparison of Components of Attitudes as an Adolescent (n=30)

Life stage	Affective			Behaviour			Cognitive			
	Mean	*SD*	Median	Mean	*SD*	Median	Mean	*SD*	Median	p-value
Adolescent	3.80[a]	0.75	3.88	2.62[b]	0.67	2.88	3.65[a]	0.77	3.81	< 0.0001**
Child	3.38[a]	0.88	3.50	2.79[b]	0.64	2.75	2.82[b]	0.62	2.93	0.0100*

Note: Differing superscripts indicate significance at a 5% level, * Significant at a 5% level; *SD* = Standard deviation; ** Significant at a 1% level.

Follow-up pairwise comparisons were conducted on the data. With three groups the critical z value for an alpha of 0.05 is 2.39. Results indicate that there is a significant difference between adolescent attitudes and adolescent behavior (Z-stat = 6.20) and between adolescent behavior and adolescent cognition (Z-stat = 5.03). However, the results for adolescent attitudes and adolescent cognition do not differ significantly (Z-stat = 1.16). As can be seen in table 4.4, there is a significant difference between child affect and both child behaviour (Z-stat = 2.78) and child cognition components (Z-stat = 2.45), while there is no significant difference between the behavioural and cognitive components (Z-stat = 0.32).

As is evident in Table 4.4 both affect and cognition have a higher mean value than behaviour, especially in adolescence. This may, as was mentioned earlier, be linked to the fact that, although the participants might overall have positive feelings and empathy towards their sibling with ASD, it does not negate the fact that it is very difficult to have a 'typical' relationship with a sibling who finds it challenging to interact in social contexts (Carrillo, 2012).

When reflecting on their attitudes as younger children, the adolescents' responses reflected a significant difference on the 5% level between child affect and child behaviour and between child affect and child cognition. Child behaviour and

child cognition showed very little difference in overall responses. These two components (behaviour and cognition) received lower mean values. It seems that although the participants remembered feeling positive towards their sibling when they were younger, their actual behaviour and beliefs about their relationship were more negative.

Overall, the participants seem to have positive attitudes towards their siblings, with only a minority reporting negative attitudes. Petalas et al. (2009) found that negative views generally revolved around concerns about the future of their sibling with ASD, feeling neglected by their parents and the impression that their sibling is rejected by others. However, having a deeper understanding of their sibling's disability and the perception that parents and peers respond positively towards their sibling was linked to more positive sibling relationships.

4.5.3   Implications for siblings who develop typically

Looking at the results in the light of other research that has been conducted previously, it would seem that the majority of adolescents cope well with the extra demands placed on a family by the presence of a sibling with ASD. However, a minority of researchers find it difficult to deal with the question of who is benefitting from intervention strategies. It might also be necessary to gauge the well-being of those siblings who seem to be coping well, since some studies did indicate that they might overcompensate out of feelings of guilt (Huff, 2006; Guzman, 2007).

Huff (2006) listed the following as aspects that siblings of children with ASD found challenging: feeling that they are receiving less parental attention, fewer family outings and not being able to participate in as many extracurricular activities as their peers do, having to take on more responsibilities at home and higher levels of stress. Additionally, these children are often exposed to having to deal with negative reactions from the public because of the behavioural or emotional problems of their sibling with ASD; and, furthermore, they are often exposed to some aggressive behaviour.

Different life stages should have an impact on how children deal with these stressors. Since adolescence is often associated emotional conflict as children seek to differentiate themselves from other family members, it would seem natural that adolescence would make it harder for children to cope with their siblings' often aggressive or embarrassing behaviour (Opperman & Alant, 2003). Adolescence is

also characterised by several transitions that need to be navigated, both external changes such as moving from primary school to high school or the pressure of having to start making decisions around career choices, as well as internal changes associated with puberty. Interestingly, though, in spite of the emotional turbulence associated with adolescence, the participants in this study indicated that they had become more positive about their sibling and their relationship with him/her.

Sibling support groups may be an effective way to provide support for these siblings (Huff, 2006). Guzman (2007) discussed siblings' need for opportunities to talk about their experiences, since they might feel they are neglected at home, are socially isolated and tainted by the stigma of having a sibling with ASD. Sibling support groups may help those siblings who perceive that they themselves are disadvantaged in regarding a more positive identity through connection with others (Guzman, 2007). Huff (2006) suggested that these opportunities could be provided by schools or in the community. Such support groups would allow siblings to meet other children who are living in the same community and share the same experiences.

Not many studies have been conducted on how these groups should be best be run; however, Guzman (2007) suggested that psycho-educational groups would probably be the most meaningful, because these groups would provide education, support and building of skill. Guzman (2007) developed a manual providing detailed information on how to run nine weekly sessions covering topics such as information on autism and the participants' feelings surrounding their sibling relationships, family and school. One of the sessions would be specifically for parents and another is meant to be with parents and children together. The manual also includes an information section for the facilitator, providing an overview of autism as well as advice on how to structure the groups.

It is important to recognise that, as the children get older, they need to continue receiving information about ASD that reflects their changing needs and understanding as they move from childhood through adolescence (Guzman 2007). As the children mature, more detail will become necessary and different topics will become important to them. Providing siblings with information that will help them to understand their sibling better will have a positive effect on sibling relationships (Roeyers & Mycke (1995). Providing information that is developmentally relevant is very important because, if they are not provided with an explanation that enables them to make sense of the condition, children often create their own version of what the cause of their

sibling's autism is. (Guzman, 2007). In a study by Lobst, Nabors, Rozenweig, Srivorakiat, Champlin, Campbell, & Segall, (2008) it was found that the type of information they received influenced adults' attitudes towards a child with ASD. It may therefore be important to determine the type of information to provide siblings with; for example, should it be explanatory or neuropsychological in nature. Guzman (2007) suggested that a forum that allows siblings to ask questions will help professionals or parents to identify misconceptions held by the children and subsequently work through these issues with them. Not only should these groups be aimed at increasing an understanding of ASD by dispelling misconceptions on the etiology of the condition and feelings of personal responsibility, but should also provide an environment where the participants can share their feelings (both positive and negative) with others who share their experiences of living with a sibling with ASD (Guzman, 2007). It should also allow opportunities for children to model for others as well as to learn about effective ways of coping and interacting with their sibling with ASD (Guzman, 2007; Huff, 2006).

