

The Effects of Autistic Spectrum Disorders (ASD) on Attachment: Experiences of Mothers from Diverse South African Socio-Economic Groups

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DECLARATION

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Signed: _____

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*For Scotty, my family and friends, who have supported me
unconditionally throughout this process.*

&

*For the brave and heroic mothers that live with ASD
everyday of your lives, and to your wonderful children
who have taught us so much about the meaning of life
and love.*

I AM AUTISM

Hello. Allow me to introduce myself to you.

My name is autism. Perhaps you know me or know of me. I am a condition, "disorder" that affects many people. I strike at will, when and where I want. Unlike Down's Syndrome or other birth "defects," I leave no marks on those I strike. In fact, I pride myself on the ability to infiltrate a child's life, while leaving him or her strikingly handsome. Many people may not even know I am there. They blame the child for what I cause him or her to do.
I am autism and I do as I please.

I am autism. I strike boys and girls. Infants and toddlers. I find my best victims to be boys around the age of 2, but any child will do. I like children and they are always the true victims, though I take hostage the others in the child's family as well. It is a bit like getting two for the price of one. I affect one child and "infect" the entire family.

I am autism. I strike rich and poor alike. The rich combat me with education and therapy. The poor shut their children away and cannot afford to fight me. I am able to win in the lives of poor children more than I am those of the wealthy, but I will try to take root anywhere.

I am autism. I am an equal opportunity disorder. I strike whites, blacks, Mexicans, Ukrainians, Russians, Poles, Slavs, Japanese, Koreans and Fins. In fact, I strike everywhere on Earth. I know no geographical bounds.

I am autism. I do not discriminate based upon religion either. I do not care what religion a person is or what beliefs he may hold. When I strike, there will be little time for any of that anyway. When they find me, they will question everything they believe in, so why would I strike only one group? I have affected followers of every religion on the planet.

I am autism and I am strong and getting stronger every year, every month, every day, every minute and every second. I am concerned that money might be allotted to combat me and my takeover of children, but so far, I have little to fear.

I am autism. When I come, I come to stay. I take the dreams and hopes of families and trample them with delight. I see the fear and confusion in the eyes of my victims and see the formation of wrinkles, the worries and pain on the face of their parents. I see the embarrassment their child causes because of me and the parents unsuccessful attempt to hide their child, and me. I see tears the parents cry and feel the tears of their child. I am autism. I leave sorrow in my wake.

I am autism. I take away and give nothing but bewilderment and loathing in return. I take speech and learning. I take socialization and understanding. I take away "common sense" and, if I am allowed to flourish, I take away all but their physical life. What I leave behind, is almost worse than death.

I am autism. I fear nothing except courage, which I thankfully see little of. I fear those who take a stand against me and attempt to fight me and bring others into the fight as well. I fear those who try to make it safe and easier for my victims in the community, and their families. I fear those who push ahead, despite the fact that I am in tow. I fear the day I will be eradicated from the planet. Yet, I do not fear too much right now. There is no need.

I am autism and I bet you know me or know of me. If you don't, you probably will soon. I am marching forward faster than I ever have before. I am looking for new children all the time. I am looking for new children to consume and new lives to destroy. I dread the day I will be looked upon with pity or worse yet, understanding, for that day, is the day I will begin to die.

But in the mean time I am safe, free to prowl onward. Free to cause the pain and suffering that I do so well. I am on a mission and have much work to do and thankfully no one is stopping me yet.

Hello. Allow me to introduce myself. My name is autism. Perhaps you know me or know of me, if not don't worry, you will meet me soon.

Written by: Marty Murphy

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- Scotty, for being there and encouraging me every step of the way. Your emotional support and faith in me has been my inspiration throughout this process.
- To my family and friends, thank you for bearing with me, for loving and supporting me no matter what.

ABSTRACT

Attachment theory is concerned with the relational ‘tie’ that exists between a mother and her child, which is said to play an imperative role in a child’s mental development and future attachment relationships. Although there is extensive research on attachment theory on an international scale, there is a paucity of information with regard to this in the South African context.

The object of this study is to investigate mothers’ experiences of attachment with their child who has an Autistic Spectrum Disorder (ASD). In addition this research aims to investigate whether this attachment relationship between a mother and her ASD child differs, or is the same across diverse socio-economic groups in the South African context.

This research was qualitative in nature, which elicited rich, descriptive and personal accounts of mothers’ experiences of attachment with their ASD child across diverse socio-economic groups. Twelve participants from advantaged and disadvantaged communities from Johannesburg and the greater Johannesburg area were invited to participate in this study.

Data was gathered through semi-structured interviews and analysed using thematic content analysis. Seven themes emerged from this study which explored mothers’ experiences of attachment with their ASD child. In addition, similarities and differences were found in mothers experiences of attachment across the diverse socio-economic groups.

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PROPOSAL TITLE

The effects of Autistic Spectrum Disorders (ASD) on attachment: Experiences of mothers from diverse South African socio-economic groups.

PRELIMINARY COMMENTS

A variety of terms are used to discuss autism, the most popular of these is Autistic Spectrum Disorders (ASD). As ASD is the most favoured term in the field, this study will use the term ASD, except where the authors or participants have specifically referred to it as autism or Asperger's syndrome.

The term 'mother' is referred to in this research to include biological mothers, legal guardians and caregivers of children with an ASD.

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CHAPTER 1

RATIONALE AND OVERVIEW

1.1 INTRODUCTION

This chapter outlines the rationale and the motivation for this study on mothers' experiences of attachment with their ASD child. This chapter also highlights the rationale for conducting this research across different socio-economic groups in a South African context. An overview of the chapters in this study shall also be discussed.

1.2 RATIONALE

'Attachment' as an interest of enquiry has been broadly researched within the realm of 'normality'; however, in recent years there has been a shift in thinking towards focussing on the effects of a disability on the attachment process between mother and child (Clements & Barnett, 2002). According to Bowlby (1973, as cited in Fairchild, 2006) attachment theory proposes that human infants are predisposed to seek and form attachments to their primary caregiver. According to Fairchild (2006), this involves an inherent biological motivation by an infant to ensure their survival and protection in a physical, physiological and psychological manner. For Bowlby (1973, as cited in Fairchild, 2006), the quality of these relationships with significant attachment figures that provide the emotional connection and support throughout ones development, is intricately associated with ones mental health and development. From this perspective, the researcher has encountered numerous studies concerned with attachment and disabilities, however very little consideration has been specifically given to mothers' experiences of attachment with their child who has a diagnosis of ASD. This presents an opportunity to research an area of enquiry that has not been over researched internationally or nationally, and it also provides an opportunity to gain access to, and research diverse socio-economic groups in South Africa.

A further motivating factor underlying this research is that autism is a very real and existent disorder in our society. Statistics released by the Centre of Disease Control in America accentuate this and indicate that research is showing that 1 in 100 children born will have an Autistic Spectrum Disorder, in South Africa this equates to a child with autism being born close to every hour (Autism South Africa, 2011). This highlights the growing need for information regarding ASD's, the diagnosis, interventions, treatments, and more importantly

to the researcher, the personal life stories and experiences of mothers with children diagnosed with this complex disorder. In South Africa, there is a deficiency of information of this kind, and ultimately there is very little research specifically concerned with the effects of ASD on the attachment process between a mother and her child.

A diagnosis of any degree is overwhelming and stressful for any parent to receive, as they are faced with a long journey of life-changing adjustments in terms of parenting, expectations of, and opportunities for their child. Having a child with ASD has been found to have a profound bearing on parents' emotional and psychological wellbeing, as well as the family unit as a whole. Research by Cullen and Barlow (2002), indicate that autism not only dominates the lives of parents and their family, but it disturbs family functioning, puts strain on marital relationships, and leaves parents feeling isolated, frustrated and bewildered. A diagnosis of autism is no different, if not more challenging for a parent to receive and Wachtel and Carter (2008), indicate that parents of children on the autism spectrum face a unique set of challenges that, not surprisingly, impact on their psychological adjustment, and may include depressive symptoms and greater levels of stress than do parents of healthy, physically ill, or developmentally delayed children. Gaining insight into these challenges and the possible effects this may have on the attachment relationship between a mother and her autistic child may have significant intervention implications.

Autism is a disorder of varying degrees, however "ALL people on this spectrum, are affected in different degrees by the Triad of Impairments" (Autism South Africa, 2011), which is characterised by a deficit in areas of communication, social interaction and repetitive behaviours. Taking this into consideration is further motivation for investigating the effects of autism on attachment, as this research is concerned with exploring that essential relationship between a mother and her autistic child: whose very diagnosis has an effect on social functioning. Children with ASD have severe and pervasive impairments in the development of social interaction, which "may affect the attachment relationship with their parents and may have an impact on parenting" (Rugters et al., 2007, p.859).

This research serves to explore this attachment relationship from a qualitative perspective in order to gain rich, valuable and significant life experiences of mothers' experiences of this fundamental bond. Not only are there a limited amount of qualitative studies in this area of interest, "few studies have documented life experiences of caring for children with autism

using a qualitative approach” (Cullen & Barlow, 2002, p.37), but information elicited from the qualitative approach can in turn, be used to inform future parental programmes as a means of support to mothers of ASD children. “Individually tailored therapeutic interventions, based on such information, may help parents to acquire alternative strategies toward developing mutually satisfying relationships that constitute the foundation upon which they are empowered to facilitate optimal development of their relationally challenged children” (Seskin et al., 2010, p.3).

An insight into this attachment relationship could be used by multidisciplinary professionals to inform intervention programmes and to promote the wellbeing of some of society’s most vulnerable. According to Kubeka (2010), there is a desperate need for parents and professionals to have easy access to information about autism as many adverse situations have been reported as a result of the people in the (SA) community not understanding why a child is reacting and behaving differently.

Research of this nature is nonexistent in the South African context, and gaining an awareness of mothers experiences of attachment with their ASD child, in the South African context, is therefore, clearly essential. Autism doesn’t discriminate, and this disorder is documented to occur in all racial, ethnic, and socioeconomic groups (Centre of Disease Control), and therefore, considering that South Africa is a very diverse country, the researcher is in the view that it is essential to this research to consider this diversity to gain a deeper understanding of the socio-economic factors at play in determining mothers’ experiences of attachment with their autistic child.

1.3 STRUCTURE OF CHAPTERS

This study and its findings are divided into 5 chapters and will be discussed as follows:

TABLE 1:

Structure of Chapters

Chapter	Content
Chapter 1	The Rationale and Overview chapter includes an introduction to the research topic and highlights the purpose of this study, specific to a South African Context.
Chapter 2	The Literature Review provides an overview of the current and pertinent literature in the field of attachment and ASD, including key concepts and current research both internationally and specific to a South African context.
Chapter 3	The Research Design and Methodology chapter describes the research procedures and includes an outline of the aims and objectives of this research, the research design and methodology, data analysis and the ethical considerations taken into account throughout this study.
Chapter 4	The Results and Discussion chapter provides a summary of the demographic details of the participants and presents the findings of the study. The findings of the study are then presented in a critical discussion with reference to the available literature and the significance for a South African context.
Chapter 5	In this chapter, the Strengths, Limitations, Recommendations, Personal Reflection and a final Conclusion of this study shall be discussed in this chapter.

1.4 CONCLUSION

This chapter has provided a rationale for this study pertaining to mothers' experiences of attachment with their ASD, across different socio-economic groups. This chapter has also provided an overview of the chapters in this study.

A review of the literature shall be discussed in the following chapter.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews the relevant literature pertaining to attachment and the theoretical development of this approach. Specifically, definitions of attachment, attachment behaviour, and the phases and development of child-mother attachment, will be discussed. In addition, this chapter will explore the history and definitions of Autistic Spectrum Disorders (ASD) in an attempt to understand the implications this disorder has on attachment. Prior research will be critically examined and reviewed, with a particular focus on studies which have explored the effects of ASD on attachment. This chapter will also address mothers' experiences of the effects of ASD on the attachment relationship, while taking into considerations the diverse South African socio-economic contexts. In addition, literature pertaining to the identified themes will be discussed in more detail in Chapter 4.

2.2 DEFINING ATTACHMENT

Attachment is a widely accepted psychological concept that has been researched almost since its conceptualisation. As early as the 1940's Bowlby revealed his theoretical and clinical interest in attachment relations, in the possibility of helping children by helping parents (Bretherton, 1992). By 1962, Bowlby had published five papers that essentially represented the first basic blueprint of attachment theory (Bretherton, 1992). Today, this theory of attachment has not only grown in popularity among attachment theorists, but is still used today as a theoretical construct in psychological academia to gain a multifaceted and consequential understanding of the bond between a mother and her child.

Attachment theory highlights the work of John Bowlby (1907-1990), and Mary Ainsworth (1913 – 1999). The term “attachment” was introduced into the developmental literature by John Bowlby, in 1958, when he proposed a new theoretical approach to the origins of a child's tie to his/her mother (Ainsworth, 1972). Attachment theory has a long developmental history that has primarily been influenced by a psychoanalytic philosophy and the work of Freud (Bretherton, 1992).

According to Bowlby, “the predictable outcome of a child’s attachment behaviour is to bring him into closer proximity with other people, and in particular with that specific individual who is primarily responsible for his care” (as cited in Ainsworth, Walters & Wall., 1978, p.6). In accordance with attachment theory, the mother figure is considered to be the principal caregiver of the child and can be the biological mother or someone else that plays that role. In addition, attachment has been defined by Ainsworth et al. (1978), as the affectionate bond or tie that an infant forms between himself/herself and his/her mother figure. Attachment theory explores this relationship between a mother and a child as a means to understand how this ‘tie’ or relationship has an effect on childhood and further development. Howe, Brandon, Hinnings and Schofield (1999), explain that these relationships provide fundamental experiences that connect children’s personal and social worlds, and it is the interaction between these two worlds that “minds form and personalities grow, behaviour evolves and social competence begins” (p.9).

In light of this, Howe et al. (1999), emphasises that the quality and character of children’s close relationships, taking in consideration with a child’s temperament, caregivers own history of relationships, and the stressors generated by the social and material environment, are of great importance. Bowlby (1969, as cited in Greenberg, Cicchetti & Cummings, 1990) views attachment as a fundamental process in human development, as it not only increases the likelihood of survival in infancy, but also because it optimises adaptive personality across one’s life span. This crucial relationship between mother and child plays a central role in the wellbeing and mental health of a child, and Bowlby (1952), states that the infant and young child should experience a warm, intimate and continuous relationship with his mother or caregiver, which they both enjoy and find satisfaction, which in turn is essential for the development of mental health.

Bowlby (1982, as cited in Muller, 1996) observed that forming attachments is a continuous lifelong experience, and a person develops internal representations or mental images of the self, others, and attachment relationships in general. According to Zeanah and Benoit (1995, in Theran, Levendosky, Bogat & Huth-Bocks, 2005) a mother’s representation of her child, which can be understood as “a mothers internal subjective experiences of the relationship with their child”, can begin during pregnancy (p. 253). This is said to occur as during pregnancy a mother experiences a shift from focussing on herself, to focussing on her infant as a separate object (Theran et al., 2005).

2.3 ATTACHMENT BEHAVIOUR

Attachment behaviour has been defined as “any form of behaviours that results in a person attaining or retaining proximity to some other differentiated and preferred individual” (Holmes, 1993, p.68). This attachment behaviour is triggered by separations or perceived separation from the attachment figure (Holmes, 1993). So in essence, when children feel distress and insecure, they want to be in close proximity to their main caregiver (Howe et al., 1999).

Generally there are three broad categories of attachment behaviour that have been identified to assist in this process as outlined in Howe et al. (1999). Firstly, a child signals behaviours to the mother to show that they are interested in social interactions, which includes babbling, smiling and, laughter. Secondly, a child can perform aversive behaviours such as crying and, thirdly, a child can crawl to or try following the mother, engaging in behaviours that are more active in nature. According to Fonagy (2001), the entire system of attachment behaviours has the common purpose of optimising proximity across a range of contexts including crawling, smiling and crying.

According to Howe et al. (1999) this child- parent relationship is normally both instinctive and reciprocal. If a child is anxious, there is an increase in their attachment behaviour with the purpose of getting back into close proximity with the mother or primary caregiver. When this has been achieved, anxiety decreases and so too does the attachment behaviour. “The behaviours and emotions associated with attachment are most clearly seen in situations of anxiety, distress, including those involving fear, danger, conflict, social challenges and threats to the caregivers physical and emotional availability and responsiveness” (Howe et al., 1999, p.16).

These situations of anxiety can be presented in various locations including *within the child* (for example, feeling sick, tired, hungry or hurt), *within the environment*, (for example, a frightening, threatening or confusing event) and *within the attachment figure* (for example, uncertainties about the location or behaviour of the attachment figure) (Howe et al., 1999). The relationship between attachment behaviours and exploratory systems is one of give and take. When attachment behaviours are stimulated, a child is unable to engage in other useful developmental experiences such as exploration, play and dealing with others for reasons other than protection (Howe et al., 1999).

2.4 THE DEVELOPMENT OF MOTHER-CHILD ATTACHMENT

Bowlby (1969) proposed that there were four phases which are concerned in the attachment process, which the child needs to progress through in order for a goal directed relationship between the child and the caregiver to develop. These phases included the initial pre-attachment stage, the phase of attachment in-the-making, the phase of clear-cut attachment and finally the phase of goal-corrected partnership (Bowlby, 1969). All of these phases are considered to be a vital component in this research, when considering the developmental delays in an autistic child and the impact this may have on the attachment process with their mother.

The phases of attachment shall be reviewed and discussed based on the works of Ainsworth et al. (1978). The initial pre-attachment stage begins at birth and is evident in the first few weeks of life. During this stage the infant begins to build expectations, that are intricately linked to the child's own sensory schemata and do not extend to using one's environmental clue as a basis for anticipating another environmental event. Phase 1, is said to come to an end when the baby is capable of discriminating his mother figure from others.

During the phase of attachment-in-the-making, the baby begins to discriminate unfamiliar from familiar figures, and is also able to discriminate between familiar figures. This discrimination is evident in the way the child is able to direct his/her various proximity seeking or attachment behaviours towards different figures.

Phase 3, clear-cut attachment was identified by Bowlby as the phase of maintenance of proximity to a discriminated figure by means of locomotion as well as signals (Ainsworth et al., 1978), and is said to start from between 6-12 months. This phase suggests that the baby is literally more active in seeking proximity and attachment with his/her preferred attachment figure, rather than relying on signal behaviours as in the previous phase. In this phase the child is more explorative of and manipulative of objects in their environment. At this stage the attachment figure provides the secure background from which the child moves out to familiarise himself/herself with his/her world, and the child begins to develop the sense of object permanence. Phase 3 is believed to continue through the second and third years of a child's life and attachment becomes increasingly a matter of inner representation of the attachment figures and of the self in relation to them (Ainsworth et al., 1978).

Phase 4, the phase of goal-corrected partnership, begins no later than two years old and at this phase the child is increasingly becoming more capable of seeing things from the point of the mother, and in turn gains some insight into her feelings and motives. This phase enables the child to develop a more complex relationship with the mother than before. According to Ainsworth (1972), that a partnership of this kind presumes “inner representations”, imagination and empathy at a level that is distinctly human.

Mary Ainsworth applied these attachment concepts to her own work, and consequently this led her to developing the Strange Situation, a standardised assessment procedure which is used to observe the attachment relationship between a mother and their child. According to Holmes (1993), the procedure focuses primarily on the response of the child to the separation and reunion of the mother and the aim is to extract individual differences in coping with stress of separation. Ainsworth (as cited in Fonagy, 2001) recognised that separation or the physical absence of the mother was not the key to understanding the infants’ responses to the Strange Situation; but it was more the infants’ appraisal or evaluation of the mothers’ departure in the context of her expected behaviour that accounts for the infants’ response.

Four major attachment patterns have been identified by Ainsworth, namely secure attachment, insecure-avoidant attachment, insecure-ambivalent attachment and insecure-disorganised attachment. These shall be discussed as outlined by Holmes (1993). In secure attachment, the infants are usually distressed by the separation, but on reunion they greet their parent and receive comfort if need be. These infants will then resume their play. In insecure-avoidant, the child shows fewer overt signs of distress on separation and they pay little attention to the parent on re-union. The child will remain observant of their parent and are inhibited in their play. Children who have an insecure-ambivalent relationship are highly distressed by separation and are not easily pacified. Their emotions also change towards their parent, and can show signs of anger to clinging to her. Exploratory play is also inhibited in children who demonstrate this kind of attachment. Children, who display insecure-disorganised attachments, show a range of confused behaviours or stereotyped behaviours when reunited with their parent.

Attachment therefore can be seen as secure or insecure, and according to Ainsworth et al. (1978), secure attachment implies representational systems where the attachment figure is seen as accessible and responsive where needed, and adversely insecure attachment implies a

representational system where the caregiver is not seen as responsive and the child therefore adopts strategies to cope with the perceived unresponsiveness of the attachment figure. Therefore, according to Fonagy (2001), the central feature of the internal working model concerns the availability of the attachment figure, which in turn affects how accepted or unaccepted the child may feel. “A child whose internal working model of the caregiver is focussed on rejection is expected to evolve a complementary working model of the self as unlovable, unworthy, and flawed” (Fonagy, 2001, p.13).

According to Bretheron (1980, as cited in Fonagy, 2001), children have the tendency to form numerous attachment relationships in early life and there appears to be a hierarchy of major caregivers with a preferred attachment figure. Numerous factors including the amount of time an infant spends in a person’s care, the quality of care, the adult’s emotional investment in the child and the frequent reappearance of an adult, plays an integral part of determining this primary caregiver (Cassidy 1999, Colin 1996, as cited in Fonagy 2001).

It is very significant for the purpose of this research to consider the developmental aspects that are taking place both at an attachment level, especially when considering the diagnostic features of an ASD. Some children with ASD depending on the severity will never develop the necessary skills for language and social interaction, which could in turn place a great amount of stress on the attachment process between mother and child. These diagnostic features will now be discussed in greater detail, to gain an understanding of how these defining features of this disorder may have an effect the attachment relationship.

2.5 HISTORY OF AUTISTIC SPECTRUM DISORDERS

The word ‘autism’ is derived from a compound of two Greek words implying ‘self’ and ‘orientation or state’ (Trevvarthen, Aitken, Papoudi, & Robarts, 1999), and therefore could be defined as “the condition of somebody who is usually absorbed in him or herself” (Reber, 1985, as cited in Trevvarthen et al., 1999, p.5). It is widely accepted in the literature that Leo Kanner and Hans Asperger have been accredited to the defining and discovery of autism and Aspergers respectively. Kanner (1943, as cited in Rutter, 1978) did careful and systematic observations of 11 children with a previously unrecognised syndrome, in which he noticed a variety of behavioural features. These features included, “an inability to develop relationships with people, a delay in speech acquisition, the noncommunicative use of speech

after it developed, delayed echolalia, prominent reversal, repetitive and stereotyped play activities, an obsessive insistence on the maintenance of sameness, a lack of imagination, a good rote memory, and a normal physical appearance” (Rutter, 1978, p.139). According to Attwood (2007), Hans Asperger described children with many traits similar to that of autism, however their intellectual functioning abilities seemed to be higher and they seemed to lack the degree of verbal communication and social difficulties of those labelled with classical autism. This later became known as Aspergers Disorder.