From feedback on a study by Dyson (in Guzman, 2007) with children who had a sibling with a disability, it seemed that most children felt that the most valuable part of the programme was learning how to improve their relationship with their sibling, as well as learning more about their sibling's disability. They also indicated that they would have liked to learn even more. It was concluded from this study that sibling support groups may be beneficial for improving sibling relationships (Guzman, 2007).

However, in spite of all indications that sibling support groups help support participation and may increase the typically developing sibling's self concept, there are not many support groups available to siblings. The main reason for this seems to be the difficulty in arranging daily or weekly meetings that suits the professionals, the parents and the siblings of the children with ASD. This might also be part of the reason why it was so difficult to find enough participants for the present study (Huff, 2006).

One possible method to overcome these logistical constraints is to establish online support groups. The internet can provide a platform where siblings can find other children across the globe whom are also affected by ASD (Jordan, 2010). It may also provide these children with an opportunity to talk about their experiences, as well as being a great platform for advocacy (Jordan, 2010). Online support groups

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have been shown to be able to help foster personal empowerment and feelings of well-being, which in turn help mediate the effects of stressors (Barak, Boniel-Nissim & Suler, 2008). In a review of 33 websites that were self-published by parents of children with ASD, Fleischmann (2005) found that these sites helped stressed parents to form bonds with other parents in similar situations and this helped them to feel less isolated. Exploring this idea for siblings may be worthwhile.

There are, however, also several potentially negative aspects of moving towards online support groups. For example, participants may become dependent on web-based interaction resulting in a decline in face-to-face contact (Barak et al., 2008). There is, additionally, also always the general risk of possible exposure to unpleasant experiences often associated with web-based social interaction (Barak et al., 2008). Web-based support groups are also difficult to be accessed by lower income families (Jordan, 2010; Mackintosh, Myers & Goin-Kochel, 2005). Information found on the internet is also often misleading, inaccurate or incorrect (Jordan, 2012; Plantin & Daneback, 2009). Furthermore, there are not many sites aimed at training families (Plantin & Daneback, 2009). Most sites also seem to be created more specifically for parents or the individuals with ASD than for the siblings (Jordan, 2010).

4.5.4   Implications for siblings with ASD

The development of positive sibling relationships may help siblings to improve their social and communication skills (Huff, 2006, Papacek, 2012). Besides benefitting the siblings who develop typically in improving their self-concept and understanding of ASD, support groups may also improve relationships and communication skills for both siblings. This is especially important to take note of when looking at, for example, Knott, Lewis et al's. (1995) study that compared how children with siblings with ASD and those with siblings with Down's syndrome interacted. These researchers found that sibling dyads where autism is present spent considerably less time together in a room and initiated less interaction than those who had a sibling with Down's syndrome. Several studies indicated that interventions that teach siblings how to interact with their sibling with ASD, might improve the quantity and quality of interaction (Czekalski, 2009; Hansford, 2012; Lingling, 2004; Lantz, 2005). Many typically developing siblings indicate a desire to have a closer relationship with their sibling with ASD, but lack the knowledge or skills to develop

their relationships (Papacek, 2012). The evidence suggests that siblings might be better teachers of social skills than teachers that are unrelated. This is however not an area where older siblings (or more capable) siblings would normally feel responsible to provide guidance in (Lantz, 2005).

Additionally, several studies have indicated that peer-mediated intervention strategies were one of the most effective means to teach social and communication skills to children with ASD. (Jones & Schwartz, 2004; Locke, et al., 2012; Oppenheim-Leaf et al., 2012). An essential aspect for this process to be effective would be that the siblings who develop typically have positive attitudes towards their sibling (Jones & Schwartz, 2004).

Because sibling-mediated intervention strategies might initially be a very labour intensive process, adults will need to drive the process; the potential benefits should outweigh the time put into the process (Jones & Schwartz, 2004). These authors also mention several benefits to this approach, e.g. the familiarity of the siblings with each other (familiarity is more conducive to imitation in ASD) and the number of interactions a sibling relationship allows on a daily basis and over a longer period of time. Although siblings are not necessarily better models than same age peers, they are nevertheless more motivational models for children with ASD than what adults are. Studies have shown that children who were trained to engage with their sibling with ASD resulted in improved joint attention and social behaviour (Tsoa & Odom, 2006). These social skills may also be better generalised to interactions with peers than adult interaction would be (Oppenheim-Leaf, et al., 2012). Improved understanding of theory of mind has also been linked to interaction with siblings who develop typically (Perner, et al., 1994).

Taking into account the positive feelings (affective component of attitudes) that the majority of participants experience towards their sibling with ASD, they would make very willing helpers in intervention strategies. Providing them with the information that would allow them to be part of intervention may prove beneficial, not only for child with ASD but also for the sibling who develops typically and who can now feel 'part of the solution'. The stronger the sense of the family being a team, the more beneficial the support the members will provide each other will be (Altiere & von Kluge, 2009).

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4.6   Conclusion

This chapter discussed the reliability of the scale (the MLSRS) and the statistical measures used to analyse the recorded data. The results obtained from these were presented and discussed in detail in order to address the sub aims of the study. The participants overall MSLRS mean values and their mean values for each subscale were compared according to the two life stages targeted by the MLSRS. This as followed by a comparison of the attitude components within each subscale. This chapter concluded by discussing the implications of the findings for siblings who develop typically as well as for the sibling with ASD.

Chapter 5

Summary and conclusion

5.1 Introduction

This chapter provides a summary of the results of the study. Conclusions are drawn in the light of the review of the relevant literature and theory. The study is critically evaluated for both its strengths and limitations. Clinical implications of the results of the study are discussed, as well as recommendations for future research.

5.2 Summary of results

Although it is clear from the literature that siblings have a significant reciprocal effect on each other's social and interpersonal development, research has provided contradictory results on what the impact of ASD is on these relationships is (Macks & Reeve, 2007; Papacek, 2012, Smith & Elder, 2010; Twoy, Connolly, & Novak, 2007). There are many possible reasons why these contradictory findings may have occurred, not least of them being the complexity of both the nature of the disorder itself and of family interactions (Smith & Elder, 2010). It seems that more recent studies have yielded more positive results than older studies, which may support the notion that an increase of understanding about ASD and the implementation of more effective intervention strategies contribute to the more positive viewpoints (Guzman, 2007; Huff, 2006). This study aimed to increase the understanding of these pivotal sibling relationships, especially with the rising prevalence of ASD. In this way, intervention can be implemented that may support both the sibling who develops typically and the sibling with ASD, influencing the dyad positively.

In order to better inform service providers and parents on how to facilitate increased quality and quantity of sibling interactions, this study investigated the present attitudes of adolescents who develop typically towards their sibling with ASD and those attitudes they remember to have had when they were younger. Attitudes were selected as the construct to be measured as they affect behavior. The more positive siblings' attitudes are about each other, the more likely they are to engage in interaction. To do this, 30 typically developing adolescents who have siblings with ASD were selected to complete the survey instrument, namely the Modified Lifespan

Sibling Relationship Scale (MLSRS). The survey instrument worked on the conceptualization of attitudes as consisting of three components, namely affective, cognitive and behavioural, which result in a readiness or tendency to respond to a given stimuli in a certain way (Oppenheim, 1998). The survey instrument was modified from an existing scale, namely the Lifespan Sibling Relationship Scale (LSRS) that measures adult attitudes towards present sibling relationships as well as those they remembered from when they were younger.

The results of the study indicated that the majority of adolescents had strong positive feelings towards their sibling with ASD (affective component) both presently and when they were younger. Their actual interaction (behavioural component) is significantly less positive than their feeling (affective component) towards their siblings, both as adolescents and as they remembered them as younger children. Their beliefs about their siblings and their relationship with them (cognitive component) are more positive as adolescents than what their remembered beliefs were. There is also a significant difference between the cognitive and the behavioural components as adolescents: as younger children the cognitive and behavioural components of their attitudes were very similar, with a significantly more positive affective component in comparison to both the behavioural and cognitive components as adolescents. This may be indicative of the fact that, although they may feel very positive towards their siblings, they find it very difficult to understand what ASD is and they experience the challenges of having to interact on a daily basis with someone who has ASD.

This study highlights that, although siblings who develop typically may experience their relationship with their sibling with ASD as positive, it may still be difficult to interact effectively with them. Thus, there is a need for siblings to be provided with age appropriate information about their sibling's disorder as well as to be taught how to engage and interact with their sibling with ASD. This is especially important if one takes into consideration that people with ASD generally have a normal lifespan. This means that the siblings who develop typically, in all probability will take responsibility at some point when their parents are no longer able to do so. An additional benefit of teaching effective ways of interaction to siblings who have a sibling with ASD, is that they make excellent role models for these children. Furthermore, studies indicate that when children who develop typically were involved in helping to manage and teach siblings with developmental delays, it resulted in

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fewer behavioural problems in the siblings who develop typically themselves (Smith & Elder, 2010).

Although most of the siblings responded positively to the questions in the instrument by indicating that they held positive attitudes towards their sibling with ASD, some siblings did respond negatively. They would most likely benefit from support that is specific to their situation. From the feedback received on the sibling days by both the children and the parents it seems that although most of the typically developing children are dealing well with the extra demands inevitably placed on them, they have a need to be able to talk freely about and share their thoughts with peers who have similar experiences.

Hopefully, this study will contribute to a better general understanding of the field of sibling relationships; such understanding may provide effective intervention strategies that will help adolescents to cope with challenges associated with having a sibling with ASD. Furthermore, it may provide these adolescents with skills that will empower them to become more effective interaction partners to their sibling with ASD in the intervention process.

5.3   Critical evaluation

This evaluation of the study will be twofold: firstly, the strengths of the study will be explored and subsequently aspects that could be seen as place limitations of the study are discussed in detail.

5.3.1   Strengths of the study

Although the study included a relatively small sample size (n=30), it was still a larger study than many of the other studies exploring sibling relationships where ASD is present. For example, both Huff (2006) and Guzman (2007) mentioned difficulty in obtaining more participants. Using an existing scale (the LSRS) that had been extensively tested for reliability and validity (as discussed in Chapter 3) also had a positive influence on the reliability of the results of the current study. The fact that the results of this study echoed the tendencies reported for studies focusing on other aspects of sibling relationships influenced by ASD (Petalas, et al., 2009; Quintero & McIntyre,2010), can also be an indication of the validity of the present study's findings.

The survey instrument used in this study, namely the LSRS, was initially developed for adult participants; it was, however, successfully modified and tested in a pilot study to measure adolescent attitudes. This allowed the study to focus on a specific life stage, in this case adolescence, while simultaneously capturing some of the changes that occur in the attitudes of siblings as they mature from childhood into adolescence. Even though the survey instrument relies on attitudes as they are remembered, this information is interesting, since there are not many longitudinal studies on families. This is especially interesting because attitudes are influenced by life stage (Davys, Mitchell & Haigh, 2010; Zomick, 2010).

An additional strength of this study is the use of 'Sibling Days' for data collection. It allowed the researcher to get a feel for some of the topics that the adolescents found of importance and that could not necessarily be captured by using the survey instrument alone. Furthermore, these Sibling Days were much appreciated by both the adolescents and their parents with many parents contacting the researcher to find out when another "Sibling Day" would again be held. The parents also expressed their gratitude in subsequent telephone calls and emails. A space was created where the participants could meet peers with similar experiences. Many of the adolescents exchanged phone numbers with each other at the "Sibling Days" in order that they may arrange subsequent meetings. This type of informal peer support is critical during adolescence (Huff, 2006; Guzman, 2007).

This study added to the discourse on the impact of ASD on sibling relationships and it provided both practitioners and parents with some insight that might help them to implement strategies that could support both children who develop typically and their siblings with ASD.

5.3.2 Limitations of the study

Due to the complexity of family relationships, the study has several limitations that have to be acknowledged since the nature of the thesis allowed the researcher to focus on very specific aspects of sibling relationships only.

As mentioned earlier, the use of a survey instrument in a questionnaire format allowed for larger amounts of data to be collected and processed in order to address the main aim and sub aims of the study. However, this meant that adolescents were able to answer questions addressed in the MLSRS only. Qualitative research methods could have allowed the researcher to explore issues that the participants find

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meaningful in more depth (Petalas et al., 2009). During the "Sibling Days" conversations with the adolescents brought up several themes that reflected some issues from the literature, for example, that children may express their relationship as positive but still carry concerns for the future of their sibling with ASD (Huff, 2006). Another theme was the perceived parental favouritism that the literature review indicated was common concerns for children with siblings who have ASD (Petalas et al., 2009). However, these themes were not further pursued for the purposes of this study as these concerns were beyond the scope of the study and were not captured by the MLSRS.