2.6 DEFINING AUTISTIC SPECTRUM DISORDERS

Autism and Aspergers are spectrum disorder that fall under the umbrella term ‘Autistic Spectrum Disorders’ (ASD’s) or otherwise known as Pervasive Developmental Disorders (PDD’s). The Diagnostic Statistical Manual of Mental Disorders, 4th Edition (DSM-IV-TR) includes five pervasive developmental disorders including: autistic disorder, Retts’s disorder, childhood disintegrative disorder, Aspergers disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS), with autistic disorder being the best known of these disorders (Sadock & Sadock, 2007).

For the purpose of this study, the defining characteristics, epidemiology and aetiology of Autistic Disorder and Aspergers disorder will be outlined.

2.6.1 Autistic Disorder

Even in stating that autism is the best known of these disorders, and considering it has been a subject of interest since its discovery, it remains to be a complex disorder, not only by definition, but also in its diagnostic attributes. Autism affects everyone differently and to varying degrees. “Autism represents not only the most severe behaviour disorder of childhood, but also the most complex in developmental pattern” (Morgan, 1988, p.263). Wing (1996, as cited in Cullen & Barlow, 2002) has described autism as a complex developmental disorder of no known cause and cure, which typically appears in the first three years of life and is part of a broader spectrum of autistic disorders.

Autism is a pervasive developmental disorder that is concerned with a ‘triad’ of deficits which can be characterised by symptoms in qualitative impairment in social interaction,

impairment in communication and restricted repetitive and stereotyped patterns of behaviour or interests (Sadock & Sadock, 2007). Autism is defined by the Autism Society of America (ASA) as a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, additionally, autism is a spectrum disorder that affects individuals differently and to varying degrees.

The first aspect of the triad is the *qualitative impairment in social interaction*, which indicates that “autistic children do not exhibit the expected level of subtle reciprocal social skills that demonstrate relatedness to parents and peers” (Sadock & Sadock, 2007, p.1193). Typical reciprocal social skills could be characterised by nonverbal behaviour such as a social smile, facial expressions, eye-contact, or even recognition of important people in their lives. “Autistic children often do not acknowledge or differentiate the most important persons in their lives - parents, siblings, and teachers - and may show extreme anxiety when their routine is disrupted, but they may not react overtly to being left with a stranger” (Sadock & Sadock, 2007, p.1193). In terms of social relationships, a notable deficit is seen in the lack of ability to play with peers and to make friends, and often this social behaviour is awkward and inappropriate.

On a cognitive level, autistic children cannot identify with, and understand the feelings or mental state of others around them. According to Sadock and Sadock (2007), autistic children cannot make attributions about the motivations or intentions of others which can delay and obstruct the development of empathy. According to the DSM-IV-TR, individuals who have autism are oblivious to other children, including their siblings and they may have no concept of the needs of others or even notice another person’s distress (American Psychiatric Association, 2000). This essentially affects the way in which they interpret the social behaviour of others and leads to a lack of social reciprocation.

The second aspect to the triad is impairment in *communication*. Autistic children have difficulty in acquiring and eliciting language as a means to communicate, and some autistic children never develop functional language at all. Deficits and delays in language development, and difficulty using language to communicate ideas are among the principal criteria for diagnosing autistic disorder (Sadock & Sadock, 2007). Children with autistic spectrum disorders can also display stereotyped phrases that seem out of context or

‘echolalia’, which has been defined as “coping or repeating the content and/or intonation patterns of another person’s speech” (Trevarthen et al., 1999, p.318).

The last aspect of the triad is concerned with *restricted repetitive and stereotyped patterns of behaviour or interests*. The problems in this area of impairment extend to a broader difficulty in thinking and behaving with flexibility and creativity, and these problems are concerned with the routines, rituals and resistance to change that are frequently seen in autistic individuals (Whitaker, 2001). In early childhood, this is reflected in the lack of spontaneous exploratory play and ritualistic manner in which autistic children play. “The activities and play of these children is often rigid, repetitive, and monotonous” (Sadock & Sadock, 2007, p.1194).

The DSM-IV –TR (American Psychiatric Association [APA], 2000), includes the following diagnostic criteria for Autistic Disorder.

- (A) A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)
- (B) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, (3) symbolic or imaginative play
- (C) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (APA, 2000, p.75)

Table 2:

DSM-IV-TR Criteria for Autistic Disorder (APA, 2000)

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:
(a) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
(b) failure to develop peer relationships appropriate to developmental level
(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
(d) lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested by at least one of the following:
(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a

conversation with others (c) stereotyped and repetitive use of language or idiosyncratic language (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
(3) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following: (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (b) apparently inflexible adherence to specific, nonfunctional routines or rituals (c) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements) (d) persistent preoccupation with parts of objects

2.6.2 Asperger's Syndrome

According to Sadock and Sadock (2007) Aspergers Syndrome is characterised by impairment and oddity of social interaction and restricted interest and behaviour symptomatic of those seen in autistic disorder (p.1201). However, in Aspergers disorder there is no evidence of significant delays in language, cognitive ability, or age appropriate self-help skills as seen in autism (Sadock & Sadock, 2007).

The DSM-IV –TR (APA, 2000), includes the following diagnostic criteria for Autistic Disorder.

Table 3:

DSM-IV-TR Criteria for Aspergers Syndrome (APA, 2000)

(A) Qualitative impairment in social interaction, as manifested by at least two of the following: (1) marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction (2) failure to develop peer relationships appropriate to developmental level (3) a lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people) (4) lack of social or emotional reciprocity
(B) Restricted repetitive & stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following: (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (2) apparently inflexible adherence to specific, non-functional routines or rituals

(3) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
(4) persistent preoccupation with parts of objects
(C) The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.
(D) There is no clinically significant general delay in language (E.G. single words used by age 2 years, communicative phrases used by age 3 years)
(E) There is no clinically significant delay in cognitive development or in the development of age-appropriate self help skills, adaptive behaviour (other than in social interaction) and curiosity about the environment in childhood.
(F) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

The cause/s of ASD still remains to be a contentious debate, and the causes of most cases of ASD are unknown (Boucher, 2009). In the years following the discovery of ASD, professionals concerned with children with mental health problems, concluded that it was a neurotic condition caused by a disturbed mother-child relationships. These mothers were referred to as the ‘refrigerator’ mothers, and were blamed for their child’s condition (Boucher, 2009). However, in contrast to this, today’s research tends to indicate that there is a genetic link to ASD. Research from twin studies suggest that genetic factors play an important role in the aetiology of this disorder and results indicate that genetic factors are associated, to some degree, with the onset of autism (Brimacombe, Ming & Parikh, 2007). According to Sadock and Sadock (2007), family studies have indicated a 50 to 200 times increase in the rate of autism in siblings of an index child with an autistic disorder. Research has also indicated that autism may have a strong biological basis, based on the high rate of mental retardation and seizures among children with autism (Sadock & Sadock, 2007).

Furthermore, according to Sadock and Sadock (2007), perinatal factors have also been considered a cause of autism as a higher-than expected incidence of perinatal complications seem to occur in infants who are later diagnosed with autism including maternal bleeding, respiratory distress and neonatal anaemia.

Like autism, there is no known cause of Aspergers disorder; however family studies suggest a possible relationship with autism and hence similar contributing factors to that that appears to cause autism (Sadock & Sadock, 2007).

2.6.3 Epidemiology

Epidemiology refers to the frequency of occurrence and the distribution of disorders in particular populations and statistics released by the Centre of Disease Control in America indicate that research is showing that 1 in 100 children born will have an Autistic Spectrum Disorder. In South Africa, this equates to a child with autism being born close to every hour (Autism South Africa, 2011). Epidemiologic studies in Europe have resulted in variable rates of autistic disorder, ranging from 2 to 30 cases per 10, 000 (Sadock & Sadock, 2007). In addition autistic disorders are also more prevalent in boys, and research has indicated that autistic disorder is four to five times more frequent in boys than in girls; however girls are more likely to have more severe mental retardation associated with the autism (Sadock & Sadock, 2007).

2.6.4 Co-morbidity

According to Boucher (2009), co-morbidity refers to the co-occurrence of two or more identifiable conditions or disorders, where one is not an integral component of the other. The occurrence of one or more co-morbid conditions is common in people with autism and Boucher (2009) has identified the following co-morbid conditions in people with autism:

- Physical and medical conditions including : sensory impairments, neuromuscular problems, epilepsy, immune system disorders and gastrointestinal disorders
- Neurodevelopmental and behavioural problems including: abnormal attention and activity levels, self-injurious and other maladaptive behaviours, sleep disturbances and specific learning impairments
- Mental health problems including: Depression, anxiety and obsessive-compulsive disorder

According to Boucher (2009) mental health problems are common in people with ASD's and Sadock and Sadock (2007) state that two thirds of children with autistic disorder have mental retardation, although it is not required for a diagnosis.

2.6.5 Implications of an ASD Diagnosis

The broad diagnostic criteria of the DSM-IV-TR (APA, 2000) above, is an indication that Autistic Spectrum Disorders is a complex disorder with many defining features and no single definition. Not only has there been disagreement over the definition of autism, but the cause of autism still remains debatable and controversial. According to Brimacombe et

al. (2007), the symptoms and characteristics of ASD can present themselves in a wide variety of mild to severe combinations, complicating epidemiologic research and the causes of these conditions. According to Attwood (2007), the DSM-IV provides only cursory guidelines for the diagnostic process and a superficial description of ASD's, and it is insufficient to just use this source of information to make a diagnosis.

2.6.6 Treatment and Interventions

ASD remains to be a complex and multifaceted disorder that is complicated in its definition, cause and treatment. However, the general agreement is that early diagnosis followed by appropriate interventions can improve outcomes in later years for the ASD individual. According to Ospina et al. (2008), a variety of therapies have been proposed to improve the symptoms associated with ASD within the last 20 years, and current treatments may include pharmacological therapies, diet modifications, vitamin therapy, occupational therapy, speech and language therapy and behavioural and developmental approaches. However, there is no clear answer regarding the most effective therapy to improve symptoms associated with autism as ASD is a complex diagnosis that represents a spectrum of symptoms (Ospina et al., 2008). Therefore, Ospina et al. (2008) stress the importance that practitioners and everyone concerned needs to target their choice of treatment and intervention to the uniqueness of each presenting child and the symptoms that are the most important for the wellbeing of each child and their family.

2.7 AUTISTIC SPECTRUM DISORDERS AND ATTACHMENT

There has been a shift in recent years in terms of the perspective role of the family and the autistic child. In the past, the autistic child's family, particularly the mother, was considered to be the blame for her presumed role in their child's ASD disorder. However, with recent research favouring the biological and genetic causes of ASD, the family is being studied from a different perspective (Morgan, 1988). Questions are now addressing the effect of an autistic individual on the family and their interactions, and research has shown that this effect is paramount in most cases as ASD children have a substantial bearing on the social and emotional functioning of their parents. DeMeyer (1979, as cited in Morgan, 1988) identified the following various problems reported by parents of ASD children which include, "depressions, fear and anxiety, difficulties in daily management of the child, burnout,

financial worries, and concerns over inadequate educational and professional resources for the child and family” (p.266).

According to Rutgers et al. (2007), regardless of the stress levels of parents, “it may be expected that the diagnosis of Autistic Spectrum Disorders also has an impact on parents’ psychological functioning and feelings of efficacy in parenting” (p.861). This is further reiterated in research documented by Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney (2009), which found that although mothers of children with autism reported significantly higher levels of stress than did mothers of typically developing children, for the autism group, “the severity of the children’s autism was related to the mother’s reports of less closeness on the Attachment subscale” (p.184).

Although there is a paucity of information particularly in relation to mothers’ experiences of attachment with their autistic child, there is a growing interest in the area of attachment *and* autism. “A growing body of research has utilized attachment research methodology to study relational behaviours in children with autism and their parents” (Seskin et al., 2010, p.2). Previous research in this area has predominantly focused on the autistic child’s attachment status, however in keeping with the progression in the larger attachment literature, autism and attachment research has expanded its focus to include examination of parental factors and children’s attachment behaviours (Seskin et al., 2010). Condon and Corkindale (1998), also emphasize that the subjective experiences of parents in relation to their infants have been underutilized in previous parent- to- infant attachment research.

Seskin et al. (2010), highlights the importance and need to address the parental attachment feature in relation to their autistic child. Parents of autistic children...

...are faced with the daunting task of reaching far deeper into themselves than parents of typically developing children for the internal resources needed to emotionally engage their relationally challenged children. It is therefore important for clinicians and educators to be aware of the strengths and vulnerabilities that not only the child, but also the parent, brings to the relationship in the design and delivery of therapeutic interventions. Identifying parents at risk may lead to more finely attuned support for those parents who may be carrying troubled attachment representations into dyadic interactions with their children (Seskin et al., 2010, p.3).

Cullen and Barlow (2002) state that gaining insight into parent's life experiences of caring for children with autism are important for a number of reasons, that include, providing individualised care packages requires a greater understanding of both parents and children's specific needs and secondly, professionals working with parents of children with autism need to take into account parents experiences. According to Seskin et al. (2010), having an understanding of the "variability in parental attachment representations may help to identify parents of children with autism and associated disorders who are struggling with insecure attachment representations, and who might benefit from more individualised therapeutic support, thus increasing their capacity to help their children" (p.3).

Benoit et al. (1997) echo the importance of the parent's representations of their infants in clinical work and have proposed that the study of the more specific internal working model that a caregiver maintains of his/her child, and the relationship with that child, has important clinical and research implications. Furthermore, the caregivers' perceptions and subjective experiences allow the clinician to tailor infant-parent psychotherapy to the specific needs of a given caregiver-infant dyad (Benoit et al., 1997).

According to Zimmerman (2003) there has been extensive research into the areas of transition to parenthood, psychological processes during pregnancy, and having a child with disabilities, however "a much needed topic of study is that of the unique experience which combines all three areas – pregnancy, and parenting subsequent to having a child with disabilities" (p. 141). According to Clements and Barnett (2002, in Howe, 2006), parenting quality partially mediates the relation between a child's disability and attachment security, however, if parents remain 'mind-minded, reflective, emotionally attuned and have resolved states of mind with respect to attachment', children are likely to be secure (Howe, 1996, p.102).

In children with ASD many of the building blocks of interpersonal relationships, such as communication, social cognition, and processing of emotional signals are impaired (Travis & Sigman, 1998). Deficits in the areas of reciprocal communications, social engagements and the inability to send and receive clear communicative signals "is likely to affect caregiver-child interactions in ways that could negatively impact the attachment relationship" (p.60). Language plays a key role in the formation of an attachment between a mother and her child and according to Travis and Sigman (1998), individuals who do not acquire language are

isolated from all but the most basic social exchanges, and these deficits in conversational skills are likely to contribute to difficulties in interactions and relationships.

However, despite these deficits in children with autism, there has been research to suggest that ASD children are able to establish relationships with parents, siblings, and peers, although these relationships are frequently more limited than those of other children (Travis & Sigman, 1998, p.65). According to Travis and Sigman (1998) the attachment relationship between a parent and their ASD child “appears to be particularly well preserved in spite of the potentially disruptive social deficits characteristic of autism” (p.70).

Research by Buitelaar (1995), on attachment behaviour in children with autism concludes that ASD children do display attachment behaviour to their attachment figure in times of distress. ASD children also are able to discriminate between caregivers and strangers by directing more social behaviours towards their caregivers (Buitelaar, 1995). In addition Buitelaar’s (1995) research has also indicated that children with ASD react similarly to separations from caregivers and increase proximity seeking behaviour on reunion, in comparison to the control group. This is echoed in research by Dissanyake and Crossley (1997), whereby on the basis of observations of ASD children’s interactions with their mothers, it was evident that ASD children develop functional attachments to their caregivers and are able to use the mothers as a secure base as do typically developing children.

In a recent study by Seskin et al. (2010), parental factors were taken into consideration with regards to the attachment relationship with their ASD child. Results from this study indicate that parents, who reported higher levels of sensitivity and reflexive functioning, demonstrated more secure attachment representations towards their child with ASD. Similar results were found in a study by Capps et al (1994, as cited in Seskin et al, 2010), where research results revealed higher levels of sensitivity in mothers of children with ASD that demonstrated more secure attachment patterns.

2.8 MULTICULTURAL CONSIDERATIONS OF ATTACHMENT AND ASD

In a diverse country like South Africa, it is imperative to reflect on the multicultural considerations of both attachment and ASD. Multi-culturalism broadly defined is not limited to race and ethnicity, but also encompasses gender, sexual orientation, and disability (Brown,

Rodgers & Kapadia, 2008). Brown et al. (2008), outline the importance of considering multi-cultural elements with regards to attachment, as attachment goals differ from culture to culture. “Attachment from a Western perspective moves the individual from reliance on a safe base to personal exploration encompassing a wider and wider periphery, with the goal of autonomy. However, in collectivist cultures, for example, the goal of the caretaker would be more apt to encourage mutual effort rather than reliance on self” (Brown et al., 2008, p. 358). One should also take into consideration family differences and expectations of when a child should become more independent which plays a role in structuring the initial attachment patterns (Brown et al., 2008). Family and extended family networks also play an important role across cultures as well as differences in relating to and rearing a child across cultures.

According to Colin (1996) demographic factors, such as the baby’s gender, birth order and social class are also considered to influence the patterns of attachment that develops in infancy, and socioeconomic status helps to predict patterns of attachment to the mother. Colin (1996) states that in the case of very poor families, anxious attachments to the mother are more common than they are at more favourable economic levels, as families in poverty are often coping with multiple problems. In addition, Colin (1996) indicates that distributions of secure, avoidant, resistant, and disorganised attachments to the mother appear to be about the same among working-class, lower-middle –class and upper-middle-class families, among firstborns and later-born, and among boys and girls.

Colin (1996) also indicates that very young mothers may be less likely to foster secure attachments than other mother are, as when the mother is very young, the grandmother is often the baby’s primary caregiver. This is significant to consider in a South African context, where poverty, illness and employment all have an impact on the nuclear family, and it is often in lower socio-economic where households are headed not only by grandparents, but children themselves.

In terms of considering ASD in a multi-cultural society, such as South Africa, King and Bearman (2011) state that it is a sociological truism that social status affects one’s life chances; including one’s health and the more resources people have access to the less likely they are to experience disease or early mortality. In a recent study by King and Bearman (2011), it is highlighted that where people live, has an effect on their health, and the physical environment can affect health both directly and indirectly, and this has a significant impact

on a family with a child with autism. In lower socio-economic areas, not only are ASD specific resources limited, but health services, social support and educational services are all affected. “Resources matter because obtaining a diagnosis can be extremely difficult. In obtaining a diagnosis and services for their children, parents often confront a dizzying institutional maze and spend considerable resources navigating through it” (King & Bearman, 2011, p.322).

Daley (2002) addresses the need to consider culture in the realm of ASD research, in terms of how mental and physical impairments are managed in different cultures and how identity is shaped by disability, and this, according to Daley (2002) is equally intriguing when asked of autism as when asked of other disabilities. Daley (2002) indicates that national organisations for children and families with autism exist in over 80 countries around the world, and given this wide range of cultures in which this disorder has been reported, one would expect to find rich and extensive research literature; instead surprisingly very little is known about autism within a cultural context. To the best of the researcher’s knowledge, there has been no research pertaining to the multi-cultural considerations of ASD and attachment specific to a South African context.

2.9 CONCLUSION

This chapter has given an overview of the pertinent literature relating to attachment theory and ASD. It has discussed the defining features of attachment theory and the development of the relationship between a mother and child, referring in particular to the works of Bowlby and Ainsworth. This chapter has also outlined the defining features of ASD and consideration has been given to ASD and attachment. Considerations have also been given to the role of attachment and ASD within multicultural contexts.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

This chapter outlines the research design and methodology used in this study. This chapter will discuss the research aims and the research design of this study and includes the research questions, research methodology, data analysis and the ethical considerations taken into account in this study.

3.2 RESEARCH AIMS

This research aimed to address how raising a child diagnosed with ASD may affect the attachment relationship, considered from the mother's perspective and, to further gain insight into how one's life circumstances may play a role in this attachment relationship. This research was also concerned with the psychological needs of mothers of ASD children, and identifies how mothers' experiences differ, or are the same across diverse South African socio-economic groups. This study aimed to highlight the impact of social and economic factors on mothers' experiences of attachment with their ASD child to further explore the need for a psychological intervention in light of this.

3.3 RESEARCH QUESTIONS

The principal research question in this study was: What are mothers' from diverse South African socio-economic groups experiences regarding the effect of ASD on the attachment relationship with their child?

In addition, the following sub-questions were investigated in order to get an in-depth representation of mother's experiences from different socio-economic circumstances:

- What are the *similarities* and *differences* between mothers' experiences of ASD and attachment from privileged communities, compared to mothers from disadvantaged communities?

- What are the psychological needs of mothers with children with ASD with regards to the attachment process from advantaged and disadvantaged communities?

3.4 RESEARCH DESIGN

The foundation of this research was to gain insight into mother's experiences of the attachment relationship with their child who has a diagnosis of an ASD. This research aimed to elicit rich, authentic, real-life experiences of mothers of ASD children in an attempt to explore the implicit attachment bond between mother and child. A qualitative interpretive research design was therefore employed to explore and portray mothers' subjective experiences of attachment with their ASD child. This study was descriptive and exploratory in nature with the purpose of eliciting meaningful qualitative data through the use of semi-structured interviews. Qualitative research aims "to provide an in-depth understanding of peoples experiences, perspectives and histories in the context of their personal circumstances or settings" (Spencer, Ritchie, Lewis & Dillon, 2003, p.17). Denzin and Lincoln (2005), affirm that the qualitative researcher studies things in their natural setting, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them.

According to Terre Blanche, Durrheim and Painter (2006), data studied from an interpretive perspective enables the researcher to interpret with empathetic understanding, and involves taking people's subjective experiences seriously and creating meaning by interacting and listening to them.

3.5 RESEARCH METHOD

3.5.1 Sample and Sampling

The sample for this study consisted of 12 mothers from diverse socio-economic groups, whose children have a diagnosis of ASD. In this study, Sample A consisted of 6 participants from a disadvantaged community in greater Johannesburg, which comprised of mothers that attended an ASD parental support group run by the Speech and Language department at Chris Hani Baragwanath hospital. Sample B consisted of 6 participants from an advantaged community and included mothers of ASD children that attended The Links School which is a private special needs school in the northern suburbs of Johannesburg.

Non – probability purposive sampling was used to select the participants, in order to investigate a specific group of individuals that have experienced or are still experiencing the subject of interest. According to Lyons and Coyle (1997), purposive sampling enables you to find a more closely defined group for whom the research question will be significant. In addition, Lyons (2000, as cited in Breakwell, Hammond & Fife-Schaw, 2002) acknowledges that qualitative research involves studying particular phenomena and social processes set in a specific context, and therefore, qualitative samples tend to comprise a small number of cases chosen on a theoretical basis. The researcher therefore in the view that twelve participants in this study would provide a rich and abundant description of their experiences in order to fulfil the aims and purpose of this study. Turpin et al. (1997, as cited in Lyons & Cole, 2007), recommended that six to eight participants for each sample group is acceptable for this type and level of research.

As this study was concerned with sensitive material two participants in Sample B withdrew from the study. In light of this another two participants were invited to partake in this study through the method of snowball sampling. Bailey (1994) defines snowball sampling as “a non-probabilistic form of sampling in which persons initially chosen for the sample are used as informants to locate other persons having necessary characteristics making them eligible for the sample” (p. 438).

The two locations were chosen for this study based on the socioeconomic status of each group, the one being a more disadvantaged community (Sample A), and the other more a advantaged community (Sample B). These locations were also chosen based on availability and accessibility to mothers from diverse socioeconomic backgrounds that had a child diagnosed with an ASD. The researcher acknowledges that she was under the assumption that mothers who attend these two locations were from different socioeconomic contexts due to geographical locality, however, clarifying questions regarding participant’s language, employment, social and economic status were addressed to strengthen the argument for the choice of these locations, as will be discussed in the results chapter.

3.5.2 Data Collection

Prior to commencing this study, a Medical Ethical clearance certificate (Appendix A) was required from the Human Research Ethics committee, of the University of the Witwatersrand,

as this study was partly concerned with participants from a hospital setting. Once ethical clearance was obtained, the researcher met with each organisation in order to explain the nature of the research as outlined in the Organisation Information Letter (Appendix B). Each organisation then completed the Organisation Consent Forms (Appendix C), granting the researcher permission to conduct this study at their organisation. Once permission was granted, each organisation distributed the Participant Information letters (Appendix D) which invited participants in their respective organisations to partake in the study.

In Sample B, the Speech and Language therapists at Chris Hani Baragwanath Hospital assisted the researcher in identifying the mothers of ASD children that attend the ASD parental support group. Participation information letters (Appendix D) were then given to the mothers of ASD children by the Speech and Language therapists inviting them to partake in the study. Once the mothers agreed to partake in the study, interview times were set up to coincide with when mothers were at the Chris Hani Baragwanath hospital. The participants that agreed to partake on the study were required to complete the consent form (Appendix E) and the consent form for the interview to be tape recorded (Appendix F).

In Sample B, the researcher worked in collaboration with the headmistress of the Links school to identify who the mothers of ASD children were. The mothers of ASD children were then invited to participate in the study by the principal who distributed the Participant Information letters to those mothers that were interested. Once mothers agreed to partake in the study they were contacted telephonically by the researcher. The participants then completed consent forms (Appendix E), consenting to this study and a separate form consenting to the interview to be tape recorded (Appendix F).

Sample A interviews took place at the Speech and Language department at Chris Hani Baragwanath hospital and participants from Sample B were interviewed either on the school premises or at participants' homes during July to September 2011. Data was collected by means of a semi-structured interview, and included 18 open ended questions which took approximately an hour to administer (Appendix G).

3.5.3 Research Instrumentation

The researcher utilised the Working Model of the Child Interview (WMCI) developed by Zeanah, Benoit & Barton, (1995), as a foundation to generate a self-designed semi-structured

interview, as it is intended to assess mother's representations of attachment to their child. Zeanah (1986, as cited in Theran et al., 2005), states that the term 'working model' is used to "describe internal representations and implies an on-going, dynamic interaction between the child's personality and the mothers internal view of the child" (p.266).

The purpose of the WMCI is to have individuals disclose information in a narrative account of their perceptions, feelings, motives, and interpretations of a particular child and their relationship to that child (Zeanah et al., 1995). Benoit et al. (1997) have also concluded that "the WMCI is a useful structured interview to categorise mothers' perceptions and subjective experience of the infant and relationship with the infant" (Benoit et al., 1997, p.107).

The WMCI is concerned with the following areas for questioning:

- Mothers emotional reactions during pregnancy
- The infants personality and development
- Characteristics of the relationship with the infant
- Perceived and anticipated difficulties with infant characteristics
- Reactions to infant behaviour and distress in a variety of contexts,
- Anticipated difficulties in later development

(Benoit et al., 1997:110)

Breakwell (2002) highlights the importance of the interview as a data collection method but also emphasises that interviews are not free of pitfalls, especially when considering the problems surrounding questions construction, and the biases introduced by the researcher and the interviewee. Breakwell (2002) suggests that although the interview approach relies upon participants being able and willing to give accurate and complete answers to questions, by constructing a systematic set of questions will provide evidence of consistency across responses. In light of this, Benoit et al (1997) suggest that there have been many instruments that have been developed to assess caregivers' internal working models of their child, relationship with the child and their parenting role; yet validity data about these measures have been limited. However, according to Benoit et al (1997), the WMCI, has a growing body of data evaluating its validity. Benoit et al (1997) continue to agree that investigations using this interview have addressed the stability and predictive validity of the WMCI. In addition, Oppenheim and Goldsmith (2007) outline the numerous published studies in which

the WMCI has been validated; additionally the WMCI has “been shown to be stable, to be associated with mother and child’s interactive behaviours, and to be meaningfully associated with both risk conditions and clinical status (p.4).

The researcher used the more applicable questions from the WMCI, which included questions: 1,2, 3,5,6,7,8,9,10,11,13,14,15,17 and 19. Specific questions were incorporated into the interview schedule that specifically addressed the possible implications of the diverse socioeconomic status of the sample groups.

3.5.4 Working in a Second Language Context

The researcher was aware that the language barrier between the researcher and the participants could place limitations on the research and couldn’t be ignored. Therefore the researcher took every effort to take into consideration that language needed to be simplified to make the interview schedule and questioning accessible to all participants. Furthermore, preparations were made to have access to an interpreter that would be used to assist in administering the questionnaire and transcribing interviews in certain circumstances. However this was not required by any of the participants throughout the study.

3.6 DATA ANALYSIS

The semi-structured interviews were tape recorded with the permission of each participant and each interview was transcribed by the researcher. The data was then analysed using thematic content analysis, as this analysis is considered a very useful research tool to potentially provide a rich and detailed, yet complex account of data (Braun & Clarke, 2006).

Thematic analysis has been defined as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.79). According to Braun & Clarke (2006), a theme captures something important about the data in relation to the research question, which represents some level of meaning within the data. Evident themes with regards to mothers’ perceptions of early attachment with their ASD children were identified and explored utilising the six phases of thematic analysis outline by (Braun & Clarke, 2006). The phases include:

1. Familiarising yourself with the data
2. Generating initial codes

3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

(Braun & Clarke, 2006, p.97).

According to Braun and Clarke (2006), a researcher's personal judgment is imperative and necessary to determine what a theme is. However, it is recommended to use investigator triangulation to decrease the bias in gathering, reporting, coding or analysing the data (Denzin, 1970, as cited in Thurmond, 2001). According to Thurmond (2001) investigator triangulation involves using more than one observer, interviewer, coder, or data analyst in the study, which can increase the values of the findings. Unfortunately due to the scope of this research and financial constraints, investigator triangulation was not possible, which may be considered a limitation of this study.

3.7 ETHICAL CONSIDERATIONS

3.7.1 Ethical Clearance

This research was only conducted once the Human Research Ethics Committee of the University of the Witwatersrand had granted an ethical clearance certificate (Appendix A) to commence this study. Medical Ethics was needed to be obtained as the researcher is using Chris Hani Baragwanath Hospital as a research location. Permission to conduct this research at the hospital was requested from the supervisor/superintendent in charge of the hospital (Appendix B). Permission was not needed from the Gauteng Department of Education as The Links School is a private organisation. Permission to conduct this research was also requested and obtained from the school principal of The Links School and the co-ordinator of the Speech and Language Department at Chris Hani Baragwanath Hospital. An information letter (Appendix B) informed each organisation of the exact nature of this study and how the research will be conducted. Mothers of children with ASD, from these two locations were then invited to participate in this study.

3.7.2 Informed Consent

Volunteers interested in this study received a participant information letter (Appendix D), detailing the exact nature and purpose of this study. It emphasised that participation in this study was voluntary and participants could terminate their involvement at any time. In addition, participants were informed that their direct quotes may be used in the write up, but no identifying details will be used in the study and confidentiality will be kept at all times. The participants were also informed that the interview material (tapes and transcripts) would not be seen or heard by anyone in their organisations and would only be processed by the researcher. Additionally the interview material would be kept locked in a filing cabinet and destroyed after two years of the research is published or after 6 years if the research is not published. If the participants would like to access the results from this study, they can contact the researcher directly or alternatively, a copy of the results from this study will be placed in the University of the Witwatersrand library.

It was also explained to the participants that although there is no direct benefits for their participation in this study, their experiences elicited during the interviews could contribute to a larger body of knowledge concerning mothers' experiences of attachment with an ASD child. If mothers were willing to participate in this research they were required to sign a consent letter (Appendix E), giving the researcher permission to use them in the study. The participants were also required to consent to the interviews to be tape recorded if they were in agreement (Appendix F).

3.7.3 Confidentiality

Confidentiality has been guaranteed to all participants, and non-identifying characteristics have been used to protect the identities of the mothers and those directly involved in this study. Confidentiality has been preserved throughout this process by not using any of the participants' names, where participants have been specifically referred to; they have been addressed as *Participant 1*, *Participant 2*, *etc.* In addition, the names of the participants children and other people mentioned by the participants in this study have not been used or otherwise been changed.

3.7.4 Support and Counselling Centres

Although this research was concerned with a non-vulnerable population (i.e. adults), the nature of this research could have been upsetting and difficult for some of the participants to deal with. It was understandable that participants in this study would be addressing personal questions regarding their relationship with their child who has an ASD. Such an interview could have elicited feelings of guilt and blame, and therefore details of support groups/counselling centres were provided if participants required further support. Permission to use the support and counselling centres were obtained from the relevant organisations (Appendix H) were required. The researcher ensured that the support and counselling centres were feasible and accessible for all participants.

- Life Line (011) 715-2000
- Emthonjeni Centre (University of the Witwatersrand) (011) 717 4513
- Autism South Africa (011) 484-9909
- Chris Hani Baragwanath Hospital, Speech and Language Department
ASD Parental support groups
Tel: (011) 933-8000

3.8 CONCLUSION

This chapter has outlined and discussed the research design and methodology used in this study. In particular it has outlined the use of qualitative methods to address the research aims and questions pertaining to this study. This chapter has also addressed the research methods used to gain access to the participants in their setting, while taking into account the ethical considerations of this study. This chapter have also outlined the data analysis methods that were employed in this study to enable a more in depth analysis of mothers' experiences of attachment with their ASD child, across socio-economic groups in South Africa.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

This chapter presents the results and a discussion of the results in relation to the significant literature concerned with mothers' experiences of attachment with their ASD child, across different socio-economic groups. The participants' demographics shall be represented graphically where necessary and compared and discussed qualitatively. The narratives from the interviews are discussed from a qualitative perspective by analysing and discussing emerging themes that transpired during this study, in relation to the research questions.

4.2 DEMOGRAPHIC INFORMATION

The sample for this study consisted of 12 participants that included mothers or caregivers of children diagnosed with an ASD from diverse South African socio-economic groups.

- **Sample A** consisted of 6 participants from Chris Hani Baragwanath Hospital, which is located in a disadvantaged community in the greater Johannesburg area.
- **Sample B** consisted of 6 participants from The Links School, which is located in an advantaged community in the Northern suburbs of Johannesburg.

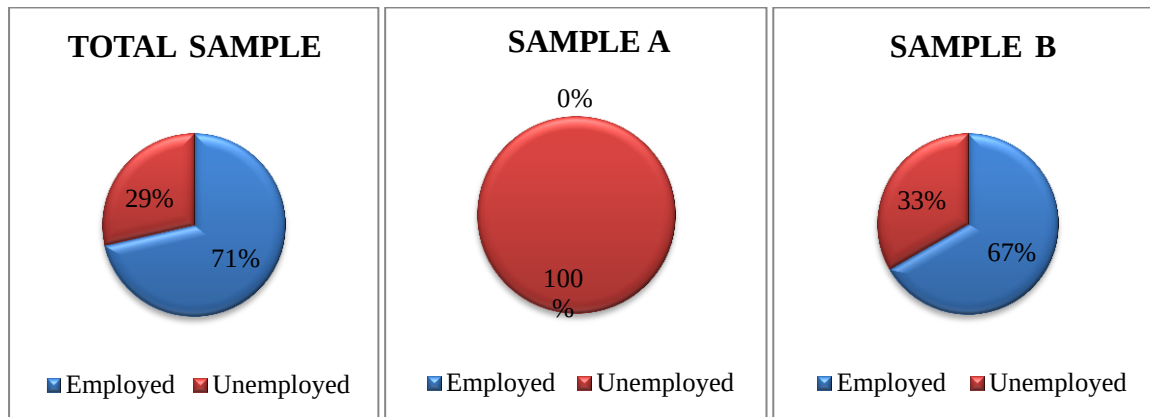
Table 4:***Demographics of Participants***

Participants	Age	Relationship To ASD Child	Marital Status	First Language	Other Languages
SAMPLE A (Disadvantaged)					
Participant 1	31	Mother	Married	Southern Sotho,	Afrikaans, English, Zulu
Participant 2	49	Grandmother	Single	Zulu	English
Participant 3	44	Mother	Single	Zulu	English
Participant 4	41	Mother	Single	Tswana	Sotho, English, Afrikaans
Participant 5	33	Mother	Single	Tswana	Zulu, English
Participant 6	38	Mother	Divorced	Sotho	Zulu, Pedi, English
SAMPLE B (Advantaged)					
Participant 7	38	Mother	Married	English	Shona
Participant 8	44	Mother	Divorced	English	N/A
Participant 9	47	Mother	Married	English	N/A
Participant 10	33	Mother	Married	English	N/A
Participant 11	42	Mother	Married	English	Afrikaans
Participant 12	45	Mother	Divorced	English	Afrikaans, Hungarian

As can be seen from Table 4, 11 of the participants in this study are the biological mothers and only one of the participants is a grandmother and full time caregiver of a child with ASD. The age ranges of the participants ranged between 31 years to 49 years old. Five of the mothers in this study are married and the remaining participants are either single or divorced. All of the mothers in Sample B speak English as their first language, in comparison to Sample A, where there is a combination of first languages spoken, including Zulu, Tswana and Sotho. In Sample A, English was a common second language

FIGURE 1:

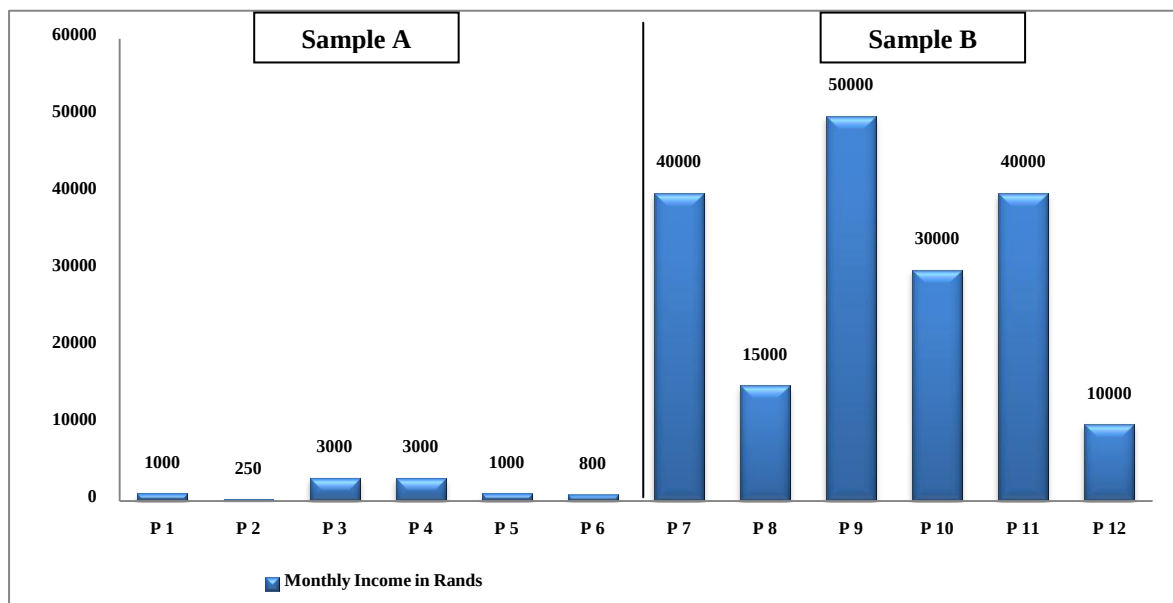
Employment Details of the Participants



As can be seen from Figure 1, the total sample of participants indicates that 71% of the participants are employed, whereas 29% of the total sample of participants reported that they were unemployed. When considering the employment status of Sample A, all of the participants indicated that they were currently not employed. In comparison, in Sample B, 67% of the participants were employed and 33% were unemployed.

FIGURE 2:

Monthly Family Income



As can be seen from Figure 2, the monthly family income differs greatly between the participants in Sample A and Sample B. In sample A, the minimum average family income is R250 and the maximum average family income is R3000. In comparison, in Sample B, the minimum average family income per month is R10000, and the maximum average income is R50000.

TABLE 5:***Demographics of ASD child***

Child With ASD	Childs Age	Sex	ASD Diagnosis	No. of Children	Childs Position	Planned vs. Unplanned Pregnancy
SAMPLE A (Disadvantaged)						
X 1	4	Male	Autism	4	4	Planned
X 2	6	Male	Autism	2	2	Unplanned
X 3	6	Female	Autism	1	1	Unplanned
X 4	5	Male	Autism	2	2	Unplanned
X 5	4	Male	Autism	3	3	Unplanned
X 6	4	Female	Autism	5	5	Unplanned
SAMPLE B (Advantaged)						
X 7	8	Male	Autism	4	4	Unplanned
X 8	13	Male	Autism	1	1	Unplanned
X 9	20	Male	Autism	3	2	Planned
X 10	8	Male	Aspergers	2	1	Planned
X 11	4	Male	Autism	3	2	Planned
X 12	11	Female	Aspergers	2	2	Planned

Table 5, outlines the demographics of the ASD children of the participants in this study. As indicated there are 9 male children in comparison to 3 female children with ASD. As indicated previously specified in the literature, the prevalence of ASD is higher in boys than in girls (Sadock & Sadock, 2007). Additionally, 11 children had a diagnosis of Autism and only one had a diagnosis of Aspergers syndrome. The ages of the children with ASD ranged from 4 years to 20 years old. With reference to the child's position in the family in this study, it is interesting to note that the child born with ASD is in most cases the last born in the family. From the total sample of children with ASD, 41% of the pregnancies were planned. In Sample A, the majority of the pregnancies were unplanned, compared to Sample B; were the majority of the pregnancies were planned.

TABLE 6:***Age of child and professionals who diagnosed ASD***

Child With ASD*	Childs Age	Age when Diagnosed	Diagnosed by
SAMPLE A (Disadvantaged)			
X 1	4	2	Nurses from the clinic and a General practitioner
X 2	6	4	Speech and Language Department
X 3	6	3	Speech and Language Department
X 4	5	5	General Practitioner
X 5	4	2	General Practitioner
X 6	4	1 year, 2 months	General Practitioner at the clinic
SAMPLE B (Advantaged)			
X 7	8	3	Paediatrician
X 8	13	2 years, 7 months	Psychiatrist
X 9	20	3	Paediatrician
X 10	8	7	Educational Psychologist
X 11	4	2	Paediatric Neurologist
X 12	11	4	Teacher

* Children with ASD shall be referred to 'my child' throughout this study

Table 6 illustrates the present age of the ASD child, the age at which the child was diagnosed with ASD and which professional gave them a final diagnosis of ASD. The children in this study received an ASD diagnosis ranging between the ages of 1 year, 2 months old to 7 years old. In Sample A, the majority of the ASD diagnoses were either given by General practitioners or by the Speech and Language department at Chris Hani Baragwanath Hospital. In comparison, in Sample B, professionals that diagnosed ASD were more diverse and included paediatricians, psychiatrists, educational psychologists, neurologist and a teacher.

4.3 THEMES AND SUBTHEMES

The qualitative data collected from the interviews that were conducted with the mothers of ASD children were analysed using content thematic analysis (Braun & Clarke, 2006). Evident themes and subthemes with regards to mothers' perceptions of attachment with their ASD children, from both disadvantaged and advantaged communities were identified from the transcribed interviews. The themes identified should not be seen in isolation, but rather appreciated and understood within the context of the whole attachment relationship between a mother and her ASD child. The similarities and differences in mothers' experiences from the two diverse groups were identified and discussed.

As seen from Table 7, seven themes were identified in this study. Although mothers' experiences of prenatal and postnatal attachment (Theme 1), were not directly investigated in this study; it became apparent from the birth history of their ASD child, that most of the mothers in this study shared similar experiences and concerns in this regard. The researcher was in the view that it was therefore necessary to include the mothers' experiences of prenatal and postnatal attachment prior to their child's diagnosis of ASD, as it is an interesting field of enquiry that may relate to attachment theory in general. In addition, themes 2 to themes 7, deal more specifically with mothers experiences of the attachment relationship with their ASD child.

TABLE 7:
Themes and subthemes

THEMES	SUBTHEMES
Theme 1: Mothers experiences of prenatal and postnatal attachment	• Prenatal attachment experience • Postnatal attachment experience
Theme 2: Mothers perceived experiences of attachment preceding an ASD diagnosis	• Developmental Milestones • Mothers intuition vs. the Neurotic Mother • Dealing with the professionals
Theme 3: Mothers reactions to an ASD diagnosis and effects on attachment	• Reaction to an ASD diagnosis • Denial and acceptance • Mothers experiences of the challenges of an ASD diagnosis on attachment
Theme 4: The role of social support and social reactions to ASD	• Social support and attachment • Social reactions to ASD
Theme 5: Maternal representations and experiences of mothering an ASD child	• Maternal representations and attachment • Maternal relationship with an ASD child • Transformation of the mother-child relationship
Theme 6: Effects of socio-economic status on attachment	• Access to education • Access to professionals • Resources and Information
Theme 7: Psychological needs of mothers	• Psychological needs of mothers

4.4 THEME 1: MOTHERS' EXPERIENCES OF PRENATAL AND POSTNATAL ATTACHMENT

As can be seen from Table 7, two main subthemes (prenatal attachment experience; postnatal attachment experience) emerged from Theme 1.

4.4.1 Prenatal Attachment Experience

In relation to mothers from the diverse socio-economic groups perceived experiences of prenatal attachment the following points shall be discussed: planned vs. unplanned pregnancy, social support, intrapersonal factors and, illness and medical problems experienced by mothers during pregnancy.

The transitioning to motherhood is a period of major life change and adjustment that brings with it challenges to the new mothers emotional balance and growth (Holmes, 2002, as cited in Araneda, Santelices & Farkas, 2010, & Speilman, 2002, as cited in Araneda, Santelices & Farkas, 2010). Although the relationship between a mother and her child has been well documented in the field of attachment theory, according to Laxton-Kane and Slade (2002), the last 20 years has seen an increased recognition that this attachment relationship begins before birth, while the mother is pregnant and the child is still a foetus. According to Zimerman (2003), there are many factors that contribute to an optimal attachment between a parent and a child and recent research suggests that this relationship can start prior to the birth of the child (p.142).

The importance of the prenatal attachment between a mother and her child has been illustrated in Muller's (1996) clinical studies on prenatal and postnatal attachment and the results support a relationship between prenatal and postnatal attachment. In addition, Zeanah (1986, as cited in Theran, et al., 2005), states that "women experience vivid mental representation of their children during their pregnancy that are similar to their postnatal representations" (p. 254).