There were various constraints regarding the sample population. The sample size, for example, made it difficult to generalise the results to the larger ASD population. However, it is important to take cognisance of the reasons that might have led to it being so difficult to recruit a greater number of potential participants. Firstly, the tight participant selection criteria made for a limited sample, even though some of these criteria were reworked in order to increase the population size. For example, initially the study would only have included older siblings since birth order has been shown to influence sibling relationships, but this criterion was relaxed to include both older and younger siblings (Mandelco et al., 2003).

There were several other variables that were also not taken into consideration, because as it would have limited the sample size. For example, no distinction was made between different cultures. The influence of culture on how siblings who develop typically process the disorder has not been adequately investigated (Guzman, 2009; Papacek, 2012). The study also did not take the educational level of the parents or the severity of the disorder into account; both factors could effect the amount of stress a family experiences (Aksoy & Yilidrim, 2008; Bemister, 2009; Bemister, 2012; Farber, 2010).

It is also possible that attending the "Siblings Days", or even just completing the questionnaire, was perceived to take too much time and commitment from parents and siblings who might already be feeling overwhelmed (Altiere & Von Kluge, 2009), especially if the parents did not feel that participating in the project would benefit their child with ASD directly. Parents might also be hesitant to expose their children to research (Papacek, 2012).

Looking at some of the participants' descriptive criteria, there is a possibility that the study might not fully represent the larger ASD population. Petalas et al.

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(2009) reports that large, cohesive families act as a buffer for the stresses associated with autism. Table 3.7 shows that 60% of the participants came from families with three or more children. The fact that the parents made the effort to help their child participate in the research could also be an indicator of a more cohesive family structure. With 22 936 divorces in South Africa in 2010 alone (Statics South Africa, 2010), the participants also do not really reflect the tendencies in the general population since most of the families in the study were still intact. However, published studies indicate that divorce is not the main demographic factor that influences sibling relationships, but rather socio-economic status, age, number and gender of siblings (Farber, 2010; Macks & Reeve, 2007).

All of the families were recruited through schools specialising in ASD and autism support networks such as Autism Western Cape and AutismSA. This might possibly bias the results, as these families were already accessing service delivery to some extent. If the participants had been recruited through hospitals or community clinics, the results might have been less positive (Guzman, 2009; Huff, 2007).

The fact that parents are concerned enough about the well-being of their sibling who develops typically to have encouraged them to participate, may also be an indication that these are families that are doing as much as possible to ensure the well-being of each of the family members (Farber, 2010).

This study also did not control for the effect of the broader autism phenotype. In other words, the phenomenon that, although other family members may not be on the autism spectrum, they may also have some personality traits similar to ASD (Rutter, 2011). It has been hypothesized that siblings who have the broader autism phenotype might find it more difficult to cope with extra stressors (Rutter, 2011).

5.4   Clinical implications

Rivers (1998) mentioned that often studies concerned with sibling relationships tend to expect negative responses to having a sibling with ASD, when in fact, many siblings reported taking pleasure in being able to take care of their siblings or to be able to amuse them when asked. Papacek, (2012) found that the more children played cooperatively with their sibling with ASD, the more helpful they were towards their sibling. Cooperative play and turn-taking play a pivotal role the development of social skills and relationships. The results of this study seem to confirm that the majority of siblings are eager to interact with their sibling with ASD,

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irrespective of age. Teaching the typically developing siblings how to interact more effectively may be of enormous benefit to both siblings, especially since many of these children naturally take on a 'teaching role' as part of their interaction with their sibling with ASD (Papacek, 2012).

All stakeholders in intervention programmes need to understand the importance of sibling relationships and fostering them. Understanding the effects that ASD has on these relationships may help to improve the design of intervention strategies that are beneficial for everyone involved (Papacek, 2012). For example, it is important to take note that having a sibling with ASD has an effect on the development of children, especially if they are younger than the sibling with ASD (Tremaine, 2011). Parents may also benefit from a deeper understanding of how their children experience the effect of ASD, especially to help them when making decisions around issues such as the sharing of chores. Other issues that parents might need to be made aware of relate to the way in which parents intervene in sibling conflict, since this has been shown to be one of the most influential factors influencing sibling relationships. The amount of interpersonal conflict in the larger family system also has an impact on the behavioural adjustment of siblings of a child with a disability (Rivers, 1998).

A better understanding of how children interact through the different life phases can also assist professionals in guiding parents in how to encourage play and social interaction amongst their children (Papacek, 2012). As discussed in more detail in Chapter 4, if we understand the experiences of the siblings of the children with ASD and the challenges they face on a daily basis better, more appropriate training may be provided for the professionals and parents of these families (Papacek, 2012). Providing appropriate training may also prevent burn-out in the siblings, which, if not addressed, may result in the sibling becoming less willing to participate in the intervention process (Reiter & Vitani, 2007). Such training should benefit both the children who developing typically and the child with ASD. The first group will experience their relationship more positively and the latter group will benefit, because their brother or sister will be more engaged and therefore be a better role model for a variety of life skills.

The provision of support networks for the typically developing siblings may also provide a forum where they can talk about their experiences with other children in similar situations. Even though many children experience their sibling positively,

one cannot ignore the fact that some of the siblings have a very stressful experience. Children who are allowed to express their feelings, even if these feelings are negative, tend to show less behavioural problems (Rivers, 1998). Those children who report that they enjoy their sibling often also have stories to tell of negative childhood memories associated with their sibling's autism (Martins, 2007). It was noted that even though parents and siblings express a need for support groups, it is not always practically possible to fit this into the family schedule. The development of web based support groups may possibly help to address the need for support groups when attending face-to-face groups is logistically difficult for families. The fact that the siblings spontaneously shared telephone numbers after the "Sibling Days" also attests to the importance of informal support for this age cohort.