Condon (1993, in Laxton-Kane & Slade, 2002), provides an understanding of prenatal attachment to be "a relationship whereby the mother seeks: to know; to be with; to avoid separation or loss; to protect; and to identify and gratify the needs of the foetus" (p.254). According to Laxton-Kane and Slade (2002), this prenatal relationship is most likely

influenced by factors such as the mothers own attachment experiences, the impact of the competing roles to that of caregiver and the support available for the pregnancy.

Mothers from both the diverse socio-economic groups in this study were faced with various challenges prior and during their pregnancies which included: the planning of the pregnancy, social support, illness, high risk pregnancies and intra-personal factors. Although there has been some research to indicate that there is a correlation between prenatal and postnatal attachment, the studies are limited and the results are incongruent and conflicting. However, for the purpose of this study on mother's experiences of attachment, it is essential to consider mothers experiences of the prenatal attachment they experienced with their child to get a deeper understanding of the attachment relationship between a mother and her ASD child across diverse socio-economic groups.

i. Planned vs. Unplanned pregnancies

In the present study, it was evident that unplanned pregnancies, in particular, bring about both positive and negative emotional responses in mothers and other individuals involved, despite socio-economic differences.

In reflection of her daughter's unplanned pregnancy, Participant 2, the full time caregiver of X 2 since he was 3 months old, indicates that the pregnancy was a very difficult time for the family, especially as the parents are not married.

- *We (the family) were angry, how could he (the father) repeat himself after the first born. He is not married and now he has another child, we were so angry (Sample A).*

Participant 7 also expressed some emotional difficulties in response to her unplanned pregnancy.

- *At the time I thought I was done with having children and I thought my life was just starting again as I had actually just gone back to school and I had started a business. So yes it was the wrong time for me (Sample B).*

Other participants, in retrospect, were excited by the prospect of their unplanned pregnancies:

- *It was not planned, but it was a surprise. I was happy as I didn't have a child and I was 30 years old. I am not married, but the father didn't run away (Sample A).*

- *At first I couldn't conceive and I was on medication to conceive and then I just gave up. But I really wanted to be pregnant so I was really happy about being pregnant. It was stunning news (Sample B).*

As illustrated in Table 5, 63% of the total sample of mothers in this study indicated that their pregnancies were unplanned. In Sample A, 83% of the mothers had unplanned pregnancies in comparison to 33% of mothers in Sample B. In this study, it was not evident that socio-economic factors played a role in mother's reactions to their planned or unplanned pregnancies as both groups of mothers either expressed concerns or anger at the news of their unplanned pregnancy or on the contrary some mothers expressed excitement and joy.

According to Laxton-Kane and Slade (2002), the planning of a pregnancy may give insight into the representational systems of care-giving and the relationship of prenatal attachment; however the research findings pertaining to this are inconclusive. Laxton-Kane and Slade (2002), highlight that in an unplanned pregnancy, it may be more likely that the baby is unwanted and lower rates of prenatal attachment would be observed, on the contrary however, higher levels of prenatal attachment may arise where the unexpected pregnancy stimulated the prenatal attachment.

ii. Social support

Mothers from both samples, who experienced support from families and partners, described their pregnancies in a more positive manner. In contrast, those mothers across both samples that did not feel supported reacted in a similar manner, and expressed more emotional concerns

The social support provided to mothers in this study during pregnancy was also varied in terms of the effect this had on their emotional status during this time. In particular, what was highlighted in this study is that mothers from both groups who perceived to receive adequate social support during their pregnancies felt more relaxed and described their pregnancies in a more optimistic manner:

- *The family was happy, so I was happy (Sample A).*
- *I was fine, absolutely fine. I was very happy. I had no stress. I had help and support at home (Sample B)*

On the other hand, mothers from either group who experienced inadequate social support from their spouses/partners and family, during their pregnancies felt more emotional during this time and described this time in a more adverse manner.

- *My husband was not fine about the pregnancy. He said we had too many children. It wasn't good (Sample A).*
- *It was hard as I didn't have family around (Sample A).*
- *There was a lot going on at that stage, especially as we were having problems in the marriage. I was a wreck. I was an emotional wreck (Sample B).*
- *I was physically well, but not emotionally well at all during the pregnancy. The father proceeded to be obnoxious throughout the pregnancy (Sample B).*

Participant 12 indicated that she not only experienced a lack of support from her husband at the birth of her child, so much so that she felt that her child was not welcomed at all. My child was 'the pestilence as far as my husband was concerned',

- *Being on my own with a four year old and a baby was interesting. I was permanently exhausted and broke. The father acted up. I was stretched beyond human endurance (Sample B)*

Support for the mother during her pregnancy is seen as an essential constituent in solidifying the attachment between a mother and her unborn child, and instances where this support is lacking or relationships are unstable, can have an adverse effect on this attachment process (Bialoskurski, Cox, & Hayes, 1999). Laxton-Kane and Slade (2002), hypothesise that for adequate prenatal attachment to occur, the mother requires adequate support herself. In a recent study by Araneda et al. (2010), they explored differences in maternal representations between pregnant women with different levels of socio-emotional wellbeing. Their study proposes that a mother's attachment experiences and particular aspects of her socio-emotional prenatal well-being and environment are related to her maternal representations of her as a mother and her child.

iii. Intrapersonal factors

The interviews with the mothers indicate that pregnancy is at times an emotionally charged experience that varies across individuals. Most of the mothers from the diverse socio-economic groups in this study indicated that their intrapersonal factors had an impact on how they felt during their pregnancies, which is hypothesised to have an impact on prenatal attachment.

Some of the intrapersonal factors experienced by the mothers in this study during pregnancy included: nervousness, depression, anxiety, and neuroticism, while some of the mothers indicated that they were fine during their pregnancies. In addition, the mothers that previously had been exposed to children or already had a child of their own reported that they felt more relaxed with their second pregnancies in comparison to their first.

- *I was stressed, so many things (Sample A).*
- *I was alright, there was nothing wrong (Sample A).*
- *I really wanted to be pregnant so I was really happy about being pregnant (Sample B)*
- *Emotionally I was devastated, I actually was depressed for the first three months of the pregnancy (Sample B).*
- *I think I was more relaxed this time as I already had a child. With my first child I was really nervous as I hadn't had any experiences with babies (Sample B).*

As with the present study, Austin (2004, as cited in Araneda et al., 2010) indicates that several studies suggest that maternal mental states in pregnancy may have a significant impact on the behavioural and mental outcomes of the offspring, and specifically “maternal psychosocial risk may be indirectly related to mother-infant attachment through its effects on how a mother functions and how she thinks about her child” (pg. 31). Although according to Laxton-Kane and Slade (2002), the research does suggest that there is possibly an association between mother’s psychological states and prenatal attachment, the levels of anxiety and depression may fluctuate with gestation due to the shifting nature of the mothers needs.

iv. Illness and medical complications

The mothers from both the groups, in terms of illness and medical conditions shared similar experiences. Mothers from both groups indicated that where their pregnancies were complicated by medical conditions, exacerbated their stress during pregnancy.

- *At first I couldn't conceive and I was on medication to conceive. It was a bad pregnancy right from the beginning. I was carrying twins and I lost the one (Sample B).*
- *Everything was fine up until 26 weeks, then I started gaining weight and my blood pressure went up. My gynaecologist diagnosed me with preeclampsia and I was put onto treatment for 5 weeks (Sample B).*

Participant 2 (Sample A) highlights the reality of HIV/Aids epidemic in South Africa, and the impact this has on a mothers experiences of pregnancy. She describes the birth of her grandson as 'a very heavy load' on his biological mother as his mother was very sickly and frequently in hospital, as a result of having HIV/AIDS. Consequently his mother was unable to care for her newborn child, and he was placed in the full time care of his grandmother.

Research in the field of medical complications and the effects of this on prenatal attachment is limited. However, research conducted by Chazotte (1995, in Laxton-Kane & Slade, 2002) hypothesises that medical complication, such as gestational diabetes, means a mother has to make psychological and behavioural adaptations. According to Laxton-Kane & Slade (2002), these adaptations could either lead to more intense interactional levels and an increase in prenatal attachment, or conversely, the associated risks could lead to a decrease in pre attachment between a mother and her unborn child.

This area of concern may be of particular importance in a country like South Africa, where the effect of medical conditions and in particular HIV/Aids on prenatal attachment, could be an area of research to assist in the psychological well-being of mothers and the prevention of early mother-child attachment difficulties. According to South African Statistics (2011) the total number of persons living with HIV in South Africa increased from an estimated 4,21 million in 2001 to 5,38 million by 2011, which indicates that for 2011 an estimated 10,6% of the total population is HIV positive. In addition, the statistics indicate that approximately one-fifth of South African women in their reproductive ages are HIV positive, which in turn

may have a dramatic effect on the attachment relationship between mothers and children affected by HIV/Aids in this country.

It is evident that the mothers from the diverse socio-economic groups that participated in this study have experienced significant factors that may have had an effect on prenatal attachment and maternal representations of their unborn child, including the planning of their pregnancies, the social support available to them during their pregnancies, intrapersonal factors and medical conditions. Pajulo, Savonlahti, Sourander, Pih, and Helenius (2001) corroborated that pregnant woman who suffer from depression, social problems and lack of social support, among other risk factors, have significantly more negative representations of their child, self-as-mother and own mother-as-mother when compared with pregnant women who do not have such trying circumstances. However, according to Zimmerman (2003), there is a lack of sufficient and appropriate research on the experience of subsequent pregnancy, which presents a disparity in the literature on prenatal and early parenting experience (p.142).

4.4.2 Postnatal Attachment Experience

Mother's postnatal attachment experiences shall be discussed in terms of: mothers' experiences of childbirth and hospitalisation and attachment.

According to Araneda et al. (2010), the importance of maternal representations is particularly evident in the mother's interactive behaviour with her baby and the quality of their attachment after birth. Postnatal experiences play a crucial part in determining the attachment relationship between a mother and child and are directly related to the history of interactions between a mother and her child (Araneda et al., 2010).

In this study mothers' perceived post natal experiences of attachment were considered, as attachment styles are developed in early infancy, of which the experienced birth of one's child plays a major role. According to Klaus and Kennel (1982, as cited in Muller, 1996), a mother feels particularly attached and responsive to their new infants immediately after birth, due to hormonal changes and physical changes. According to Bialoskurski et al. (1999), postnatal attachment should then be considered as an automatic process as the process has already been initiated and may continue on its own momentum.

i. Mothers experiences of childbirth

This study highlighted the complex and fragile nature of childbirth as experienced by the mothers from diverse socio-economic groups in this study. The mothers from both groups in this study that reported the birth of their child to be uncomplicated appeared to experience childbirth as a positive experience. On the contrary mothers from both groups that experienced a lack of support or medical complications during this time found it to be a stressful and traumatic event.

As indicated by Table 8, not much difference in terms of mothers experiences of childbirth were found between the diverse socio-economic groups. Eight of the mothers in this study from both groups experienced complications at birth, and the majority of their newborns had to be hospitalised for a certain length of time. Although the medical complications of child birth are beyond the scope of this study, the implications of these medical conditions may have a significant effect on the attachment between a mother and her newborn child.

TABLE 8:

Mothers' experiences of childbirth

Mother	Child	Mothers experiences of childbirth
SAMPLE A (Disadvantaged)		
Participant 1	X 1	It was fine, it was not difficult
Participant 2	X 2	He stayed in hospital for 10 days as it was hard for him to breathe and he was supported by a machine. Mom couldn't stay with him in the hospital
Participant 3	X 3	She had a little problem with her chest, but after 6 months she was fine
Participant 4	X 4	No complications
Participant 5	X 5	There were problems. When he was born he didn't cry. The doctors took him away and I didn't know what was happening. Only the following day I was allowed to see my baby.
Participant 6	X 6	They had to give me medication for the pain, I was in so much pain
SAMPLE B (Advantaged)		
Participant 7	X 7	I understand there were complications at birth. What I understand is that during child birth he gasped, which I only found out much later when I was trying to find out what exactly had happened. He was put into the neo-natal ward for 48 hours
Participant 8	X 8	He had jaundice and he was underweight. He was hospitalised after a day to have blood tests
Participant 9	X 9	No complications
Participant 10	X 10	He was born premature at 26 weeks and weighed 1.7 kg's. He spent 3 weeks in ICU and he came out of hospital weighing 2kg's
Participant 11	X 11	He was born 5 weeks premature and he was an emergency Caesar. They had to take him out because his heart stopped. He was hospitalised for 6 days.
Participant 12	X 12	She stopped breathing after 24 hours of birth. At 3 days she vomited fresh blood and stopped breathing again at about 2 weeks. She was on a heart/lung monitor in the first few months of her life

ii. Attachment and hospitalisation

Mothers' experiences of attachment and hospitalisation across the different socio-economic groups did not elicit any significant differences in their experiences. Mothers whose children were hospitalised in both Sample A and Sample B found this to be a very stressful and traumatic experience.

As indicated by Table 8, most of the mothers from Sample A and Sample B, indicated that their newborn's had to be hospitalised, and some mothers indicated that this early experience of hospitalisation was traumatic and had an effect on the attachment relationship with their child.

- *The doctors took him away and I didn't know what was wrong, what was happening. They didn't bring him to me; I stayed the whole day without seeing him. I asked the doctor and they said nothing. Only the following day was I allowed seeing my baby. My baby stayed in hospital for 3 days, they then discharged him and said he was all right, and there was nothing wrong with him (Sample A).*
- *The hospital didn't offer kangaroo care, which I think would have made a massive difference to him. The hospital was very military in the sense that they were very strict about how long I was able to hold him, and I think this really affected him in terms of bonding. I had fixed time of 10 minutes and couldn't just hold him when I wanted to. The concern was hard to understand but I don't believe that he got the same bonding experience as my second son did (Sample B).*

Although some of the mothers reported that they could stay with their child during this hospitalisation period, many could not, and they would have to travel in everyday to the hospital to see their newborn child, which compounded their stress at the time.

- *I felt sad. I didn't know anything and I was scared. I didn't know if my baby was alive or dead and the sisters didn't tell me anything. I asked them where my baby was and they didn't tell me anything. They didn't tell me that he had a problem (Sample A).*
- *He was in hospital for 6 days. I was in hospital for 2 days and then my husband would drop me off in the morning and fetch me after work while I was with my child* for the day. It was very stressful... the first few weeks were chaotic to say the least. It was crazy, it was really crazy (Sample B).*

Although most of the research encountered has been predominantly focused on the effects of premature newborn's and attachment, it can be hypothesised that a newborn placed in hospital for any length of time, regardless of the nature of the medical condition, may have some consequential effect on the attachment relationship between a mother and a child.

The findings from the present study are reflected in the literature which indicates that there is an association between a mother's psychological distress in correlation to the health of their child at birth. Singer et al. (1996, as cited in Bialoskurski, et al., 1998) highlights that mothers of low birth weight infants experienced a significantly higher incidence of psychological stress during the neonatal period. In addition, this study postulated that this would place a greater strain on the mother's parenting roles, as mothers of sick and low birth weight infants feel less confident in the parenting role, which in turn affects the attachment relationship.

Of particular importance to this study is the research conducted on the early separation of a mother and her new-born child due to medical complications. According to Bialoskurski et al. (1998), the process of mother-infant attachment may become problematic or delayed when the infant is placed in an Intensive care unit, as isolation of the infant from the mother affects the attachment process. "Because of the requirement for complex technologic support, attachment may become delayed because the mother and infant are separated physically by the mechanical and technological interventions required to sustain the viability of the infant" (Bialoskurski et al., 1998, p.68). Borghini et al. (2006) also indicated that premature birth is often associated with lengthy hospital stays, and there have been concerns about the extended parent-child separation and the impact it has on normal attachment.

Bialoskurski et al. (1998) concluded that immediate attachment was found to be more likely to occur if the mother was able to see the infant immediately after birth and when there was physical contact between the mother and the infant. In addition, delayed attachment may be compounded by the reality that full-term infants are more able to "initiate reciprocal bidirectional behavioural sequences with the mother" (Bialoskurski et al. 1998, p.72), while a premature infant may present with disrupted patterns of interaction with the mother. Furthermore, this research indicates that "when the infant's appearances and behaviour do not conform to the maternal expectations at a conscious or unconscious level, the bond formation may be delayed because the infant is not able to play his or her part in the establishment of attachment" (Bialoskurski et al., 1998, p.72).

As attachment is seen as a dyadic relationship between a caregiver and his or her child, hospitalisation of a newborn complicates this relationship as more people (doctors, nurses) are entered into this relationship. According to Bialoskurski et al. (1998) the presence of

hospital staff and particular nurses turns the dyadic relationship into a triadic relationship, which effects attachment in that “a triadic relationship alters the attachment process as the care of the infant is shared between the mother and the nurses” (p.74). Despite some of the difficulties experienced by the mothers during their pregnancies and the birth of their child, all of the mothers expressed positive and optimistic emotions in light of the difficulties they had faced. Mothers from both groups in this study expressed feelings of love, joy, excitement and happiness towards their newborn child.

4.5 THEME 2: MOTHERS PERCEIVED EXPERIENCES OF ATTACHMENT PRECEDING AN ASD DIAGNOSIS

Theme 2, discusses mothers perceived experiences of attachment with their child, prior to and leading up to an ASD diagnosis and the following sub themes emerged from the content analysis: developmental milestones, mothers’ intuition vs. neurotic mother, and dealing with the professionals. These shall be discussed in order to gain insight into the entirety of mothers experiences of attachment with their ASD child. In terms of the theme focussing on mothers perceived experiences of attachment preceding an ASD diagnosis; it is evident that mothers from the diverse socio-economic groups share many of the same or similar experiences.

4.5.1 Developmental milestones

Considering the mothers reported experiences of their children’s developmental milestone delays, there is no evidence to suggest that these experiences differ across socio-economic groups in this study. Mothers from Sample A and Sample B appeared to share similar experiences in terms of reporting delays in their ASD child’s milestones, which in most cases prompted cause for concern across both groups.

During the interviews, most mothers from the diverse socio-economic expressed that they first began to notice that there was ‘something wrong’ with their child when they noticed a delay in their child’s developmental milestones and in particular their child’s language. Some other developmental delays reported included a delay in crawling, walking, sleeping, sitting and smiling.

Most of the mothers from both groups in this study reported that their child's developmental milestones were delayed in more than one area; however a lack of language caused the biggest concern for the mothers in this study.

- *Crying and sleeping were difficult. He didn't want to sleep. The delay was just the talking. This took a long time, and he had no speech at four years old. Before he was just pulling and pointing, and if you didn't know what he wanted he would just hit you (Sample A).*
- *Sleeping was difficult; she used to cry a lot. Every day and night I didn't know what was going on. She started talking when she had been watching the TV; she repeats what they say in the programmes and adverts. But her and I never talk or have a conversation (Sample A).*
- *He was slower than the other kids in walking, and his talking was obviously delayed as he never even had a baby language at all, and that is when I noticed a problem (Sample B).*
- *Only when he was 2, I said to my husband that something was wrong. He never crawled, and he started walking at 14 months. But he was slow, compared to other children he was delayed. He could only able to say a few words a time. But he was an unhappy kid, you could see it. He could never express himself. But we could see that something was up with him. He just didn't react like a normal baby (Sample B).*
- *The speech was the biggest thing, he was able to understand and point, but he could never verbalise it. Thinking back now speech was the milestone that he never reached (Sample B).*

Some of the mothers from both groups even reported that their child was developing normally and then they noticed changes or a regression in their development.

- *She was perfect. Walking was perfect. She has a little problem with talking because she can't talk properly (Sample A).*
- *No problem, he was sleeping through the night at 3 weeks and then it all changed. Everything was perfect, milestone for milestone; he was eating, sleeping and gaining weight. He was perfect. Up until 7 months, and then things changed. No sleeping, rocking, screaming, that madness. But nothing before that, and then he stopped developing almost, no rolling, no sitting, nothing (Sample B).*
- *In the beginning he was wonderful. He slept. But I only noticed developmentally that there was a problem when he didn't start talking. His other milestones were perfect and all on time (Sample B).*

The results from the present study are in accordance with the literature. According to Goldfarb and Roberts (1996), the process of development can be conceptualised as a result of a mutual interaction between a child and his or her environment, each profoundly influencing the other. Development proceeds along four basic fundamental aspects including motor, language, cognitive and social and emotional development (Goldfarb & Roberts, 1996).

The implications of delayed milestones on attachment, is that attachment arises from interactions, both verbal and non-verbal communications between a mother and a child. In terms of language development, Goldfarb and Roberts (1996), state that the fascination of baby with parent and parent with baby ensures attachment in the babies' first social relationships. According to Howe (2006), a parent's ability to "recognise, understand and interpret their child's behaviour, body language, facial expressions and speech largely depends on parental sensitivity and emotionally attunement with their child" (p.97). However Howe (2006) acknowledges that in the case of children with disabilities, the precision with which a parent and child communicate their mental states may be compromised due to the presence of functional and sensory impairments.

Taking into consideration the mothers reported experiences of the development of their child, in conjunction with the phases of attachment as outlined by Bowlby (1969) and Ainsworth (1972) discussed in the literature review, it becomes apparent that a large number of the children in this study have not developed the cognitive, language or social skills to move beyond the pre-attachment phase or attachment in the making phases. The implications of this can thus be hypothesised to have an effect on the attachment relationship between a mother and her child, as the child is not actively engaging in the attachment process.

According to Cox and Lambrenos (1992), the manner in which a parent and a child respond to each other contributes to the formation of an attachment relationship, and specific disabilities can influence the development of the early social and emotional interactions between parents and children that lead toward the establishment of attachment relationships (p.1043). According to Howe (2006), "the intuitive suspicion is that the behavioural, interactional and communication characteristics of some children with particular disabilities are more likely to effect the levels of parental stress, quality of care giving and therefore security of attachment" (p.95).

Goldfarb and Roberts (1996), state that deterioration or plateauing of language skills at 18 to 24 months is cause for concern, and combined with flat affect, social withdrawal, or poor engagement can signify the onset of an Autistic spectrum disorder (p. 1531).

4.5.2 Mothers Intuition vs. the Neurotic Mother

In trying to find a diagnosis for their child, it is evident that mothers from both Sample A and Sample B experienced some form of adversity and blame for their child's behaviour.

However, in this study, it appears that mothers from the advantaged communities were more targeted in terms of been 'blamed' for their child's condition as elicited during the interviews.

Mothers from both groups expressed that attempting to find out what was 'wrong' with their child was a very devastating and frustrating process. Not only in terms of a lack of information and knowledge of ASD, but predominately in the manner in which others, specifically professionals, responded to these concerns. Most of the mothers' expressed that they intuitively knew something was wrong with their child. However mothers concerns about their children's behaviour and delayed developmental milestones were often dismissed and met with criticism, leaving the mothers feeling helpless and unsupported. In particular, many professionals attributed that it was in fact the mothers own paranoia and neuroticism that was contributing to their children's behaviour and developmental delays. One specialist even went so far as to refuse to cooperate with a mother, on the basis that she was neurotic and nothing was wrong with her child. Most of the mothers indicated that the implications of these judgements against them had a detrimental effect in terms of questioning their own competence as a mother, as well as delaying the process of getting a diagnosis.

- *I didn't want to be this paranoid mother. But your stomach tells you there is something wrong. I just said that something wasn't right and everybody just said give him time, give him time (Sample A).*
- *That fear that something is wrong and nobody can see it but me. And people thinking that I am mad and looking for something to be wrong. What mother would want something to be wrong with their child? People just thinking that I was crazy (Sample A).*
- *I was saying that something was not right and my child was not doing what other kids were doing. The ENT [sic. Ear, nose and throat specialist] then phoned my husband and said that I was neurotic and nothing was wrong with my child and he would only deal with my husband from now on. At the time I was devastated as I could see that there was something really wrong with this child, but nobody would acknowledge it and said he would grow out of it (Sample B).*

- *I knew something was wrong. However when you know you go and see people, and I thought I much rather err on the side of caution, even though I may look neurotic, rather than be dismissive. But they just said that your scope of normalcy is so large, so don't worry. But you know as a mother when something is wrong. When all of a sudden your child does something that is out of the norm, you can see things are wrong. So I knew something was wrong, but I was told I was neurotic (Sample B).*
- *The majority of the time, you think it's you, it's you that is crazy and you are doing something wrong. I said to the paediatrician, much rather tell me if it is me, because I can change me if I am doing this to my child. But if there is something wrong with him then we need to fix it (Sample B).*
- *When I got a diagnosis, the first question I asked is what I did wrong. But know I now know that I didn't cause the Aspergers. There is a stigma to it and people blame you...didn't you stimulate your child enough, what did you do (Sample B).*
- *I was given this old book to read where they blame the mother, the 'refrigerator mother', and I was supposed to feel at ease. How can you say that because of me not bonding with my child that I have wrecked this entire human being, when I wanted this child so much. It was totally unfair and very narrow minded. The orphanages are not full of autistic children. Unfortunately, until you do know, you do blame yourself. It must have been something I had done, maybe because I worked all the time, but when you are desperate you are willing to believe anything. In hindsight, I can now say it is not my fault and his autism is not because of anything we did, because I love him to death. So it defiantly wasn't a lack of love, and I am sure too much love can't make you autistic either (Sample B).*

The results from the present study is well reflected in the literature and according to Hayes (1996, as cited in Sousa, 2011), the image of a 'good mother' is a socially constructed notion subject to historical and cultural influences. Interestingly enough, the cause of ASD was historically attributed to intrinsic mothering abilities. According to psychoanalysis, 'good' mothers rear healthy and emotionally secure children, while those that fail to meet proscribed standards raise children with psychopathology (Sousa, 2011). According to Sousa (2011), the scientific explanation of mother blame is particular apparent in professional inquiries describing the "cold, insensitive mothers to the atypical development of autistic children" (p.222). According to Baker (2010), countless parents in the 1950's that sought professional help for their ASD children, were themselves sent for help "intended to help them understand how they had, unknowingly, rejected their child" (p.1102). According to Bettelheim (1972, as cited in Sousa, 2011), "mothers are a source of animosity in the lives of children with neurological differences, rather than keys to the children's happiness and development" (p.225)

Bruno Bettelheim (1972, as cited in Sousa, 2011), referred to mothers of ASD children as ‘refrigerator mothers’ and compared the symptoms of children with autism with those of Nazi concentration camp prisoners. “Children with autism are under the vise grip of ‘refrigerator mothers’ who withhold affection and routinely neglect their children, much like the SS guards of Nazi Germany” (Bettelheim, 1972, as cited in Sousa, 2011, p.222). It is also suggested by Grinker (2007, in Stace, 2010) that Kanner also initially blamed parents, and particular mothers, for the autistic conditions in their children as he said “parents kept their children neatly in a refrigerator that did not defrost” (p.68), referring to the detached, unavailability and maternal deprivation of the mother to her child’s needs.

This notion of blaming mothers for ASD conditions and characteristics in their child, although contested, still perseveres even today as evident from mothers experiences in this study in trying to find out what was ‘wrong’ with their child. According to Baker (2010), for many in the autism community, the popularity of the refrigerator-mother hypothesis continues to be remembered as an example of ‘the tyranny of expertise’, the danger of giving professionals too much power. Sousa (2011) also acknowledges these notions and states that while few contemporary professionals adhere to the relic ‘refrigerator mother’ construction, the vivid imagery is symbolic of both historical and ongoing medical designations of mothers’ culpability for many children’s disabilities (p.222).

According to Stace (2010), the influence of blaming mothers for their child’s autism is significant because mothers have been fighting it ever since, especially in the way mothers have fought back against such views by becoming experts on child development themselves. Baker (2010) also acknowledges that many autism interventions today are a result of parents’ rejection of the refrigerator-mother paradigm, by becoming actively involved in the decision making process with regards to their ASD children.

4.5.3 Dealing with the professionals

In terms of dealing with the professionals, it was predominantly the mothers in Sample B that reported taking their child to several professionals in search of a diagnosis for their child, whereas in Sample A, mothers generally only took their child to only one professional. This may be an indication that mothers in more advantaged communities have more access to specialised professionals in comparison to mothers in the disadvantaged group.

Mothers from the diverse socio-economic groups in the study indicated that trying to find out what was wrong with their child was a very traumatic time in their lives. Not only were mothers confronted with fears that they were the cause of their children's abnormal behaviour as evidenced above, but dealing with the professionals added to their stress and frustration. As evidenced from Table 6, mothers in this study consulted various professionals including: General practitioners, paediatricians, speech therapists, neurologist and educational psychologists. It also took some mothers many years to receive a diagnosis of ASD for their child. Mothers indicated that some of the delays in receiving a diagnosis of ASD can be attributed to some of the professional's lack of knowledge of ASD, miss-diagnosis and professionals unwilling to make a diagnosis on the basis that the child would 'grow out' of the symptoms.

- *My paediatrician told me there was nothing wrong. The ENT also said he was a perfectly normal child with a speech delay and he would catch up. When I asked for Speech therapy they said no. So I decided myself that I couldn't leave it so I went to and had him assessed. One diagnosis I got was that they thought he was moderately retarded, then we went for a full assessment and they also said he was mentally handicapped. I don't know in those days if they didn't have the heart to tell me he was autistic (Sample B).*
- *I wanted to start him on speech therapy, but I was told that he was too young. I never had a doctor guiding me and wherever I went, they would say that there was nothing wrong with him, all his physical milestones were perfect and he looked like a normal kid (Sample B).*
- *Eventually I mentioned 'Autism' to my paediatrician, and he said he actually thought I was right. My paediatrician then made an appointment with another doctor and he said that my child definitely had autistic traits and he is behind developmentally (Sample B).*
- *We went to the paediatrician in Zimbabwe, and she was like 'You old moms you like comparing your children to others, children are different. Give him until he is two years.' but I just knew that something was wrong (Sample B).*
- *So we started with speech and that result was inconclusive. She tried to do the testing but my child wouldn't allow the speech therapist to do it. We then went to another speech therapist and my child wouldn't allow her to do anything. We took him to a third speech therapist and she referred us to a paediatrician, who diagnosed him with sensory integration difficulties because he used to hate loud noise and new sounds and he closes his ears (Sample B).*
- *If someone had said I am your doctor and we do see that he has problems but we can work through them. But I had nobody telling me that. I was in it by myself. So I took him to the neurologist and he thought that my child suffered from Petimal epilepsy. So I thought that finally we knew what it was and now he can progress. He was on it for 8*

months and there was no improvement, it felt as if he was getting worse because he was falling behind (Sample B).

As indicated by the above statements given by mothers in this study it becomes evident that many of them have found that trying to get a diagnosis for their child has been very challenging. This is also well described in the research literature. According to Goin-Kochel, Mackintosh and Myers (2006), due to the complicated nature of ASD, parents are frequently faced with a slow frustrating period of uncertainty and worry and find themselves in the position of trying to convince their children's doctors that there is a need for a specialist assessment. In line with the mothers experiences in this study, studies that have qualitatively examined parents views on the diagnostic procedure have noted a tendency for some physicians to minimise or dismiss parents concerns about their children's development and, instead, to encourage them to wait for their children to "grow out of" their problems" (Ahernm 2000; Gray, 1995, Schall, 2000, as cited in Goin-Kochel et al., 2006, p.440).

According to Goin-Kochel et al. (2006) research on parental experiences of a diagnosis indicate that 8% of families received a diagnosis upon their first clinical visit, 40% received a diagnosis through a referral agency, and 63% received a diagnosis by their third clinical visit. Over a quarter of the parents waited 5 years before a diagnosis was confirmed. Some explanation for delayed and miss-diagnosis includes: the lack of information on ASD, as well as the continuum of symptoms that can range from mild to severe (Goin-Kochel et al., 2006).

The implications of a delayed diagnosis of ASD is said to contribute to parental distress and difficulties in coping with an ASD diagnosis, as well as implicates children's likelihood of receiving early interventions which subsequently has an effect on the long-term outcomes of the child and all those involved (Goin-Kochel et al., 2006).

Sousa (2011) evokes the image of a mother as a warrior "fighting the edifice of professionalization to garner services and support that reflect the experiences of their children and families" (p.229). According to Kearney and Griffin (2001), practitioners must develop "a consciousness of the experience of living with a child with a disability as one that is highly individual – there may be pain, suffering and sorrow, but also joy, hope and optimism" (p.589).

4.6 THEME 3: MOTHERS REACTIONS TO AN ASD DIAGNOSIS AND EFFECTS ON ATTACHMENT

Theme 3, discusses mothers reactions to an ASD diagnosis and the perceived effects of an ASD diagnosis may have on the attachment relationship between a mother and her child. The subthemes that were elicited include: Reaction to an ASD diagnosis, denial and acceptance, and mothers perceived experiences of the challenges of ASD on the attachment relationship.

4.6.1 Reactions to diagnosis

In terms of mothers experiences from the diverse socioeconomic groups in relation to their reactions to a diagnosis and the perceived effects this has on attachment, indicates that mothers from Sample and Sample B share many similar experiences, despite the socio-economic differences.

A diagnosis of any sort is devastating for any parent to receive and the mothers in this study have related to this experience as being ‘traumatic’, ‘scary’, ‘stressful’ and ‘helpless heartache’. Many of the mothers from both groups found that a lack of knowledge of ASD and the stressful and distressing events that led up to a diagnosis contributed to their reactions to a diagnosis. However, many of the mothers were relieved to finally have a diagnosis after trying for many years to find out what was wrong with their child.

- *First I say maybe God punished me, but now I have let that go. I have just read the pamphlet that they gave me about children with autism. I just read to try and understand a little better. Not a lot of information, but I am just trying to read more (Sample A).*
- *It is so stressful you know. I didn't know anything about autism, around my area or anywhere. I found out about autism through the doctor (Sample A).*
- *We never used to understand his tantrums until we had a diagnosis. The diagnosis was like a door opening. Once we had opened that door everything settled down (Sample A).*
- *I was very sad when we got a diagnosis, it was just a confirmation. I wish I knew what was going on. I am still sad, but it is a learning curve, you learn to live with it (Sample A).*
- *He only got a diagnosis almost 2 years later, and by then he had almost every test imaginable done. He had been tested for everything, I did everything. And the diagnosis was traumatic, very traumatic. Because you don't really know what autism is, but at the same token you are glad that there is something you can work on now (Sample B).*

- *The doctor assessed my child and he asked if I had heard of anything called PDD and I said no, and he explained it to me as a developmental disorder. Although it was scary because I didn't know what it was, I was relieved at the same time (Sample B).*
- *I found it difficult, I was heartbroken I can't even begin to tell you, for me it was my biggest fear coming true and secondly what was I going to do, how am I going to deal with this. It was helpless heartache, it was horrible. You think your life is over and you going to be miserable for the rest of your life. But I think from a mother's point of view, you worry more because you are the caregiver (Sample B).*
- *When I finally got a diagnosis, I just cried. To take your child from one assessment to the next for four years is difficult (Sample B).*
- *My worst memory was when I came to Johannesburg and I went to Dr B. We had already been given a diagnosis of PDD-NOS by another doctor but we just wanted another opinion. And Dr B confirmed that it was ASD. I think I was at my worst. I just started crying and I just asked the lord: why why why! I believe in God and I believe he has his own way of doing things. I just burst into tears and my friend just held me and said it was going to be all right (Sample B).*
- *When I got the diagnosis, I just read and read and I actually just cried, because if we had had a diagnosis earlier we would have known how to handle his tantrums and how to handle his communication better, we would have known all of that. We are talking years of absolute frustration; he was almost 7 when he got a diagnosis. That was bad memories, especially as you are consciously aware of your own behaviour (Sample B).*

Results from this study is in accordance with the research literature and research by Kearney and Griffin (2002), on parents reactions to diagnoses indicate that parents have feelings of “fear, denial, anger, frustration, guilt, grief and mourning”, following the initial diagnosis of severe impairments in a child (Kearney & Griffin, 2001, p.583), as demonstrated by some of the mothers in this study. Similarly Sousa (2011), states that when signs of atypical characteristics yield evidence of neurological differences, a “mothers expectations of normalcy are challenged and mothers can express confusion, fear, self-blame, and a sense of grief for the ‘child who would have been’” (p.226).

Furthermore, according to Oppenheim and Goldsmith (2007), many parents who receive a diagnosis of a serious developmental disorder like autism for their child, have assimilated this experience to “a metaphorical loss of a child” (p.109). “It is as if the wished for child has been lost, and instead the parents are faced with many questions, anxieties, and fears regarding their child's development” (Oppenheim & Goldsmith, 2007, p.109). Marvin and Pianta (1996) also highlight that parents who receive a diagnosis of any sort endure a period

of mourning or grieving, which if not resolved may serve the foundation for relational implications between a parent and their disabled child.

Cicchetti and Schneider-Rosen (1988, as cited in Cox & Lambrenos, 1992) draw attention to the wide variety of compensatory adjustments that parents of disabled children have to embrace. In terms of attachment theory, parents who successfully make these essential adjustments and are able to cope with the emotions evoked by their child's diagnosis and who, over time, revise their view of their child, are considered 'resolved' with respect to the diagnosis (Oppenheim & Goldsmith, 2007, p. 110).

4.6.2 Denial and acceptance

Mothers from both sample groups indicated that receiving an ASD diagnosis was traumatic; however both groups of mothers reported that they have come to accept this diagnosis. Mothers across socio-economic groups in this study were in agreement that having the knowledge about particular disorders such as ASD, helped them to understand their children better and to enabled them to have a more secure and meaningful relationship with their child.

Most of the mothers from both groups in this study indicated that a lack of understanding of autism and a lack of support contributed to their feelings of sadness, anger, denial and frustration, in terms of coming to terms with the ASD diagnosis of their child. Some of the mothers from both groups indicated that having a perceptive understanding ASD as a disorder has assisted them in the process of coming to terms with the diagnosis. Most of the mothers from Sample A and Sample B acknowledged that over time, they had come to accept their child's ASD diagnosis, and in doing so have found it easier to progress and continue with their lives. Some of the mothers in this study even indicated that if they had to do it all over again, in terms of having another ASD child, they would. In relating mother's experiences of coming to terms with an ASD diagnosis, one almost gets the sense that the mothers in this study have almost been emotionally empowered by the acceptance of an ASD diagnosis, and in doing so appear to be stronger and more resilient in themselves and in their relationship with their child.

- *My child is not that bad, I just have to hope that one day she will be perfect because she keeps on changing (Sample A).*

- *Now I know my child in this way, and sometimes I think what he would be like if he wasn't autistic, but he is my child and I love him. You have to deal with it, you have to (Sample A).*
- *I was angry sometimes but when they told me she had autism I accepted. My heart was very sore. I didn't know anything about autism It is not easy, but now I have accepted it, because she is trying to communicate (Sample A).*
- *At first we couldn't understand her because she had this 'thing' (Autism), she would just ignore you. Now we know that she has this thing we understand and accept her (Sample A)*
- *People generally believe it would never happen to them, I was like that, but when it does happen to you, you stop and think well this has happened to me. Heartbroken, sad and despondent. You keep questioning why? Why did this happen to him? Scared and sad. You just wonder what you are going to do for the rest of his life. It is so difficulty and scary because you do not know what the future will hold. But for me, one day I just woke up and it was ok. I think it was also my husband who said that my child was just different. But it was ok, I think once you accept it, and nobody can tell you how or long it is going to take, it just happens. And I was ok; I wasn't sad or scared anymore. And if I had another autistic child I didn't mind, because I was ok, and he would be ok (Sample B).*
- *If you could get over the initial shock it is well worth it, it is wonderful; you just have to get over that bad ride. If you can hang in through the beginning and the not knowing and not receiving help. You will be fine. Because once you accept it you will be fine. The joy you get is really worth it (Sample B).*
- *My husband was in denial for a long time, he just said leave him, he is just a boy. But boys don't do things that my child did. A mother knows these things (Sample B).*
- *And after the diagnosis I just realised that I just had to be strong for my child because I was going to fight his battles for him. And from then on I was strong, and I was going to fight the battle for my son and I believe that I have fought this battle for him (Sample B).*

Similar results were described in the literature. Marvin and Pianta (1996), on their research conducted on parents' attachment and the consequences of their child receiving a diagnosis of cerebral palsy, indicates that parental resolution vs. non-resolution of a diagnosis was strongly associated with secure vs. insecure child-parent attachments. According to Howe (2006), parents who had been able to resolve their reaction of grief, as well as those parents that held more of a realistic representation of their child after a diagnosis, were more positive in their care giving role and consequently were more likely to have securely attached children. According to Oppenheim and Goldsmith (2007) a resolution of a diagnosis is thought to promote acceptance of the child and promote care giving that is matched to the child's unique characteristics, which in turn is likely to contribute to the child's sense of being understood, accepted and secure. On the contrary, a lack of resolution can lead to

parents viewing their child solely in the light of the diagnosis, and can therefore lead to responses that are not congruent with the child's needs (Oppenheim & Goldsmith, 2007).

Bowlby (1980, as cited in Oppenheim & Goldsmith, 2007) refers to this resolution of 'loss' as 'reorganisation', whereby a grieving individual is able to align their representational world in line with the new reality that includes the loss (p.110). This alignment according to Bowlby (1980, as cited in Oppenheim & Goldsmith, 2007) includes the accepting the irreversible nature of the loss, working through and discarding old patterns of thinking, feeling, and acting, and a gradual acceptance that the loss in truth is permanent, and that life has to be shaped anew (p.110). According to Howe (2006) parents that have unresolved losses and traumas, which include those surrounding the diagnosis of a disability itself, are at risk of becoming dysregulated and emotionally unavailable, as their child's attachment needs can unconsciously activate "unprocessed mental representations of the self as helpless, rejected, unloved, isolated, ineffective, flawed or inadequate" (p.102).

Most of the mothers from both groups in this study, could be described as 'reorganised' or 'resolved', in terms of coming to terms with their child's ASD diagnosis. Many of the mothers have indicated that although ASD is a very difficult diagnosis to come to terms with it, especially as most of them were unaware as to what ASD was, through the process of accepting a diagnosis their relationship with their child has become more secure. Pat Evans (1993, as cited in Kearney & Griffin, 2001) wrote that "every woman who gives birth to a handicapped child does so in a climate of rejection and fear" and she refers to a mother's transformation from fear to love as "coming out of the rubble of broken dreams" (p.588).

4.6.3 Mothers experiences of the challenges of an ASD diagnosis on attachment

Mothers from Sample A and Sample B indicated that they are faced with many behavioural challenges, however most mothers were in agreement that an increase in communication skills has played a significant role in lessening their ASD children's behaviour, which has prompted a more secure relationship between mother and child.

ASD is a complicated pervasive developmental disorder, and the mere aetiology of ASD as prescribed by the DSM-IV-TR, elicits some presumed challenges for caregivers, especially considering the socialisation and language implications of ASD. These shall be further discussed in terms of mother's experiences of physical affection, separations, challenging

behaviour and the role of communication and language in the process of and implications for attachment with their ASD child.

i. Physical Affection and Attachment

Most mothers from Sample A and Sample B in this study indicated that consequent to some beliefs, their ASD child enjoys engaging in physical affection and will often seek comfort from their mothers in times of distress. Some mothers in both groups have indicated that their child's ability to be affectionate and comforted, have progressed and developed positively with time. In addition, mothers in both groups experienced that they themselves have been 'overly' affectionate and physical with their ASD child, in comparison to their other children, as they indicated that they used touch as a form to soothe and comfort, instead of communication, and they did not want their child not to be physical.

- *He loves his kisses and hugs. He likes being touched (Sample A).*
- *He likes that a lot. He comes and sits on my lap and rests his head on my shoulder. He hugs and kisses me (Sample A).*
- *She likes it very much; she is very affectionate even to strangers (Sample A).*
- *He likes being hugged. When he is crying he comes for hugs (Sample A).*
- *Yes he loves hugs (Sample A).*
- *He did like physical touch and he would come to mum if he was upset. He was fine during his first few years of his life, he was fine being cuddled, and he was ok. As he grew older he tended to not wanted to being cuddled and he didn't like physical touch (Sample B).*
- *He always wanted to be with me and close. He didn't have a physical touch problem (Sample B).*
- *He loves it. I think it is him. But also when he was younger that was one thing that I never let go off, I over played with him and hugged and kissed him because I didn't want him to not want people to touch him. I even explained it to my older son one day as he was getting a little jealous. So I said to him you know what 'for 10 minutes you are not allowed to say a word, what you are thinking and feeling', but when you love someone and you have that human contact, you feel better, you are not alone. Even if you can't say something, you feel better. I used to spend hours just with him. He loves physical contact, the more he gets the happier he is. He reaches out in a physical way (Sample B).*

- *If we hug and kiss and he is fine with it. He likes the emotional part of it but not too much. He had his moments. Out of the blue he will just say I love you mum, so it depends on his mood that day. Some days he doesn't even come near me. It kind of hurts, you close the door and shed a tear, but then you deal with it. It depends on each situation and look at it, yes it hurts you; emotionally it is not what you want. But this is the Asperger's talking, and you deal with it (Sample B).*
- *He loves it, absolutely loves it now that he is bigger. When he was small he didn't like being held, he went crazy. But now he would come and kiss and hug you he is fine with it (Sample B).*

The limitations in social behaviour in autism have been documented extensively and numerous studies have indicated that children with ASD are “less socially orientated or engaged, less responsive, and they tend to decline, ignore, or reject their mothers social initiatives” in comparison to typically developing children (Meirsschaut, Roeyers & Warreyn, (2011, p. 44). The limited social and communication skills of children with ASD are considered to have a subsequent effect on the interaction and attachment relationship between a mother and her child.

According to Spiker et al. (2002, as cited in Meirsschaut et al., 2011), developing and maintaining a well-balanced interaction is difficult for the parent of an ASD child. However, research has indicated that despite these limitations in social interactions, mothers of ASD children exhibit an equal number of social approaches to their child, and have been shown to be equally as sensitive and responsive as mothers of typically developing children (Meirsschaut et al., 2011, p. 44). In addition, Spiker et al. (2002, as cited in Meirsschaut et al., 2011), indicated that in order for mothers of ASD children to get a higher engagement and responsiveness from their child, they seem to adapt more directive interaction strategies, which was also evident in some of the mothers in this study. According to Lemanek et al. (1993, as cited in Meirsschaut et al., 2011), mothers of ASD children, spend more time holding their child and they increase their physical proximity through more interaction. As evidenced in a study by Meirsschaut et al. (2011), they concluded that a mother of an ASD child adopts a compensatory interaction style with her child with ASD, and they have had to change the way they interact with their ASD child, in comparison to their other children, to compensate for the social limitations of their child (Kasari & Sigman, 1997, as cited in Meirsschaut et al., 2011).