5.5   Recommendations for future research

Recommendations for future research based on the results from this study include:

- To investigate the attitudes of typically developing adolescents towards their sibling with ASD in more depth by using qualitative research designs. This will allow for a deeper understanding of how these relationships are affected. Each sibling is an individual that will be affected differently and is therefore expected to respond differently (Bloch & Weinstein, 2009).
- To investigate sibling relationships using longitudinal research designs in order to gain a better understanding of how these relationships change over time and what the long-term effects of ASD on sibling interactions may be. This can also help inform intervention strategies for different developmental stages, since these stages may influence the type of support that a family needs (Rivers, 1998).
- To investigate ways in which typically developing siblings may be supported through social media support groups on platforms such as Facebook or e-mentoring programmes (Shpigelman, Reiter & Weiss, 2008). This might help overcome some of the problems faced with other group programmes where parents and professionals find it difficult to find the time to participate in these programmes (Guzman, 2007; Huff, 2006).
- To explore in more depth the effects of factors such as cultural expectations, household structures, gender, degree of Autism, socio-economic status and

education on family interactions and responses to the impact of ASD. Thus far, the findings on the effect of these have been mixed; for example, some studies have shown that large families can be more distressed, especially if they feel overwhelmed by having to meet the needs of so many children while others have found larger families to be better adapted, especially if they are financially stable (Mandelco et al., 2003). This may be because there are more members to help with caretaking roles. Studies on the role of birth order and gender show mixed results, as well as those on type of disability.

- To investigate what variables mediate the effects of ASD on family systems. The systemic view of families suggests that the adaptive and functional patterns of families will have an effect how stressors are absorbed by the family system (Mandelco et al., 2003). Additionally, different types of stress may have different effects on a family system (Rivers, 1998). It would be interesting to explore these patterns in greater depth.

- To explore the actual impact of ASD in terms of the time spent on therapy and services and other factors influencing family routine and how this influences the time spent with the other children.

- To investigate what methods would best allow children to become effective models for their sibling with ASD and to research the effects of training in play and interaction from a young age on the development of sibling relationships (Papacek, 2012).

- To investigate what would be the most effective way to help children understand their sibling's disorder throughout the various life phases, taking into account that the present study showed that children's understanding of ASD tended to be lower than their tested level of cognitive processing (Bloch & Weinstein, 2009; Glasberg, 2000; Vliem 2011).

5.6   Summary

This chapter provides a conclusion to the results of this study. The results were summarised and integrated with the current literature, relevant to the research topic. The strengths and weaknesses of the study were critically evaluated and the clinical implications explored. Finally, recommendations for future research were discussed.

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APPENDICES

Appendix A:

Ethical clearance

letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

19 July 2012

Dear Dr Harty

Project:	**An investigation into the attitudes of typically-developing children towards their siblings with Autism Spectrum Disorder in relation to participation**
Researcher:	**C van der Merwe**
Supervisor:	**Dr M Harty**
Department:	**Centre for Augmentative and Alternative Communication**
Reference number:	**97019420**

Thank you for your response to the Committee's letter of 12 May 2011.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 19 July 2012. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. John Sharp
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof A Mlambo, Dr C Panebianco-Warrens; Prof J Sharp (Chair); Prof GM Spies; Prof E Taljard ; Dr FG Wolmarans, Dr P Wood

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Appendix B: The Modified Lifespan Sibling Relationship Scale (MLSRS)

Have you been explained what today is all about?

YES   NO

Do you understand that it is you choice to help me today?

YES   NO

Do you understand that you can stop anytime you want to?

YES   NO

Biographical information	For official purposes only	
1. Do you have a sibling with autism? Yes: ☐ No: ☐	A1	
2. How old are you now (in years)? ☐	A2	
3. How old is your younger sibling with autism (in years)? ☐	A3	
4. What is your gender? Male: ☐ Female: ☐	A4	
5. What is the gender of your sibling with autism? Male: ☐ Female: ☐	A5	
6. Do both you and your sibling live in the same house? Yes: ☐ No: ☐	A6	
7. Do you have other siblings living with you (in the same house)? Yes: ☐ No: ☐	A7	
8. How many siblings are you altogether? ☐	A8	
9. Are your parents still married? Yes: ☐ No: ☐	A9	

3

Lifespan Sibling Relationship Scale

This survey is to learn more about how teenagers feel about their brother or sister. The first part looks at how you feel about your brother and sister now that you are a teenager. The second part looks at how you felt about them when you were younger.

Remember we are interested in how you really think and feel about your brother or sister.

There are NO wrong answers!!!!

Instructions: please read carefully

1. Circle the number that is the closest to how you feel about that question.
2. Only give one answer per question.
3. Answer the questions with only ONE of your YOUNGER brothers/sisters with autism in mind.

Practise items						For official purposes only
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	
1. I enjoy going to the movies with my friends	1	2	3	4	5	
2. I like getting lost in the mall	1	2	3	4	5	
3. I enjoy playing video games	1	2	3	4	5	

Lifespan Sibling Relationship Scale						For official purposes only	
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree		
1. My sibling makes me happy	1	2	3	4	5	A1	
2. My sibling's feelings are important to me	1	2	3	4	5	A2	
3. I enjoy my relationship with my sibling	1	2	3	4	5	A3	
4. I am proud of my sibling	1	2	3	4	5	A4	
5. My sibling and I have a lot of fun together	1	2	3	4	5	A5	
6. My sibling frequently makes me angry	1	2	3	4	5	A6	
7. I admire my sibling	1	2	3	4	5	A7	
8. I like to spend time with my sibling	1	2	3	4	5	A8	
9. I presently spend a lot of time with my sibling	1	2	3	4	5	A9	
10. I call my sibling on the phone frequently	1	2	3	4	5	A10	
11. My sibling and I share secrets	1	2	3	4	5	A11	

5

12. My sibling and I do a lot of things together	1	2	3	4	5	A12	
13. I never talk about my problems with my sibling	1	2	3	4	5	A13	
14. My sibling and I borrow things from each other	1	2	3	4	5	A14	
15. My sibling and I 'hang out' together	1	2	3	4	5	A15	
16. My sibling talks to me about personal problems	1	2	3	4	5	A16	
17. My sibling is a good friend	1	2	3	4	5	A17	
18. My sibling is very important in my life	1	2	3	4	5	A18	
19. My sibling and I are not very close	1	2	3	4	5	A19	
20. My sibling is one of my best friends	1	2	3	4	5	A20	
21. My sibling and I have a lot in common	1	2	3	4	5	A21	
22. I believe I am very important to my sibling	1	2	3	4	5	A22	
23. I know that I am one if my sibling's best friends	1	2	3	4	5	A23	
24. My sibling is proud of me	1	2	3	4	5	A24	