Physical affection and proximity seeking behaviours play a major role in the formation of an attachment between a mother and her child, as evidenced in the literature. Although, social interaction between a mother and her ASD child may be compromised because of the very nature and aetiology of an ASD, it was evidenced in this study that most of the mothers experience their ASD children to be affectionate and seek physical interactions and comfort.

ii. Separations and reunions

The way in which a child is able to separate from their mother, from the basis of secure and insecure attachment relationships and according to Howe (2006) research findings generally suggest that children with autism do show attachment behaviour. In this study, mothers in both groups indicated that their ASD child did not have any difficulties in separating from them, especially as their children were at times not aware of their mother's absence. One mother in particular described her child as being in a 'bubble' and she felt that at times her child was unaware of her presence.

- *Sometimes he likes to play alone, he enjoys playing alone. Just being alone... sometimes he doesn't like playing with toys. He likes his bike, not toys in general, just bike and ball (Sample A).*
- *He was just in a bubble. He was not interacting with anybody. I used to say that if we left X alone for a month, he wouldn't even notice that we were not there. We would call his name and he wouldn't even turn around (Sample B).*

Mothers from both groups in this study indicated that separations were not really an issue especially since there have never been very long separations.

- *I have never left him for a long time, just short periods (Sample A).*
- *I only leave him on Saturday, it's painful to leave him, but my family takes care of him (Sample A).*
- *He was fine, but I have always been a stay at home mom so the separations were never that long maybe a few hours at a time. I can't imagine being separated for a long time (Sample B).*
- *He didn't separate from me. I kept him with me until he was 18 months. Then I tried to put him in a day-care, but he did not react badly from separating from me. You know when you leave them and you cry, but he was fine, he just went. The thing is that I had waited so long for this child; I was crazy about him, maybe over crazy (Sample B).*

- *He didn't have a problem. He had no concept of fear so there was no problem with separation. He has been going to school for 2 years and he loves it, he has his friends there and has no problem with separating. There haven't been times when we have been separated from each other for long (Sample B).*

Mothers in Sample A and Sample B however did express that at times they experienced that the separations were more difficult and emotional for them to endure rather than their children.

- *It's painful to leave him, but not that painful because my family takes care of him. But it is hard to leave him behind, because he gets aggressive and people can't understand the child with autism (Sample A).*
- *He cries for a little bit. But once I have left he is ok. I feel something in my heart, it is painful. I feel that pain (Sample A).*
- *Leaving him at school, in the beginning it was hard, it is still hard. Especially when I am working, but I know that he is in good care and it is in his best interest (Sample B).*

According to Howe (2006) children whose caregivers are responsive and available at times of need and who are sensitive and emotionally attuned are likely to be classified as having secure attachments. Recent research has also indicated that children with autism respond preferentially to a caregiver, show distress on separation, and seek proximity on reunion (Travis & Sigman, 1998, p.70). Additionally children with ASD direct their social behaviour to a caregiver rather than to a stranger (Sigman & Mundy, 1989, as cited in Meirsschaut, et al., 2011).

iii. Challenging Behaviour

Although not described in the DSM-IV-TR as a sign or symptom of ASD, many of the mothers from both Sample A and Sample B indicated that their children present with many challenging behavioural difficulties, of which aggression is the most prominent. Mothers from both groups indicated that their children have frequent tantrums, are destructive, get upset, and can be manipulative. Some specific behavioural challenges, as will become apparent in the quotations, that the mothers from both groups have encountered include: hair pulling, banging their head, screaming, excessive crying, scratching, hitting, and biting. Mothers from both Sample A and Sample B have indicated that their children's challenging behaviour have often left them feeling 'devastated', 'helpless', 'angry', and one of the biggest challenges they as mothers have to face raising a child with ASD. Mothers from the diverse socio-economic groups in this study also indicated that at times, they perceived that they had

contributed to their child's behaviours by doing something wrong and failing as a parent, which often left them feeling guilty and depressed.

- *He can get cross when you tell him to stop doing something wrong. He gets cross and aggressive and he wants to beat something. He can bang his head on the walls when he is cross. Sometimes I don't get cross; when he has finished banging his head I am sad because he can hurt himself (Sample A).*
- *Aggressive, too much aggressive. Aggressive. He also takes other people things, especially small children's things. He scratches too. You get used to it, the difficult behaviours, he is into everything. We have to hide everything on the top shelves (Sample A).*
- *Yes he is very angry, he is very angry and I don't know what makes him so angry. He likes to beat other kids. Sometimes I get angry and I say to him not to do it as some children are sick as well and their parents they are going to hit me one day. I try and make him stop but sometimes I am harsh and I whip him. The tantrums and aggression happens a lot, but now as he is getting older he is sitting and listening but not before – he just did whatever came to his mind. He can be a good boy, but sometimes I don't know what is happening, he starts his behaviour again (Sample A).*
- *Her behaviour, you can't handle it. But when you are at home you can just leave her, she can do whatever she wants. But when the other people are around they get angry and they look at you as if to say why you don't discipline your child, your child is naughty. She is very busy and she is on medication to calm down and not be so hyper. You don't feel ok (Sample A).*
- *If you stay in the routine, she is not that bad, as long as she has everything that she likes or wants. The problem is when someone else wants to watch the TV; she says no it's my turn. She will scream and scream, and cry then after a while she will calm down. Sometimes she manipulates you to get her own way. But she is much better, because if you say no she understands more (Sample A).*
- *He will throw things, bang doors, and switch the TV on and off. It happens a lot and most of the time he breaks his toys and he doesn't play with them. I just wish there was something that I could do to deal with that thing. I just talk to him tell him not to do these things because they are bad. He understands and he stops. I have no idea I think there is hope (Sample A).*
- *My child was so destructive, he would pull out huge chunks of his mattress at a time, and he would destroy everything in the house. There was nothing left standing. He has also destroyed a Mac computer, he ate the keys of the keyboard...he actually chewed them and swallowed them...no nappy changes were very interesting around the house as you can imagine. Also his aggressiveness, beating up his sister. The aggressiveness was difficult. He was very aggressive. He would slap her, kick her and even bite her. But now all three of them can sit together and play which they could never do before (Sample B).*

- *If he doesn't like something he will throw a tantrum and people don't understand him and I feel hurt and sad. I feel very bad and it hurts inside because he can't tell me how he is feeling (Sample B).*
- *When he does get upset he kicks, throws things he will do anything. I just want him to calm down and say what the problem is. I just want him to act normal and say what the problem is and not lash out. I also get upset sometimes. It is painful to watch your child in that state and you can't do much. My child hates being restrained so I try and sit him in a corner to vent his anger and calm down and we try and talk through it after that (Sample B).*
- *The aggression when he gets frustrated, but the older he gets the less difficult it has become to try and control him. The aggression is the biggest challenge that we have. Now it is better as we know what triggers the behaviours and upset him, so at home it is less. But you feel very frustrated, I was crying just as hard as he was. Yes you get very frustrated. Sometimes you just think where did I go wrong, where did I fail as a parent. But as you learn more about it, you get better at it, but still get hectic when he has a tantrum but we are coping. Devastated. You are helpless. There are so many emotional things going on but the sadness overtakes all things and getting frustrated because of it (Sample B).*
- *I just feel like talking to him and trying to make him understand, and he seems to listen to me compared to everyone else. He listens to me. Maybe because I know how to do it, as I know him so well he does tend to listen to me (Sample B).*
- *Hair pulling till he had bald patches. He used to bash his head, he used to bite himself. He would scream and shout. Awful. You just don't know what you doing is right. You don't feel worthwhile, you don't feel good. You don't feel anything. I felt very bad then, in a very bad place. But you feel sorrier for your child, because you know that this is not normal and something is going on and you know that he is not in a happy place. So it is more of a depression and heartbreak for your child. And you think that maybe you have contributed in some way, maybe you did do something wrong for this to happen to your child. So you just feel this despair almost. There is no behaviour now. He has learnt to become more socially acceptable (Sample B).*

The behaviours of their ASD children, as described by the mothers from the diverse groups in this study are congruent with the literature and according to the World Health Association (1993), a range of behaviour problems including, “anxiety, depression, sleeping and eating disturbances, attention issues, temper tantrums and aggression and self-injury” are common in children with ASD. Howe (2006) states that, “it is of course ironic that children in need of sensitive caregiving might challenge parent’s ability to provide such care” (p.99), which was evidenced in mothers accounts of the challenging behaviour they are faced with caring for an ASD child.

Research has also indicated that a child's level of behavioural difficulties is apparently the most critical element of 'feelings of burden' for a parent (Gallager, 1997, as cited in Schwartz, 2003). Floyd and Gallagher (1997, as cited in Schwartz, 2003) have also indicated that parental levels of stress can be correlated with a child's behaviour problems and consequently parents cope better when they do not have to put up with difficult behaviours. Lefley, (1997, as cited in Schwartz, 2003) states that mental illness "usually has episodic peaks and valleys, remissions, and decompensation, and these affect the hopes, expectations and burdens of parents" (p.577).

In addition, research has indicated that the challenging behaviours of children with ASD may leave parents feeling at a loss in relation to behaviour management (Dunlap et al., 1991, as cited in Cullen & Barlow, 2002), which is presumed to have an effect on the well-being and stress levels of carers of ASD children, as evidenced in mothers experiences of their ASD child's behaviour in this study to. According to Moran et al. (1992, as cited in Howe, 2006) it is only when mothers are able to attribute the stresses of parenting to the inherently demanding but essential tasks associated with a raising a child with a disability, and separating these out from the child himself or herself, that levels of parent sensitivity and therefore child security arise.

iv. Language, communication and attachment

For mothers from Sample A and Sample B in this study, the lack of their child's ability to communicate, in their experience, has exacerbated their children's behaviour and they perceive the lack of communication to be one of the perpetuating factors for their children's frustration. Many of the mothers from both groups indicated that over time, they feel that their children's behaviour have lessened, which could be attributed to many factors, including an increase in communication on their children behalf. Mothers from the diverse socio-economic groups have shown that they have had to accommodate for their children's lack of communication and through a better understanding of ASD, have found ways to communicate with their ASD child.

- *At first we couldn't understand her because she had this 'thing', she would just ignore you. Now we know that she has this thing we understand. Sometimes she wouldn't even look at you, but since coming to Speech therapy she is much much better. The speech department are very good teachers. They have managed to teach her to talk (Sample A).*

- *It seems like he is dealing with his aggressiveness much better, especially now that he can talk it is not as bad as it was. I think the older he gets the better he is dealing with things (Sample A).*
- *He still gets upset a lot but I think he is getting better now. The frustration is still there but he can communicate more so he doesn't get as upset as he used to. So communication has really made life much easier for me and him (Sample A).*
- *It was very difficult, when you have a child that ignores you when you talk to them. She doesn't listen to her, and she wants things her way, but she is better since attending the Speech therapy (Sample A).*
- *Now he gets angry but he is able to talk, and he is not violent any more (Sample A).*
- *I am hoping that as he learns to communicate more, the more the behaviour will completely go away and he will be able to say how he is feeling and he will be able to control his emotions. So I am hoping that it will normalise (Sample A).*
- *He used to scream from morning to night. He had no form of communication and as a little boy he had his needs and wants. So when he wanted something, but he didn't know how to tell me and he would just scream. So I would run around trying to find out what he wanted and when I did he would stop screaming and he would be OK. But then he wanted something else so the screaming would start all over again... that was so draining for me that was hectic. I was exhausted, as all I was doing was trying to find out what he wanted (Sample B).*
- *He learned himself, these kids are so clever, and this kid learnt how to communicate. He would take me and show me what he wanted. Now he just does it all himself and if he can't he will come and 'ask' me/show me. Kids and their mothers, when you have this kind of a relationship with a child, normal kids can speak, you develop other skills with a child like mine because you can't just listen to what they want, you actually have to 'feel' your way and learn to read them. Now I can just look at him and I know how he is feeling and if he wants something. You have to learn other ways and compensate for the lack of language (Sample B).*
- *The speech and that absolute frustration at seeing a child that is wanting to try and communicate but can't. I said to the speech therapist that it felt like he had all of these words muddled up in his head but he can't get it. I am not a specialist or a Speech therapist, but I could feel his frustration and I did not know what to do about it. That was the hardest part. He has never gotten sick but he wants to talk, he wants to communicate but he can't. That was beyond frustration (Sample B).*
- *He will get upset, but over time we can now talk to him. Someday he will get really upset and he does not know how to verbalise what is going on. I will sit with him and talk through it and we have been practising this. So he is learning to talk things out and he will be ok (Sample B).*
- *He is not as bad anymore as he is growing up and he is learning how to deal with his crises. But yes he used to get upset about everything. And I think also not being verbal*

was frustrating for him. I think that now he is verbal he is much more able to verbalise things (Sample B).

- *His communication is getting better and he has managed. From about 2 -7 years his tantrums used to be very bad and that was due to a lack of communication. We have taught him to deal with his tantrums by talking through it, as if we don't talk about it we don't know what he is going through (Sample B).*

Kobayashi (2000) indicates that communication can be commonly understood as a construct for the mutual exchange of concepts, which is characterised by duality that “also represents the existence of mutual sharing of emotion as its foundation” (p. 236). In addition, this mutual sharing and unfolding of emotion is a product of affective communication between mother and child and a result of good affect attunement between the two (Kobayashi, 2000). According to Kobayashi (2000) when this attunement is disrupted, one is unable to convey meaning to their ever-changing environmental world, “transforming the environmental world into a chaotic and fearful entity for them” (p. 236).

As also evidenced in this study, language plays a fundamental role in the acquisition of a secure attachment as outlined in the literature. According to Vaughn and Bost (1999, as cited in Howe, 2006) parents that tend to have securely attached children are those caregivers who are sensitive and responsive to their children's communicative signals. On the contrary, Howe (2006) states that children who feel their needs are unrecognised, ignored and misunderstood by their carers often become distressed, which in turn increases children's attachment behaviour, perpetuating a carer's distress and frustration.

In light of the communication between a mother and her ASD child, reciprocal communication is a challenge taking into consideration that it is one of the defining characteristics of ASD. According to (Kobayashi (2000), a diagnosis of ASD has a profound effect on the way that children with ASD “apply meaning through the auspices of language which in turn has an impact on the way they share their perception of the environmental world” (p.236). Howe (2006) reiterates this and states that the clarity with which children with disabilities can communicate their mental states might be compromised by the presence of one or more of a number of functional and sensory impairments.

According to Howe (2006) there is evidence to suggest that there is increased risk of parental stress in looking after children with disabilities, often based on problems of communication,

understanding and interpretation. Cox and Lambrenos (1992) have also indicated that parents of ASD children need a higher level of skill, and possibly instruction, to help them read the emotional clues given by their child and to communicate in ways they can comprehend. As evidenced in this study, mothers have had to adjust their way of communicating to meet the needs of their ASD child, and increase in communication; both through verbal and non-verbal means have had a perceived positive effect on the behaviour and frustration levels of their ASD child. In light of this, Kobayashi (2000) highlights that it is therefore emphasised that development in communication should be the priority for interventions (p.236).

4.6 THEME 4: THE ROLE OF SOCIAL SUPPORT AND SOCIAL REACTIONS TO ASD

This theme is concerned with mother's experiences of social support and the social reactions to ASD mothers have experienced, and the perceived effect this has on a mother's attachment relationship with their ASD child. This theme explores mothers' experiences of social support in terms of: marital support, close family relationships and includes the social support from their community at large. This theme also addresses the social reactions mothers from both groups have experienced with regards to their ASD child.

4.6.1 Social Support and Attachment

In this theme concerning mothers' from both groups' experiences of social support and their perceived experiences of 'other' people's reactions to their ASD child and parenting, there are some similarities and differences evident across the diverse socio-economic groups.

In terms of social support, mothers from Sample B reported that they received more support from their spouses than did mothers in Sample A. The marital status of participants in this study could have an effect on the perceived social support received by the mothers. In addition, some of the mothers in Sample A reported that not only did they not receive any support for their ASD child from their spouse; the fathers of the ASD child often blamed them for their child's disability, which was not evidenced in Sample B. In this study, it also appeared that the mothers in Sample A had a closer connection to the wider community, which was not entirely evident in Sample B.

It has been well documented in the literature that parents of disabled children require support on many different levels to help them cope with the daily struggles of having a disabled child including marital, family and community support. From Table 4, it is evident that from the total sample, 46% of the mothers were married, 36 % single and 18 % divorced. In considering Sample A, 67% of the mothers from disadvantaged communities are single, 17% divorced and 16% Married. On the contrary in Sample B, 67% of the mothers from advantaged communities were married and 33% divorced.

Mothers in Sample B appeared to experience more secure and supportive relationships with their partners in comparison to Sample A. Mothers in Sample B reported that the role of the child's father assisted them in their own relationship with their child, in a more positive manner.

- *If it wasn't for my husband I would have packed my bags and left. I did everything a mother should have done but my husband took care of my child. He just saw what was going on and he could deal with my child much better than what I could at that stage (Sample B).*
- *My husband was amazing, to this day he never thought of my child as having a problem. He would say that my child was different, and different wasn't bad, just different, it's not less, it's just different (Sample B).*
- *My husband on the other hand was great and we just focused on getting him better. He was very supportive of everything (Sample B).*

On the contrary, mothers that did not have the support of a partner or close family members, were in some instances blamed for their child's ASD and the mothers did not receive any support in terms of raising their child. This was predominantly the case in Sample A.

- *The father was supporting us until he was about 2 years old. So after he was 2, I called the father and I said to him, the doctors said that my child has a problem. The father said it must be a problem from my side of the family not his. I never blamed anyone one. I just told him that the baby has a problem I don't know whose family it has come from. His father has never come back. Three years later I phoned the father again to help me with money as I wanted to take my child to the crèche and I didn't have money. I can't afford to take him to crèche because I pay for food, clothes... anything my child wants. The father said he doesn't work he doesn't have money. So since then we have not communicated. The community likes him and they have accepted him. They support me (Sample A).*

- *The father's side, they talk about him which I don't like. I remember one day, my cousin came to me to say that they are talking and saying that my baby is not right. I confronted the granny and said that this is my child, whatever is happening to him it is my child and I am not going to take him away. If there is something wrong I just need to accept it because it is my baby which God has given me. You can like it or not this is my baby (Sample A).*
- *Some people don't understand his problem. Like my mother, she doesn't want to understand him. And I have told her and explained to her about autism and she doesn't understand. She just hits him and said he is naughty (Sample A).*

Some of the mothers in Sample A that have not received relevant support from relevant partners and family members have turned to the community for support. Some of the mothers in this group have indicated that their community has provided a lot of support for them and their child with ASD.

- *I have a lot of support from the community and the church (Sample A).*
- *The community loves him, more than my family you know; they are very supportive (Sample A).*
- *They didn't understand her at first because of the autism. I also didn't understand at first and I just thought that she was naughty. Now the family knows her and her disease. At first the community did not understand, but now I have explained that my child is not well, she has autism (Sample A).*

One mother in Sample A indicated that their immediate community had not accepted their ASD child which obviously has an effect on the way she herself is accepted into the community.

- *These kids are not silly, they are just different to what we are used to. The community doesn't like him; they say that I am spoiling him. And the neighbour knows my child has a problem and you have to admit that he makes mistakes just like any other children, so if the neighbours don't want to meet him, I can't sympathise with them. At first I was angry when the community acted like this, but now I just ignore them and take my child and get in the house. I am no longer frustrated. Children are children (Sample A).*

As in accordance with the results in this study, the literature indicates social support from family, friends, neighbours, teachers and peers, is fundamental for parents who are trying to cope with developmental delays and stress in having a disabled child (Fiammenghi et al. (2010). According to Montes and Halterman (2007), perceived social support has been identified as an important stress buffer that influences the parenting of mothers with an ASD

child. As it has been previously acknowledged in this study, an increase in maternal stress may have an effect on the attachment relationship with one's child, which in retrospect can be understood that a lack of support for a mother of a disabled child may adversely affect the attachment relationship. According to Kazak (1987), this increase in 'stress' that caregivers of disabled children endure is said to arise from the caregivers' increased responsibilities and demands that arise on a daily basis.

In addition, Kazak (1987) indicates that the impact of a child's disability should be viewed from a socio-ecological model to include the effects on parents, siblings, extended family members and communities. The importance of considering the families' relationships and social support systems, assists in understanding successful adaptations to a child disability (Kazak, 1987).

Furthermore, research in Kazak (1987) indicates that marital relationships in families with children with disabilities are particularly vulnerable and can be correlated with maternal psychological distress, as evidenced in some of the mothers' experiences in this study. On the contrary, research by Akerly (1984, as cited in Morgan, 1988), cited cases in which the presence of an ASD child has strengthened, rather than weakened the marital relationship, which was also evidenced by some mothers in this study. Additionally, Morgan (1988) states that mothers who experienced strong support from their spouses, reported fewer depressive symptoms and were assessed to be more accepting of their ASD child. Gervai (2009) states that secure attachments between a mother and a child are promoted by the psychological health of mothers.

4.6.2 Social Reactions to ASD

To the best of the researcher's knowledge, no research pertaining directly to mother's experiences of societal reactions to their ASD child and the effects this has on attachment relationship with her child has been sourced. However, negative societal perceptions of children with ASD can be said to contribute to one of the many challenges faced by mothers, including an increase in stress, stigmatisation and isolation as evidenced in this study, which consequently has an effect on the way in which a mother views her child and their relationship.

Most of the mothers in this study in the advantaged and disadvantaged communities expressed that the most challenging thing about raising a child with ASD, is not the ASD itself, but other people. Other people's reactions to the ASD children did not appear to differentiate across socio-economic groups as most of the mothers shared the same or similar experiences.

Although mothers experiences of the social reactions to their ASD child, was not a direct line of enquiry in this study, the majority of the mothers from both groups reported that 'other' people's reactions to their ASD child and peoples judgements about their style of parenting was often one of the hardest things about raising a child with a disability. Mothers from both groups reported that 'other' people make a disability like ASD so difficult, in the way that they treat and respond to both mothers and children with ASD. Mothers from both groups indicated that a lack of awareness of ASD has made it more challenging to integrate and make their children more accepted by society. Most of the mothers in Sample A and Sample B also commented that there have been many incidences where the mothers have been approached by other people to control their child's behaviour, and as a result mothers have often been blamed for bad parenting. Mothers from both groups also indicated that they suppose other people's perceptions of their ASD child and of their parenting, is due to a lack of understanding of ASD and a lack of willingness to accept 'difference' in our society, at the detriment of the mothers own emotions.

- *People have made it hard. The way people look at you when your son throws a tantrum; they look at you like you are not a good mom, why is your son behaving like that. But you get used to being a mum of a special needs child; it gets easier (Sample A).*
- *When we were in the queue trying to pay for the things we bought, all the people just stand and watch you. They think that you are a bad parent, and you don't teach your child nicely. They don't know the child, they judge you, and maybe it's a spoilt child or a bad mother, that's why the child is naughty because the mother doesn't discipline the child. That was very hard. Some people just judge you and they don't even ask, they just say that this child is spoilt and they didn't teach her nicely. And this child has a problem. But since we have been open with some of the people, that this child has a problem, they don't judge us. Because they know what is wrong. But if we are in the taxi, they just judge you. But we don't put it in our hearts that much because we know that they just don't understand (Sample A).*
- *Raising an ASD child is not difficult, it has its challenges – however it would be so much simpler if people's attitudes towards 'different' people/children would change. Half the battle is trying to integrate our angels with bloody morons (Sample B).*

- *Other people are appalling, wherever you go people have something to say 'look at your child he is out of control, he is this he is that. People look at him funny. That really frustrates me about the society that we live in. People don't like different, they like normal. They want to label something and put in a box and shelve it, you are not supposed to be different and people look down on you. And it hurts a bit. The amount of times I have been in an argument in the supermarket is frightening. If you start with my child, you start with me; he is my child no matter what. People make comments like 'look how aggressive that child is' or 'can't you get that child to shut up', he is out of control and you get it wherever you go. We as parents have rights... we have a right to shop, go to church ect. but aren't we allowed to do these things just because we have an autistic child. We have just as much rights as parents of normal children. It is not on, and I wish it would change but people don't like changes or different. I would get extremely angry and annoyed. It is like people question your parenting, it is bad enough people bad mouthing my child, but it is a direct insult to me as people think that you are a bad parent. But you are not; you try your hardest (Sample B).*
- *Especialy because he looked so normal and behaved out of the norm, you straight away think that this child is a brat, and his mother doesn't discipline him properly. One day he was screaming in a shop, and he was having a tantrum in his push chair, and this stranger comes up to me and she said 'this is the most revolting child I have ever come across'. And I was so heartbroken I actually thought my world was crashing down around me, I was devastated. I don't know why I cared, but it was so upsetting to me. But once I explained to strangers and then they would feel sorry. But until you tell them they just think he is a naughty child. It is negative until you explain to them (Sample B).*
- *Shopping was a nightmare! He would just grab anybody that would just walk past him. He has been slapped by people in shopping centres because he would just pull someone's hair. Do you know how many people have walked up to me and said 'If that was my child I would beat it? So I was just defensive. Only when I told them that he was autistic did their attitude change. Not that they knew what autism was but then they somehow felt that he must have something wrong with him (Sample B).*
- *Other people – that is the hardest. Because you as a mother, love this child regardless. You know that the behaviour is not normal, but other people's behaviour and how they make your child seem and how they treat your child. That has been hard, not dealing with my child's autism, because that hasn't been hard, it hasn't been fun. But I have never been desperate; I have never regretted having my child. But people's attitudes have been the worst. And I think it is because you see such a normal looking child and then you have these wacked out things that they do. The first thing they think of is no discipline; I just let this child do whatever he wants. There is very little wrong with your child. You, as a mother, don't set boundaries and rules. This is not the case. People don't look at the potential reasons behind the behaviour they just look at the behaviour, not the cause. People's perceptions are that they see a normal child with abnormal behaviour and they cannot correlate the two. This is where I feel so sorry for autistic children as they are not carrying a visible signs of special needs and they are treated badly by other people (Sample B).*

Results from mothers from both groups experiences that concern 'other' people's attitudes towards their ASD child in this present study, are in accordance with the literature. According

to Kearney and Griffin (2001) people with disabilities have long been viewed as “burdens on society, which generally views the presence of a child with a disability as a tragedy from which the family may never recover” (Kearney & Griffin, 2001, p.582). More specifically, the autistic child has been constructed in the public mind over the decades as “locked inside, a non-fitting jigsaw piece, the child poisoned by immunisation, a suffering child in need of rescuing or curing, both heroic and tragic” (Stace, 2010, p.68). Sousa (2011) also highlights that more often than not the social systems designed to help families through the experience of disability, are in fact the ultimate antagonists on mothers’ attempts to secure better lives for their children.

Research by Holroyds and McArthur (1976, as cited in Morgan, 1988), indicates that mothers of ASD children reported more problems than mothers of children with other disabilities which included more difficulties in taking their ASD child to public places, family outings and vacations. In addition research by Morgan (1988) in a study of 45 mothers of ASD children concluded that informal social support was crucial to successful adaptation to their child with ASD. According to Ryan (2005), the way in which a child reacts in public is often seen as a demonstration of a caregiver’s competence as a parent. This is reiterated by Cahill (1987, as cited in Ryan, 2005), who states that “through smiles, glances and other subtle indications, other adults continually remind children’s caretakers that their children’s public behaviour is a reflection of their own moral character” (p.293). According to Read (2000, as cited in Ryan, 2005) for mothers of children with disabilities, therefore, going out in public spaces with their children can involve considerable layers of “negotiation, mediation and management” and mothers of children with disabilities have to transform the uncertainty created by the presence of their children in public spaces into something which is “legible, predictable and reliable” (p.294).

Negative perceptions of people with disabilities and specifically ASD, still appear to be ingrained in our society today, which perpetuates mothers’ feelings of ‘helplessness’, ‘depression’, ‘anger’ and ‘devastation’, which was evidenced by some of the mothers in this study. As mentioned by one of the mothers in the study, she believes that the physical normality of ASD children may in fact be a hindrance to their acceptance in society as people cannot visibly see any abnormalities. Gray (1993, as cited in Cullen & Barlow, 2002, p.36)) indicated that the normal physical appearance of children with ASD makes it difficult for others to understand such behaviours which may leave the parents feeling stigmatised.

4.7 THEME 5: MATERNAL REPRESENTATIONS AND EXPERIENCES OF MOTHERING AN ASD CHILD

Theme 5, discusses mother's maternal representations and perceived experiences of the maternal relationship they have encountered with their ASD child. The subthemes that were elicited include: Maternal representations and attachment, maternal relationship with an ASD child, and transformation of the mother-child relationship.

4.7.1 Maternal representations and attachment

Mothers from both Sample A and Sample B, share similar experiences in terms of how they describe their ASD child. The way a mother perceives and experiences her child can be said to have an effect on the mother-child attachment relationship. When interviewing the mothers in this study it was unmistakable that their children, despite their disabilities, were a significant part of their lives. Most of the mothers in this study described their children's personalities in enthusiastic and dynamic terms and reflected that their children were: 'clever', 'smart', 'good child', 'likes playing', 'happy', 'loving', 'strong', and have a sense of humour.

- *She is a very good girl, she is kind. When she is happy she will just laugh. She runs around with other kids. She likes to play. She is different because of her autism (Sample A)*
- *He is a lovely, bubbly, lively little boy. So full of strength and energy and a huge sense of humour. He is so friendly and greets everyone by name (Sample A).*
- *I think he has a good sense of humour. And he is kind; he is so so so kind and helpful. To me he is loving, very loving. Outgoing, very much, he chats nonstop (Sample A).*
- *He is very friendly; I think he is very outgoing. He loves people. I don't know if this is typical autism, compared to the child sitting in the corner and rocking, but he is very loving (Sample B).*
- *Now he has got the cutest, happiest, sweetest nature. To me, he is a very happy boy. When he is happy nothing can get to me. Yes he still has those moments when he is angry and frustrated but he is happy 90% of the time. Generally he is a happy, and he has a funny sense of humour, and he loves very normal things like soccer and rugby (Sample B).*
- *He is very friendly and very social, which contradicts what you have read about Asperger's children. The friendliness is completely controversial to the Asperger's criteria, but I think as parents we have helped him (Sample B).*

According to Stern (1997, as cited in Araneda, et al., 2010) maternal representations are both conscious and unconscious; they include mothers fantasies, her hopes and fears, as well as her expectations and her perception of herself, and in particular, her baby. Although this area was not directly investigated in this study, what was evidenced is that mothers of ASD children in this study have unique hopes, fears, concerns and worries about their children that mothers of typically developing children may not experience. In particular mothers in this study worry about the future for their child in terms of self-sufficiency and independence, sexual development, getting lost and being taken advantage of by other people. Most of the mothers expressed particular concern about the reality that one day they will no longer be able to care for their ASD child. One of the mothers also hoped that their ASD child will one day have a sense of who he is as a person and feel worthwhile as a human being.

- *Just that he is happy, that is my priority. And too be happy and carefree and that he doesn't worry, especially when he can't tell someone he is worried and the worries are just going to sit in his head. My fears are that he needs to be safe. I need to know that people are watching him, even at school, because he doesn't have a sense of danger. My fear is that something would happen to him. That I fear all the time. I worry about his safety (Sample A).*
- *I hope that he will have learnt enough to do something that makes him feel that he is a human being, that will make him feel a sense of self-worth, boost his self-esteem. I fear that he might never really be accepted by society as a normal human being. But my biggest fear is that he sees it, I hope he will not see it as I fear if he does see it, it will do what it has done to me. When I take my child somewhere and he doesn't behave appropriately, I just see people looking at him and it just tears me apart. I hope he never sees that. I hope he will learn enough to have a normal life (Sample B).*
- *Fears that he might not be accepted into his social circle and lead a normal adult life and show the love and care that I know he has. His difficulty shouldn't hold him back and I think he has a future, but is just going to take more work than raising a normal child. You worry about what he is going to be like when we are not around, so we are trying to make him as independent as possible (Sample B).*

Maternal representations, according to Stern (1997, as cited in Araneda et al., 2010), are based on and built from interactive experiences and, more specifically on subjective experiences of being with another person. From this study it was evident that despite the challenges of raising a child with ASD, mothers describe their children in positive and caring ways, which in turn can be hypothesised to strengthen the maternal representations these mothers have of their ASD child in a more optimistic manner, ensuring a more secure attachment.

4.7.2 Maternal relationships with an ASD child

According to research caring for a child with a disability has led some parents to personal growth and a deepening sense of self-awareness, and parents have documented that they have ‘became stronger, more tolerant, less judgemental, and more sensitive and empathetic towards others (Schwartz, 2003, p.577). These perceived benefits and feelings of gratification have been termed ‘caregiving gratification’ (Greenberg et al., 1994, in Schwartz, 2003). According to Schwartz (2003), this new construction of meaning and new perspective on life as a result of parent’s experiences and challenges of having a child with disabilities, is integral to psychological functioning. In a study by Schwartz (2003, in Fiamenghi et al., 2010), it concluded that parents reported receiving gratification from fulfilling their parental duties and from learning about themselves, as evidenced by some of the mother in this present study.

Mothers from Sample A and Sample B share similar experiences in terms of how mothers describe their relationship with their ASD child. Mothers from both groups in this study have expressed that they have a very close relationship with their ASD child. Mothers from both groups also indicated that they perceive that their child was closest to them in comparison to their fathers and other family members, and most of the mothers from both groups have expressed that their relationship with their child is what pleases them most.

- *Much love, he can hug me and kiss me, but he doesn’t allow his father and sister to hug and kiss him. He only allows me. Love and happiness. He makes me happy, that’s the only way. Closest to mom (Sample A).*
- *We have a good relationship. I love him, I love very much (Sample A)*
- *Very close. He needs me as support and confirmation all the time. It is a very good relationship (Sample A).*
- *Very close, very loving. He knows I love him because I tell him all the time (Sample A).*
- *I think what pleases me the most is that I know that he knows that I love him and am always there for him (Sample B).*
- *He is closest to mum. It has always been this way as his dad has always worked and I have always been a stay at home mum. But not with my other kids as they spend more time with their dad. My child and I have spent so much time away from his dad, but I am sure he still loves his dad, it is just that we have spent so much time together (Sample B).*
- *Our closeness does, and our attachment. My child pleases me regardless (Sample B).*

- *It is a normal mother and son relations. We love each other to bits. When we are at home, my child will play a bit and if I am not in the same room he will come and find me to check on me (Sample B).*
- *Fabulous. Now defiantly. We are very close, the whole family is close, and he is a mommy's boy. He can be very caring. And the progress that he has made, that is beyond my wildest dreams, I never thought that he would get as far as he has come so I am very pleased with him. And he can talk... that to me is everything, which is a big thing for me (Sample B).*

One of the mothers in particular commented on an experience she endured on the misconceptions that ASD children cannot form attachment bonds and express love towards their mothers.

- *I once took my child to see speech therapist and she said to me, one of the most hurtful things anybody could have said, a lot of people said a lot of hurtful things, but she said 'it must be terrible to love a child that can't love you back'. I was devastated because I knew that he loved me in his own way, it really upset me. And he does love me.*

In comparison, another mother in this study found that her relationship was difficult at times, due to the perceived lack of bonding that occurred as a result of her child being in ICU for an extended amount of time. Despite this, this mother indicates that she still has a good relationship with her child.

- *Difficult at times. I think a lot of the foundation was set in the first year of his life and we were so focussed on keeping out of hospital... I was too young to have an ICU child and I think a lot of the bonding should have happened then. We have our good times as well, and I think he sometimes finds it hard to know that I can also be fun. We have had a couple of rough years though, and at times he finds me a difficult person, but I have also had to change and we have had to compromise, especially when we have had a fight. He has learnt to say I am sorry. But at the end of the day I try and put him to bed with a smile on his face (Sample B).*

In terms of the uniqueness of their ASD child, two of the mothers from Sample B expressed that they found their ASD child to be more 'perceptive', 'initiative' and 'loving' than typically developing children.

- *In comparison to my children, he is more loving and more concerned. He can see when mum is upset and will look at me and ask if I am all right. What I love about X is that*

there is no pretence; he does not know how to pretend, what you see is what you get. If he is angry he will lash out, if he is happy he will show the whole world (Sample B)

- *To me I think that he is more perceptive than kids of his normal age (Sample B).*

In addition, during the interviews with the mothers of ASD children from both of the groups, it became surprisingly evident that faced with the challenges of raising an ASD child has in fact been a strengthening experience for some of the mothers ‘they constructed meaning and developed new perspectives on life as a result of their experience and challenges’ (Kearnery & Griffin, 2001, p. 588). Some mothers claimed that despite some of the most challenging difficulties they had had to face, was made worthwhile by the inspiration they have derived from their ASD child. In addition some mothers feel that mothering an ASD child has not only made them into better individuals, but better mothers. Such maternal gratification can be said to not only contribute to these mothers psychological wellbeing, but contribute to more secure attachments to their ASD child.

- *I think I am a better person for having my child, a much better person. I am so blessed to have him. I can never be the person I am without him. He has made me a completely different person to what I was. I couldn't thank him enough; he is an amazing child (Sample A).*
- *God has put us together as a family for a reason and God has a plan for everybody. We were picked to have each other as a family. There are no mistakes and there is a reason we are all together as a family (Sample A).*
- *The beginning was hard just accepting it, it was my worst nightmare had come true and why me. But it has made me a stronger person. Everyone has their stuff in life and you can't enjoy the highs without the lows else you wouldn't appreciate the good times. Now when I am faced with difficulties I am able to cope better (Sample B).*
- *In all this it has just made me realise that I am actually stronger than what I ever thought, that I can do so much more than I ever thought I could. I think it has been good in that it has showed what is inside of me, which I would have never known. I don't know if I would have ever been able to show someone so much love if I had a normal child. You take so much for granted, but when you have a special child you appreciate the small things, the little things and you just take it one day at a time (Sample B)*
- *Whatever happens in your life in makes you a stronger person. Especially bad things make you appreciate things more, and having my child has done that for me. He has taught me to be patient; I don't think I would have ever been this patient without my child. He has given me a different perspective on life which I would never have had without having him (Sample B).*
- *Never in my wildest dreams did I think of having a child like this, it changes you. I have learnt to be more tolerant. I see the bigger picture now and I am very happy, and I am*

happy with my family and even if my child is so difficult, he brought something very special into my household. It is a challenge, but I think it is what everybody needed (Sample B).

Zeanah & Benoit (1995, as cited in Theran et al., 2005) have stated that mental representations can be also understood as mother's internal subjective experiences of their relationship with their child. In considering the impact of a disability on the attachment relationship between a mother and her child, it has been argued that the interactions between a mother and her disabled child differ from this in comparison with typically developing children and their mothers as "disabled children provide less readily readable cues, demonstrate less or muted affect and have more difficulty synchronising turn-taking" (Cox & Lambrenos, 1992, p. 104).

In considering mothers experiences of their relationship with their ASD child from diverse socio-economic groups, it is evidenced that this is a very unique mother and child relationship. Although the interactions between a mother and her ASD child may be limited in terms of challenges prescribed by ASD, the mothers from both Sample A and Sample B in this study provide an extraordinary account of mothering and ASD child, in terms of their perceived relationship with their child, their child's uniqueness and the positive effect having an ASD child has had on them as mothers and as individuals. Such positive accounts and experiences of mothering an ASD child as described by both groups of mothers in this study can be hypothesised to be representational of secure attachments.

4.7.3 Transformation of the mother-child relationship

These similar experiences of mothers from diverse socio-economic groups have indicated that raising a child with ASD, not only challenges a mother in every possible way, but many mothers in this study from both groups have demonstrated the profound affect their ASD children have had on them as mothers and individuals functioning in this world. With respect to these mothers' experiences of attachment, it becomes evident that they have endured many challenging obstacles, including the lack of communication and behavioural difficulties of their child, which in retrospect may have a consequence on the attachment relationship with their child. However, most of the mothers in both Sample A and Sample B have expressed that they have secure and loving attachment they have with their ASD, and some mothers indicated that at times they feel closer to their ASD child in comparison to their other children. These mothers' experiences have highlighted the essentiality of not only viewing

the attachment relationship between a mother and her ASD child in terms of the impact of a disability, but being considerate to the uniqueness of each child, their contributions to attachment, and mother's individual experiences of this relationship.

As far as the researcher is aware, no research exists in terms of a transformation in the mother- child relationship in terms of mothering a child with a disability. However, it was interesting to note in this study that some of the mothers indicated that their relationship with their ASD child had changed over time, and most often mothers reported that these changes have been positive in nature. Some of the mothers in this study emphasised that having an ASD child has also influenced their mothering, in that they have learnt to be less 'neurotic', 'overprotective', and 'more relaxed' as a consequence of being a mother to an ASD child.

- *Yes, I am more relaxed so he feels more relaxed. I can enjoy him now without the fear. There is not this constant fear about what is going to happen and how to do things, I just live day by day. When he does the smallest little thing and I feel that I have won the lotto, even the lotto wouldn't be as good as that (Sample A).*
- *Initially I used to be overprotective and now I am learning to let go and let him be. So as he is getting older I am letting him go bit by bit, but it is not easy. And he is no longer as clingy as he used to. He will play with other children and he doesn't mind if his sister comes and sits on my lap, he is learning to share me now. I am fine with these changes as my needs to have a life, besides a life with his mum; he needs to have his own life. So the more he learns to be independent the better for him and the better for me (Sample B).*
- *You can see there is growth and there is a lot of love with him that a few people get to see. I always say that I am not raising a boy I am raising a man. And I hope one day he is able to turn around and say that my mom has helped me through this. I hope one day he will be able to say that with all his difficulties I am a better person today. Our relationship has changed in a way to make me more understanding of him. I have learnt to talk him through those times when he is frustrated and it has made me see him in a new light as well. I have had to change. He used to react to me in a very fearful way, but that is because I used to react to him in a very frustrated way. But now he can see that I can be reasonable at times. I try and do things that are exclusively his time, to see how special he is (Sample B).*
- *I think I am much closer to him now that ... it sounds terrible, but I am now in a position where I can now live with him. When he was small I just couldn't cope with him. But now I am not feeling depressed and tired. Our relationship is much more relaxed now compared to what it used to be (Sample B).*
- *I am extremely happy, very very happy. You don't want one child that you don't feel the same towards. You want to love them equally ... but I am in a good space with him now and it has been like that for a long time now. I can now deal and cope with things that are thrown my way and it is fabulous (Sample B)*

- *My style of motherhood is completely different to anyone I know, and I think it is because of my child. I think I am more of a cautious mother because you feel vulnerable and you feel things can happen, life happens and things can go wrong. You always think that bad things can happen. That is the only downside (Sample B).*

4.8 THEME 6: EFFECTS OF SOCIO-ECONOMIC STATUS ON ATTACHMENT

This theme discusses the perceived effects of socio-economic status on the attachment relationship between a mother and her ASD child. This is particularly important in a country like South Africa, where socio-economic disparity is so apparent, as portrayed by the employment status and average monthly family income across socio-economic groups in this study.

In terms of this study, this theme has demonstrated the most differences in terms of mother's experiences from advantaged and disadvantaged communities. As evidenced in this study, mothers from disadvantaged communities in particular, are not only faced with the challenges of having a child with ASD, but their challenges are compounded by a lack of finances, limited educational resources, interventions and information with regards to ASD, in comparison to mothers from advantaged communities. In terms of attachment theory, such stresses experienced by mothers in Sample B, which have been compounded by the financial constraints they are faced with, may contribute to more insecure attachments between a mother and child in disadvantaged communities.

Although there has been a limited amount of research and studies with regards to the impact of social-economic factors on attachment, it has been evidenced in this study that a lack of resources and knowledge impacts on early interventions and educational opportunities of ASD children, as well as access to support facilities for both mother and child.

As Figure 1 and Figure 2 indicate, there is a huge disparity between the mothers of the disadvantaged community (Sample A) and the advantaged community (Sample B) in terms of employment and monthly family income. In Sample A, it was indicated that not one of the mothers in this study are employed and most of them are reliant on government grants for themselves and for their ASD child. In Sample A, the minimum monthly income was R250, and the maximum was R3000. In comparison, 67% of the mothers from the advantaged group were employed and two of the mothers that indicated that they were not employed, had

chosen to be stay at home mothers. In Sample B, the minimum family income was R10000 and the maximum was R50000 per month.

Due to these financial constraints mothers, particularly in Sample B, have experienced difficulties in trying to find the correct educational facilities for their ASD child. Most of the mothers from the disadvantaged communities expressed concerns that there is such a shortage of specialised schools for their ASD children to attend in their area and most mainstream schools will not accept their ASD child in the school. Some of the mothers had tried to enrol their children into a mainstream crèche or school, but only after a few days the mothers were told that the schools were unable to cope with the demands placed on them by their child. Due to the lack of educational facilities in the disadvantaged communities, most of the mothers from this community indicated that their children do not attend school at all, and the only intervention they receive is from the Speech and Language department at Baragwanath Hospital on a weekly or monthly basis. Some of the mothers had found placement for their ASD child in a mainstream school as this is the only possibility, however they expressed concerns that their children were unable to keep up and did not receive the individualised interventions that they requires. Some of the mothers also indicated that a lack of social grants from the government meant they could not afford to pay for the education of their ASD child, as well as the transport to get their ASD child to school.

- *What I am afraid of now is that he is at a government school and there they do the curriculum quickly, so he is going to be delayed in finishing his school work. I am getting worried that he might not cope. I hope he is going to be a learned child. I can feel that he is going to be a learned child. I don't think that he is going to manage at the higher standards, so I think if he can find a way for special school so he can do more. The options I don't have and I am afraid as I am not working now, because of my sickness and the ages. The mother she can work, but her life is on and off. One day she is fine and the next day she is sick again. She has so many diseases on her. My worry is that if he is going to get money for his education, for his needs when he grows up. What can the government do for him to educate him and do whatever is right for him? (Sample A).*
- *The teachers said they couldn't control him and they didn't want him in the crèche. That day I cried, I cried a lot, I didn't know what was happening with my child. He only went to crèche for half a day and they wouldn't let him stay, and there is only one crèche where we stay (Sample A).*
- *She stays with me. She doesn't go to the crèche. Before I knew about her autism, I took her to the crèche. She was very naughty at the crèche and they told me they didn't want her at the crèche any more. She only went her for one day, last year. At first I didn't understand why, but I know that she is not well so I understand why the crèche said that.*

We are still looking for a special school to send her to. She is always with me. Also I can't send her to school as I don't have the money, but I don't mind staying with her. I don't trust anyone, I teach her at home. I think she won't be able to go to the schools around us because she has this problem. We have schools around us but she won't be able to go and she is 6 now. Other children are attending schools and they don't even have to use transport. But this child, because she has this thing she will have to go far for a school (Sample A).