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	For official purposes only	
25. My sibling bothered me a lot when we were younger	1	2	3	4	5	A25	
26. I remember loving my sibling a lot when we were younger	1	2	3	4	5	A26	
27. My sibling made me miserable when we were younger	1	2	3	4	5	A27	
28. I was frequently angry at my sibling when we were younger	1	2	3	4	5	A28	
29. I was proud of my sibling when I was younger	1	2	3	4	5	A29	
30. I enjoyed spending time with my sibling when we were younger	1	2	3	4	5	A30	
31. I remember feeling close to my sibling when we were younger	1	2	3	4	5	A31	
32. I remember having lots of fun with my siblings when we were younger	1	2	3	4	5	A32	
33. My sibling and I often had the same friends when we were younger	1	2	3	4	5	A33	
34. My sibling and I shared secrets when we were younger	1	2	3	4	5	A34	
35. My sibling and I often helped each other when we were younger	1	2	3	4	5	A35	
36. I looked after my sibling when we were children	1	2	3	4	5	A36	

37. My sibling and I often played together as children	1	2	3	4	5	A37	
38. My sibling and I did not spend a lot of time together when we were younger	1	2	3	4	5	A38	
39. My sibling and I spent time together after school when we were younger	1	2	3	4	5	A39	
40. I talked to my sibling about my problems when we were younger	1	2	3	4	5	A40	
41. My sibling and I were 'buddies' when we were younger	1	2	3	4	5	A41	
42. My sibling and I were closer when we were younger	1	2	3	4	5	A42	
43. My sibling and I were more important to each other when we were younger	1	2	3	4	5	A43	
44. My sibling had an important and positive effect on my childhood	1	2	3	4	5	A44	
45. My sibling knew everything about me when we were younger	1	2	3	4	5	A45	
46. My sibling and I liked all the same things when we were younger	1	2	3	4	5	A46	
47. My sibling and I had a lot in common when we were younger	1	2	3	4	5	A47	

THANK YOU FOR YOUR PARTICPATION

8

Appendix C: Consent letters for principals

XXX
XXX
XXX
17 April 2012

XXXX
XXXX
XXXX

The Principal and Trustees of XXX School

REQUEST TO CONDUCT RESEARCH AT YOUR INSTITUTION

I hereby request permission to conduct my proposed research study at your institution.

Research topic:
An investigation into the attitudes of typically-developing adolescents towards their siblings with autism

Rationale for the study:
In the past decade there has been a shift from focusing on impairments to looking at how able an individual is to participate in his or her community. The literature indicates that for a child to learn and develop socially, active participation is essential. However, due to the combination of impairments in social interaction, communication and imagination, children with autism generally don't interact very well with either their siblings or peers, and will not easily initiate play. This may result in frustration for their neurotypical sibling, as their attempts at interaction may fail regularly, leading to minimal positive daily learning opportunities. Without intervention, children with autism are therefore very vulnerable to being excluded from their peer group and being able to participate fully in society.

Research indicates that siblings are one of the greatest influencing factors in a child's development. In fact, sibling relationships are normally the second strongest bond that a child forms after that with their parents. Early social development generally starts with sibling interaction. These interactions play an important role in a child's social life - whether they have autism or not - and are deemed pivotal for developing relationship skills. One's social understanding increases with exposure to a variety of social experiences. Encouraging positive sibling relationships can, therefore, provide a rich source of interactional experience.

The neurotypical sibling is also affected in their development by their autistic sibling. A review of the literature, however, shows mixed results relating to the social, emotional and behavioural adjustment of siblings of individuals with ASD. Some studies have shown higher levels of depression in the neurotypical siblings, while others seem to indicate that sibling relationships can be mutually beneficial and positive.

This study will focus on sibling attitudes. Literature shows that obstacles faced by the disabled, are largely due to societal attitudes. Research indicates that interaction between children is more likely where positive attitudes towards disabilities are held. Very little research, however, has been done to explore the attitudes of neurotypical children towards their sibling with ASD, especially in regards to interaction.

Although it is well known that family-members are key role-players in the decision-making process, siblings still often feel excluded. Assessing children's attitudes towards their sibling with autism may provide important information when designing comprehensive and meaningful interventions that are aimed at improving attitudes and behavior towards children with autism.

What are the objectives of this study?
The primary objective of this study is to determine and describe the attitudes of typically-developing children towards their siblings with autism who have specific communication difficulties.

The following sub-aims were formulated to attain the primary objective:
  ➢ To adapt the Lifespan Sibling Relationship Scale (LSRS) (Riggio, 2000) in order for it to be appropriate for use on typically developing adolescent towards their sibling who has autism.
  ➢ To apply the scale in order to determine the attitudes of typically-developing adolescents towards their siblings with autism.
  ➢ To describe the results obtained from the attitude scale as it pertains to the attitudes of typically-developing adolescents towards their siblings with autism.

What will be expected of us as an institution?
Upon approval of this request, you will grant the researcher permission to conduct the proposed research study using the older siblings of learners at your school. Data Collection will take place as follows:

- A letter will be sent home with the children stipulating the selection criteria and requesting interest in participating in the study. The parents who have indicated that their children meet the selection criteria and are willing to participate will then be contacted telephonically.
- Parents will be provided with all the relevant documentation pertaining to the study. This will include an information brochure and an informed parental consent form.
- A sibling day will be scheduled at UNICA School (if possible, otherwise another venue will be found) on Saturday Morning, the 28th of July. The program for the morning will run from 11:00 till about 14:00. It will include some fun activities, time to fill in the questionnaire and group sessions in which the children can talk about their experiences with each other. Lunch will be provided for the children.

Will we have access to the research results?
The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the University of Pretoria for 15years as part of the ethical requirements of the University. Results may also be shared with other professionals in article format.

Who can be contacted if we have any further questions?
Should you require any further information, you are welcome to contact the researcher at XXXXX or XXXX@gmail.com
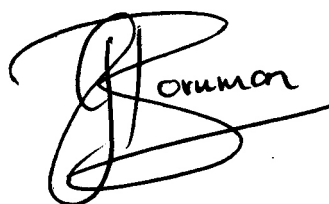
I trust that this letter has provided you with sufficient information as to allow you to grant the researcher permission to conduct the proposed study at your institution.

Please inform me in writing of your decision.

Yours sincerely,

Christine van der Merwe   Prof Juan Bornman
Researcher   Supervisor

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Appendix D:
Consent letters for
parents

16 July 2012

Parental Informed Consent Letter

THE ATTITUDES OF TYPICALLY-DEVELOPING CHILDREN TOWARDS THEIR SIBLINGS WITH AUTISM SPECTRUM DISORDER

Background to the study

In the past decade there has been a shift from focusing on impairments to looking at how able an individual is to participate in his or her community. The literature indicates that for a child to learn and develop socially, active participation is essential. However, due to the combination of impairments in social interaction, communication and imagination, children with autism generally don't interact very well with either their siblings or peers, and will not easily initiate play. This may result in frustration for their neurotypical sibling, as their attempts at interaction may fail regularly, leading to minimal positive daily learning opportunities. Without intervention, children with autism are therefore very vulnerable to being excluded from their peer group and being able to participate fully in society.

Research indicates that siblings are one of the greatest influencing factors in a child's development. In fact, sibling relationships are normally the second strongest bond that a child forms after that with their parents. Early social development generally starts with sibling interaction. These interactions play an important role in a child's social life - whether they have autism or not - and are deemed pivotal for developing relationship skills. One's social understanding increases with exposure to a variety of social experiences. Encouraging positive sibling relationships can, therefore, provide a rich source of interactional experience.

The neurotypical sibling is also affected in their development by their autistic sibling. A review of the literature, however, shows mixed results relating to the social, emotional and behavioural adjustment of siblings of individuals with ASD. Some studies have shown higher levels of depression in the neurotypical siblings, while others seem to indicate that sibling relationships can be mutually beneficial and positive.

This study will focus on sibling attitudes. Literature shows that obstacles faced by the disabled, are largely due to societal attitudes. Research indicates that interaction between children is more likely where positive attitudes towards disabilities are held. Very little research, however, has been done to explore the attitudes of neurotypical children towards their sibling with ASD, especially in regards to interaction.

Although it is well known that family-members are key role-players in the decision-making process, siblings still often feel excluded. Assessing children's attitudes towards their sibling with autism may provide important information when designing comprehensive and meaningful interventions that are aimed at improving attitudes and behavior towards children with autism.

What are the objectives of this study?

The primary objective of this study is to determine and describe the attitudes of typically-developing children towards their siblings with autism towards their siblings with autism.

The following sub-aims were formulated to attain the primary objective:
- ➢ To adapt the Lifespan Sibling Relationship Scale (LSRS) (Riggio, 2000) in order for it to be appropriate for use on typically developing adolescent towards their sibling who has autism.
- ➢ To apply the scale in order to determine the attitudes of typically-developing adolescents towards their siblings with autism.
- ➢ To describe the results obtained from the attitude scale as it pertains to the attitudes of typically-developing adolescents towards their siblings with autism.

Why is my child's participation important?

Your participation in this research project will have no direct benefit to you.

Your input will, however, contribute to the development of high-quality, comprehensive and meaningful service delivery and intervention for families of children with Autism.

What is expected of my child as a participant?

To enable your participation in this study, you are requested to complete the *Parental Informed Consent Slip* attached to this pack and send it back to school with your child attending XXXX School. Please indicate on the form what day would suit you best to bring your child to school

A sibling day will be scheduled at XXXX School on Saturday Morning, the 18th of August. The program for the morning will run from 11:00 till about 14:00. It will include some fun activities, time to fill in the questionnaire and group sessions in which the children can talk about their experiences with each other. Lunch will be provided for the children.

I do understand that you have a busy schedule. It would, however, be of great value if you should agree to let your child participate in this study, as your child's input is highly valued.

Will I experience any risk or discomfort during this study?

The only discomfort that you may experience whilst participating in this study is the sacrifice of your own free time so your child can complete the attitude scale.

The actual filling in of the survey should only take approximately 30 minutes of your time. The day will, however, also provide the children with an opportunity to connect with other children who are in a similar situation to themselves.

All the information obtained from you and your child during the study will be handled confidentially as your child will be assigned a respondent number. You will not be subjected to any other risks.

What are my rights as a participant in this study?

You or your child may at any given time throughout this study decide to withdraw. Should you or your child decide to withdraw, your decision to do so will in no way penalize you, or the services offered to your child.

Will I have access to the research results?

The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the *Department of Library Services* at the University of Pretoria for 15 years.

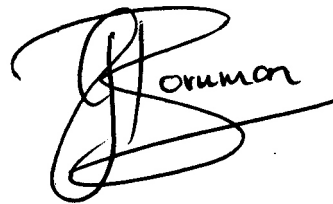## Who can be contacted if I have any further questions?

Should you require any further information, you are welcome to contact me at xxxxxxxxx or xxxxxxx@gmail.com

Thank you in advance for your time and co-operation!

Yours sincerely,

Christine van der Merwe
Researcher

Prof Juan Bornman
Supervisor

Please complete this form and return it, to the researcher

Office use
Participant Nr

All data collected will be kept anonymous.
Section A: Are questions to ensure that your child fits in the profile of the participants this study is aimed at.
Section B: is to establish dates that would suit most parents

SECTION A:

How old is the brother or sister who will be participating in the study?	
Is he or she attending an **English** or dual medium High school?	
Is he or she permanently **living with** the sibling with ASD?	
What grade is he or she currently in?	

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

Fax/Faks: + 27 86 510 0841
Tel: + 27 12 420 2001

juan.bornman@up.ac.za
www.caac.up.ac.za

Parental Informed Consent: Consent Reply Slip

Name of Participant: _____

Name of Parent: _____

Project title:
The attitudes of typically-developing adolescents towards their siblings with autism.

Researcher: Christine van der Merwe
                        Master's Student
                        University of Pretoria

Supervisor: Prof. Juan Bornman

I   --- herby:
                        Name and surname

☐   Give consent for my child to participate in this study

☐   Do not give consent for my child to participate in this study.

☐   I understand all information used and obtained in this study will be treated as
       confidential.

_____   _____

Participant Signature   Date

_____   _____

Researcher   Date

I would like to get feedback about the results of this study

☐

Appendix E: Flyer for the sibling days

1 8   A U G U S T   2 0 1 2

Autism Sibling Day

Share your experience with us!

As part of a research project to learn more about the experience having a sibling with autism spectrum disorder (ASD) in the family, we are having an Autism Sibling day at xxxx School.

Everyone's experience is unique and we would love to hear more about how having a sibling with ASD impacts your life!

Meet other teenagers who have siblings with ASD

If you are an adolescent (13-18) and your sibling has ASD, please join us on Saturday, 18th of August for an ASD sibling day.

You will need your parent's to sign a consent form to say that they give you permission to particpate. They can do this by sending an email to Christine or completing a form on the day.

Please email Christine at xxxxxx@xxx.co.za or phone xxxxxx for further details

Program

11:00 Welcome and icebreakers
12:00 Filling in the questionnaires
12:30 Lunch
13:00 Video on sibling experiences, followed by a group discussion

Hope to see you there!

WHERE?

XXXX
XXXXX
XXXX

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Appendix F: Permission to conduct research from Western Cape Education Departments

awyngaar@pgwc.gov. za
tel: +27 021 476 9272
Fax: 0865902282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

WESTERN CAPE
Education Department

Provincial Government of the Western Cape

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

REFERENCE: 20110808-0033
ENQUIRIES: Dr A T Wyngaard

Miss Christine van der Merwe
14 Neave Street
Claremont
7708

Dear Miss Christine van der Merwe

RESEARCH PROPOSAL: AN INVESTIGATION INTO THE ATTITUDES OF TYPICALLY-DEVELOPING ADOLESCENTS TOWARDS THEIR SIBLINGS WITH AUTISM WHO ARE USING PECS (PICTURE EXCHANGE COMMUNICATION SYSTEM) AS A METHOD OF COMMUNICATION

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1.   Principals, educators and learners are under no obligation to assist you in your investigation.
2.   Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3.   You make all the arrangements concerning your investigation.
4.   Educators' programmes are not to be interrupted.
5.   The Study is to be conducted from **15 August 2011 till 30 September 2011**
6.   No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7.   Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number.
8.   A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9.   Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10.   A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11.   The Department receives a copy of the completed report/dissertation/thesis addressed to:

> **The Director: Research Services**
> **Western Cape Education Department**
> **Private Bag X9114**
> **CAPE TOWN**
> **8000**

We wish you success in your research.

Kind regards.
Signed: Audrey T Wyngaard
for: **HEAD: EDUCATION**
DATE: 08 August 2011

MELD ASSEBLIEF VERWYSINGSNOMMERS IN ALLE KORRESPONDENSIE / PLEASE QUOTE REFERENCE NUMBERS IN ALL CORRESPONDENCE /
NCEDA UBHALE IINOMBOLO ZESALATHISO KUYO YONKE IMBALELWANO

GRAND CENTRAL TOWERS, LAER-PARLEMENTSTRAAT, PRIVAATSAK X9114, KAAPSTAD 8000
GRAND CENTRAL TOWERS, LOWER PARLIAMENT STREET, PRIVATE BAG X9114, CAPE TOWN 8000

WEB: http://wced.wcape.gov.za

INBELSENTRUM /CALL CENTRE

INDIENSNEMING- EN SALARISNAVRAE/EMPLOYMENT AND SALARY QUERIES ☎ 0861 92 33 22

© University of Pretoria

Appendix G: Permission to conduct research from the Gauteng Department of Education

education

Department: Education
GAUTENG PROVINCE

For administrative use:
Reference no. D2013/124

GDE RESEARCH APPROVAL LETTER

Date:	**12 July 2012**
Validity of Research Approval:	**12 July 2012 to 30 September 2012**
Name of Researcher:	**Van der Merwe C.**
Address of Researcher:	**6 Arrow Court**
	263 Main Road
	Sea Point
	Cape Town;
	8004
Telephone Number:	**076 138 3205**
Email address:	**kinavdmerve7@gmail.com**
Research Topic:	**An investigation into the attitudes of typically-developing adolescents towards their siblings with autism**
Number and type of schools:	**TWO LSEN Schools**
District/s/HO	**Johannesburg Central and Tshwane South**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1. _The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study._

Making education a societal priority

2. The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.

3. A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.

4. A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.

5. The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.

6. Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.

7. Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year.

8. Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.

9. It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.

10. The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.

11. The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.

12. On completion of the study the researcher must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.

13. The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.

14. Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

[signature]

....

Dr David Makhado

Director: Knowledge Management and Research

DATE: 2012/07/13

Appendix H: Title Registration letter

Our Ref: Ms P Woest / 97019420
Tel: 012 420 2736
Fax: 012 420 2698
E-mail: petru.woest@up.ac.za

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

8 July 2013

Miss C van der Merwe
PO Box 72045
LYNWOOD RIDGE
0040

Dear Miss van der Merwe

TITLE REGISTRATION: FIELD OF STUDY – MA IN AUGMENTATIVE AND ALTERNATIVE COMMUNIATION

I have pleasure in informing you that the following has been approved:

TITLE: **The attitudes of typically developing adolescents towards their siblings with Autism Spectrum Disorder (ASD)**

SUPERVISOR: **Prof J Bornman**

CO-SUPERVISOR: **Prof M Harty**

I would like to draw your attention to the following:

1. **ENROLMENT PERIOD**
    (a)   You must be enrolled as a student for at least one academic year before submission of your dissertation/essay.
    (b)   Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree.   You will only be able to have supervision if you provide a proof of registration to your supervisor.

2. **APPROVAL FOR SUBMISSION**
    On completion of your dissertation/essay enough copies for each examiner must be submitted to Student Administration, together with the prescribed examination enrolment form signed by you, which includes a statement by your director of studies that he/she approves of the submission of your dissertation/essay.

3. **NOTIFICATION BEFORE SUBMISSION**
    You are required to notify me at least three months in advance of your intention to submit your dissertation/essay for examination.

4. **INSTRUCTIONS REGARDING THE PREPARATION OF THE DISSERTATION/ESSAY AND THE SUMMARY APPEAR ON THE REVERSE SIDE OF THIS LETTER.**

Yours sincerely

for **DEAN: FACULTY OF HUMANITIES**

Appendix I: Declaration of originality

Faculty of Human Sciences
Fakulteit Geesteswetenskappe

UNIVERSITY OF PRETORIA

DECLARATION OF ORIGINALITY

This document must be signed and submitted with every assignment.

Full names of student:..……… …………………………………………………………………………………….

Student number:………………… …………………………………………………………………………………

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.

2. I declare that this ………… assignment is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

3. I have not used work previously produced by another student or any other person to hand in as my own.

4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

SIGNATURE OF STUDENT:......…………… ……………………………………………………………………………………

SIGNATURE OF LECTURER:……………………………………………………………………………………………………