- *Now he is in a government school, I didn't have the money for a special school. I tried to make the grant and I failed, twice so I didn't even go again to see the doctor that diagnosed him, to tell him that we fail again, so I am taking him to the local school. Maybe if he gets more difficult, I will be back and ask for another grant, but now he is progressing. He can write he can read, and count (Sample A).*
- *It's a day-care centre. It's for normal children; he attends with all the normal children. It is helping him a lot as there are no special needs schools around us so we have to send him to a normal school (Sample A).*
- *He is not in school; I don't have the money to get him to a proper crèche. I guess we just need to take one day at a time. I have learnt through the support groups when they give us the books (Sample A).*

In contrast to mothers from the disadvantaged communities, all of the mothers from the advantaged communities expressed that their children attend specialised schools that have the resources and knowledge to implement interventions for their ASD children. Most of the mothers also indicated that their ASD child receives additional therapies and interventions that include Speech and Language, Occupational therapy, Play therapy, Sensory integration therapy, art therapy and Applied Behaviour Analysis (ABA). However, most of the mothers from the advantaged community also found that there is a lack of educational support systems for ASD children and they have had to move schools several times to find the right school for their ASD child. One mother in particular has moved countries several times to try and find the best educational facility for her child.

- *Initially we went to England as Zimbabwe had no school and South Africa, I only knew about one school. I didn't really want him to go to that school as I wanted him to do ABA. So we left home when he was 5 years, we were in England for about 1 and a half years, but it wasn't really working out. So we decided to try SA and we came here last year May (2010). But when we got the diagnosis it was very hard to get a nursery school in Zimbabwe that knew how to deal with children with autism. When the nursery school found out he had autism they said they couldn't take him, they wouldn't be able to give him the help he needs. And that was so heartbreaking for me, but they were right, but you can't help feeling rejected. You just feel that everywhere you go you face rejection. It is really difficult (Sample B).*

- *Up until he started school was a setback, because he stayed at home as we didn't know what was wrong. But now he is in the right kind of environment that is helping him to keep focused and helped him progress. He is overcoming his setbacks (Sample B).*
- *I then put him into a private special needs school as they get all the therapies and he will be with children like himself and people could understand his behaviour (Sample B).*

According to Goin-Kochel et al. (2006) parental education and income have also been associated with an earlier diagnosis. This was also evidenced in this study, in particular reference to the mothers from disadvantaged communities, where a lack of knowledge of ASD, both on their part, and on the part of the professionals have contributed to delayed diagnosis and interventions for their children.

- *I would like to get more information on autism. I am learning from the books that they gave us, but I would have like to know more and do more research. I didn't go to lots of doctors, but they didn't tell me a lot at the clinics, they don't even know about autism. They just say he is mentally disturbed. They don't take care of these children and they are not mad. And the clinics just take these children as been mad, but they are not (Sample A).*
- *I would like to know more about autism. I learnt about it on the TV and my sister did some research. I want people to learn more about autism. There are some mothers in the community that doesn't know anything about autism. I want them to give their children love. It is hard to cope but there are others out there who are worse (Sample A).*
- *If I had had access to the internet I would have known more. When he was supposed to develop his speech, I would have immediately starting to seek help, because the early they get help the better he would have developed. Tantrums would have been coped with better, he would be more social and his speech probably would have developed at an earlier age (Sample B).*

According to Goin-Kochel et al. (2006) healthcare and education providers who work with families with children with disabilities should make every effort to ensure that parents and children from lower socio-economic brackets receive equitable resources and interventions. Ensuring that underprivileged groups are receiving the same services as are those from more advantaged backgrounds is pertinent to the global management of ASD's and their effects on children and families Goin-Kochel et al., 2006).

According to Egeland and Farber (1984, as cited in Theran, et al., 2005) research indicates that stability of infant attachment is related to socio-economic status and maternal distress and it has been identified that in a low income, high-risk sample, stability of infant

attachment was lower than in middle-class samples, suggesting that environmental factors may contribute toward change in the quality of attachment. As evidenced in this study, both the behaviour and communication of ASD children have been a significant challenge for mothers. It was found that as their children's communication increased through interventions, education and therapies so did the behaviours decrease. This signifies the vital importance of the educational interventions of children with ASD as well as the necessity for early interventions in the process of integrating ASD children into society to become more functional and independent. Essentially this would lead to a decrease in maternal stress thus contributing to a more secure attachment with their ASD child.

4.9 THEME 7: PSYCHOLOGICAL NEEDS OF MOTHERS

This theme is concerned with the psychological needs of mothers of ASD children which emerged from both groups during this study. As evidenced in this study, mothers of ASD children from both advantaged and disadvantaged communities are faced with challenges of not only raising a child with ASD, but these challenges are compounded by external and societal influences and attitudes towards ASD and disability. The journey the mothers from the diverse socio-economic groups, in this study have endured has been extraordinary: from experiencing difficulties with pregnancies and the birth of their child, to trying to find a diagnosis, from dealing with professionals, to accepting a diagnosis of ASD, enduring people's unawareness of ASD and a lack of support, to trying to find the best educational facility for their child.

In this study it was evident that mothers from both groups not only experience stress, but most of the mothers from both groups reported feeling depressed at times, guilty, devastated, helpless, angry, regretful, rejected and heartbroken. Mothers from both Sample A and Sample B, also expressed their fears of failure as a parent, and questioned what they had done wrong. In addition to these challenges, the mothers from both groups reported that they have regrets about the way in which they have brought up their ASD child.

- *It just very difficult to raise a child with autism, sometimes I am getting cross. Sometimes I am getting depression. I can't get some support from my husband and my family and it is difficult (Sample A).*

- *I wish I could have done more in terms of early intervention, but it wasn't available to me. If I could rewind, I would want to do more therapies. If I had learned more and if there was more available to me. There was nothing else, so I can't regret, but I regret I didn't know these things (Sample B).*
- *I regret not having the answers and the access of knowledge which I now have with the internet (Sample B).*
- *If I had known how much I love him now and I love him as he is. I just wish I could have done more to make him better for him (Sample B).*

Mothers' experiences in this study are in accordance with the literature and according to Fraude (1992, as cited in Cullen & Barlow, 2002) parents of children with disabilities may experience anger, depression and inadequacy as parents. Furthermore, research by Jones (1997, as cited in Higgins, Bailey & Pearce, 2005), also elicits that mothers of ASD children experience feelings of helplessness, inadequacy and failure, anger, shock, guilt, frustration and resentment as experienced by the mothers in this study. These demands of having to cope with the physical and emotional demands of caring for a child with ASD is said to create a threat to the psychosocial wellbeing of parents and carers (Higgins et al., 2005). In addition Schwartz (2003) states that mothers need to balance their own lives with the need to do anything they can to help their child, which "functionally means mothers must protect themselves from being overwhelmed by the demands of caregiving, without feeling that they have abandoned a loved one" (p.577).

In addition it has been well documented that mothers of ASD children have higher levels of stress in comparison to mothers of typically developing children and other disorders. According to Higgins et al. (2005), this stress can be attributed to some extent to the anti-social and disruptive behaviours of ASD children which may affect the normality of everyday life.

Although there have been numerous studies on the psychological wellbeing and stress profiles of mothers with ASD children, to the researchers knowledge, there is limited information specifically regarding mothers psychological wellbeing and the attachment relationship with their ASD child. According to Montes and Halterman (2007), there has been research to suggest that having a child with autism has a negative impact on maternal psychological functioning. However in recent research by Montes and Halterman (2007), on psychological functioning and coping among mothers of children with autism, it was

concluded that mothers of a child with autism were more likely to report a close relationship with their ASD child and mothers of ASD children “showed remarkable strength in the parent-child relationship” (p. 1040). This was also evidenced by some of the mothers from diverse socio-economic groups in this study.

In terms of the psychological needs of mothers from advantaged and disadvantaged communities, it was evident that they shared the same or similar experiences. In most cases, even though the mothers expressed feelings of depression, sadness, or regrets or guilt in the way they have raised their ASD child, they appear to have secure attachments with their ASD child.

4.10 CONCLUSION

This chapter has described and discussed the results gathered from the semi-structured interviews with mothers of an ASD child, and the similarities and differences in mothers’ experiences have been highlighted. The semi-structured interviews provided mothers of ASD children an opportunity to explore their experiences of attachment with their ASD child from advantaged and disadvantaged communities in the Johannesburg and greater Johannesburg area. Relevant literature has also been included to support the findings in this study.

Chapter 5 will discuss the strengths and limitations of this research study. In addition, the necessary recommendations for future action and research will be highlighted. The researcher will also provide a personal reflection regarding this study experience. A final conclusion, summarising the findings of mothers experiences of attachment with their ASD child across diverse socio-economic groups will be discussed, in terms of the similarities and differences found in this study in relation to the research questions.

CHAPTER 5

STRENGTHS, LIMITATIONS, RECOMMENDATIONS, PERSONAL REFLECTION AND CONCLUSION

5.1 INTRODUCTION

This chapter gives a conclusion of the results in this study and further serves to discuss both the strengths and limitations of this study on mothers' experiences of attachment with their ASD child across socio-economic groups. Considerations for future research in this field shall be discussed and the implications of this shall also be discussed with reference to a South African context.

5.2 CONCLUSION

The aim of this research study was to investigate mothers' experiences of attachment with their ASD child, across diverse socio-economic groups in the South African context. The research further aimed to investigate the similarities and differences in mothers' experiences between the diverse groups.

Results from this study identified 7 themes, which produced some similarities and some differences. Theme 1, mothers' experiences of prenatal and postnatal attachment, highlighted the importance of children's birth history and the effects medical complications may have on attachment, which can be applicable to attachment theory in general. In this study, mothers from both groups shared the same or similar experiences in terms of prenatal and postnatal attachment.

Theme 2, mothers' perceived experiences of attachment preceding an ASD diagnosis highlighted some of the challenges mothers in this study were faced with in trying to find a diagnosis for their child. Mothers from both groups shared similar experiences in terms of their experiences, which addressed the challenges mothers from both groups encountered while trying to find a diagnosis for their ASD child, and dealing with the professionals.

Theme 3, mothers' reactions to an ASD diagnosis and the effects on attachment was concerned with mothers' reactions to a diagnosis of ASD, and the importance of resolution and acceptance of a diagnosis in terms of promoting more secure attachments with their ASD

child. Mothers from the diverse socio-economic groups' shared similar reactions their child's ASD diagnosis and mothers from both groups indicated that they have come to accept this diagnosis. In term of their ASD children's challenging behaviours, mothers from both groups shared the same or similar experiences and indicated that this is one of the greatest challenges of raising an ASD child. However, mothers from both groups felt that an increase in their child's language has lessened the challenging behaviour and has contributed to a better relationship between them and their ASD child.

Theme 4, the role of social support and social reactions to ASD, highlighted the significance of social support in promoting more secure attachments between a mother and her ASD child. In addition this theme highlighted some of the adverse social reactions mothers of ASD had experienced. Mothers' from the advantaged and disadvantaged communities have also shared the same or similar experiences in terms of the social reactions they have endured in terms of 'other' people's reactions to their ASD child. Mothers from both groups indicated that 'other' people make raising a child with ASD so much more challenging. Mothers from both groups have encountered adverse reactions from people in the public, which they perceived to be a consequence s a result of a lack of information and understanding of ASD.

Theme 5, maternal representations and experiences of mothering an ASD child, was concerned with the way in which mothers in this study viewed their ASD child. In addition it explored mothers' experiences of mothering an ASD child. It can be concluded that mothers from both groups in this study experience secure attachments with their ASD child. This was elicited in the interviews by mothers from both groups in their perceived experiences of attachment with their ASD child. Mothers from Sample A and Sample B expressed that they feel that they have a very good and loving relationship with their ASD child. Mothers from both Sample A and Sample B describe this relationship with their ASD child to be unique, and mothers from both groups indicated that they feel that they have a very strong relationship or bond with their ASD child, despite their ASD child's limitations of social interaction. In some instances mothers from both groups even feel that this bond is stronger in relation to their typically developing child. Mothers from both groups describe their ASD children in an enthusiastic manner and mothers from Sample A and Sample B have positive maternal mental representations of their ASD child. During the interviews with both groups of mothers it was evident that their ASD child plays a significant role in their lives, and mothers from both groups indicated that they would do anything to enhance the wellbeing of

their child. Mothers from both groups have experienced maternal gratification in raising their ASD child, which can be concluded to strengthen the attachment relationship between a mother and child.

Theme 6, the effects of socio-economic status on attachment, highlighted some of the challenges mothers are faced with in terms of financial difficulties and access to resources and the perceived effects this has on the attachment relationship with their ASD child. Some differences were also experienced by mothers from the diverse groups in this study. Firstly, experiences of social support and attachment differed from Sample A and Sample B. In this study it was found that mothers from the disadvantaged communities reported less support from their spouse/partner and, at times the mothers' in this community were blamed for their child's disability. In comparison, the mothers in the advantaged communities reported that their spouses/partners were very supportive with regard to their ASD child, which is fundamental in terms of developing more secure attachment relationships between a mother and child.

One of the significant differences in mothers' experiences from the diverse groups was particularly concerned with mothers' perceived effects of socio-economic status on the attachment relationship with their ASD child. This difference in experiences between the two groups, highlighted the added challenges mothers from disadvantaged groups are facing, including a lack of finances, educational facilities, interventions and resources. These socio-economic challenges were directly or indirectly reported by the mothers in the disadvantaged communities to add to their challenges and stress of raising an ASD child.

Finally this study aimed to investigate the psychological needs of mothers, which indicated that mothers of ASD children in this study require psychological and social support to assist them in maintaining secure attachments with their ASD child.

In terms of the third research question pertaining to the psychological needs of mothers with children with ASD with regards to the attachment process this study highlighted the emotional challenges that mothers with ASD children from advantaged and disadvantaged communities are faced with on a daily basis. Mothers' experiences from both diverse groups raise awareness of the substantial social support and counselling services mothers of ASD children require in order to help mothers with their own psychological wellbeing. This in

turn, can assist mothers from diverse socio-economic groups to cope with the daily struggles faced with raising an ASD child, and essentially assist in helping mothers develop secure attachments with their ASD child. Interventions aimed at the psychological well-being of mothers of ASD children, need to be developed on many societal and individual levels to ensure and promote effective caregiving of some of society's most vulnerable children and mothers.

In conclusion, mothers from both groups expressed that mothering a child with ASD has been a journey of personal and individual growth for them as individuals and as mothers. They have found that raising a child with ASD, although extremely challenging at times, has in essence given them strength to face other adversities in their lives and they feel they are better individuals because of it. As evidenced in this study from, there exists a paucity of information and support for mothers of ASD children. Mothers require counselling and effective support structures throughout the whole diagnostic process and continuing throughout the ever changing developmental challenges brought about by an ASD diagnosis. Professionals responsible for diagnosis and treating ASD, should be more considerate to the individualistic nature of each ASD child, and be more accepting of mothers concerns with regarding their child wellbeing. In addition, there needs to be more of an awareness of ASD, especially in the disadvantaged communities. In retrospect, individuals and communities need to be more accepting of ASD children and their mothers, and they need to provide the necessary emotional and functional support to facilitate children with disabilities to contribute to the psychological wellbeing of mothers, and in essence promote more secure attachments between mothers and their ASD children.

5.3 LIMITATIONS OF THIS STUDY

- This study consisted of a very small sample size so the mothers' experiences of attachment with their ASD child in this study cannot be generalised to include the entire population of mothers with children with ASD.
- This study relied on mothers personal accounts of the attachment relationship with their child and no direct observation of this relationship was made by the researcher. Therefore the researcher was entirely reliant on the mothers' accounts and experiences of this relationship.
- This study was conducted by a single researcher and investigator triangulation was not possible due to the scope of this study and financial constraints.

5.4 STRENGTHS OF THIS STUDY

In South Africa, there is evidence to suggest that the prevalence of ASD affects about 1:100 children, which validates the necessity of research of this nature.

To the researcher's knowledge, there has been no other study, specifically documenting mothers' experiences of attachment with their ASD child, across socio-economic groups in South Africa. This study therefore aimed at providing insight into a previously underexplored area of investigation, in an attempt to consciously raise awareness and interest in this field of enquiry.

Gaining personal perspectives of mothers' experiences of attachment, both in advantaged and disadvantaged communities in South Africa, raises awareness of mothers endured challenges and gives rise to future intervention plans. This study has also enabled the mothers the opportunity to be given a voice not only to advocate for their ASD children, but they have been given the opportunity to tell their own narrative of having an ASD child, which has been said to be a therapeutic experience in itself. Most of the mothers in this study readily accepted to be a part of this study in the hope that their stories could help other mothers of ASD children experiencing the same challenges they had endured and they hoped their stories could contribute to a better understanding of ASD, even if in the smallest way.

5.5 CONSIDERATIONS FOR FUTURE RESEARCH

During the implementation of this study, some areas for future research were identified, which included:

- A future area of investigation could include paternal experiences of attachment with their ASD child, especially taking into consideration the role of the father in shaping mothers experiences in this study.
- Mothers' experiences of the effects of HIV/AIDS on attachment across diverse socio-economic groups in South Africa could also be further investigated.
- Taking into consideration the experiences of mothers in dealing with professionals in an attempt to find a diagnosis for their child, another avenue of research could be conducted with the professionals involved in diagnosing ASD and their perceptions of the diagnostic process and experiences of dealing with the mothers of ASD children.

5.6 PERSONAL REFLECTION

Lyons (2000) makes note that in qualitative research, the researcher is seen as an important part of the knowledge production, bringing to it their own understandings, and they are expected to reflect on their actions and reactions during the research process. From this view it was important for the researcher to reflect on her own experiences of the research process, as well as to be reflective of her own attitudes and opinion towards mothers of ASD children.

Prior to the commencement of this study the researcher was an educator in the realm of special educational needs, both in South Africa and the United Kingdom for the last six years. Three of these years were specifically spent teaching children with ASD. This study was therefore perpetuated by the researcher's prior interests in ASD. While dealing with parents and specifically mothers in an educational setting, the researcher began to encounter some of the challenges that mothers of ASD children are faced with on a daily basis. Therefore an interest in this study grew out of the researchers concern of the numerous challenges mothers are faced with, and the effects ASD may have on the mother and child attachment relationship.

The researcher recognised that so often the needs of mothers with children with disabilities are neglected and ignored as the priority is understandably on the wellbeing on the child. These feelings were reiterated in this study and the researcher was overwhelmed by the extent

to which the mothers in this study go in order to provide the best care for their child. At times during this study, the researcher actually felt quite emotional listening to the mothers reflecting on their experiences of having an ASD child, as the journey they have endured has not been easy. However, the researcher also felt very inspired by these mothers' stories and encouraged that in the face of such adversity; most of the mothers feel that they are stronger for facing these hardships.

The researcher believes that in light of this study, she has become more sensitive and understanding of the challenges faced by mothers of ASD children. This has not only contributed to the personal growth of the researcher, but can be considered to be a great benefit when working with mothers of ASD children and other disabilities in her future professional career.

REFERENCE LIST

- Ainsworth, M. (1972). Attachment and dependency: A comparison. In J.L. Gewitz (Ed.). *Attachment and dependency*. John Wiley and Sons: New York.
- Ainsworth, M., Walters, E., & Wall, S. (1978). Patterns of Attachment: Observations in the strange situation and at home. Lawrence Erlbaum Associates, Hillsdale.
- American Psychiatric Association, 2000. *Diagnostic and Statistical Manual of Mental Disorders, 4th ed., Text Revision*. Washington, DC: American Psychiatric Association.
- Araneda, M., Santelices, M. & Farkas, C. (2010). Building infant-mother attachment: The relationship between attachment style, socio-emotional wellbeing and maternal representations. *Journal of Reproductive and Infant Psychology*, 28 (1), 30-43
- Attwood, T. (2007). *The complete guide to Aspergers Syndrome*. London: Jessica Kingsley Publishers.
- Autism society of America. About autism. Retrieved 6th March 2011 from <http://www.autism-society.org>
- Autism South Africa (2011). What is autism? Retrieved 6th March 2011 from <http://www.autismsouthafrica.org>
- Bailey, K. D. (1994). *Methods of social research*. New York: Free Press.
- Baker, J. (2010). Autism in 1959: Joey the mechanical boy. *Paediatrics*, 125(6), 1101-1103
- Benoit, D., Zeanah, C., Parker, K., Nicholson, E., & Coolbear, J. (1997). "Working Model of the Child Interview": Infant Clinical Status Related to Maternal Perceptions. *Infant Mental Health Journal*, 18 (1) 107-12.
- Bialoskurski, M., Cox, C., & Hayes, J. (1999). The nature of attachment in a neonatal intensive care unit. *Journal of Perinatal and Neonatal Nursing*, 13 (1), 66-77
- Borghini, A., Pierrehumbert, B., Miljkovitch, R., Muller-Nix, C., Forcada-Guex, M., & Anserment, F. (2006). Mothers attachment representations of their premature infant at 6 and 18 months after birth. *Infant Mental Health Journal*, 27 (5), 494-508
- Boucher, L. (2009). *The autistic spectrum: Characteristics, causes and practical issues*. Sage: London.
- Bowlby, J. (1952). *Maternal Care and Mental Health*. World Health Organisation: Geneva.
- Bowlby, J. (1969). *Attachment and Loss*. London: Hogart press.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in Psychology. *Qualitative Research in Psychology*, 3, 77-101.

- Breakwell, G. (2002).). In G. Breakwell, S. Hammond., & C. Fife-Schaw (2000).
Research Methods in Psychology. Sage: London.
- Bretherton, I. (1992). The origins of attachment theory: John Bowlby and Mary Ainsworth.
Developmental Psychology, 28, 759-775.
- Brimacombe, M., Ming, X., & Parikh, A. (2007). Familial risk factors in autism. *Journal of Child Neurology*, 22 (5), 593-597.
- Brown, D., Rodgers, Y., & Kapadia, K. (2008). Multicultural considerations for the application of attachment theory. *American Journal of Psychotherapy*, 64 (4), 353-362.
- Buitelaar, J. (1995). Attachment and social withdrawal in autism: Hypothesis and findings.
Behaviour, 132, 319-350.
- Centre of Disease Control and Prevention. Autism Spectrum disorders (ASDs). Retrieved 6th March 2010 from <http://www.cdc.gov/ncbddd/autism/data.html>
- Clements, M., & Barnett, D. (2002). Parenting and attachment among toddlers with congenital anomalies: Examining the Strange Situation and Attachment Q-Sort.
Infant Mental Health Journal. 23 (6), 625-642.
- Colin, V. (1996). Human attachment. McGraw-Hill Companies.
- Condon, J., & Corkindale, C. (1998). The assessment of parent –to –infant attachment: development of a self report questionnaire. *Journal of reproductive and Infant Psychology*, 16 (1), 57-76.
- Cox, A., & Lambrenos, K. (1992). Childhood physical disability and attachment.
Developmental Medicine and Childhood Neurology, 34, 1037-1046.
- Cullen, L., Barlow, J. (2002). Parents experiences of caring for children with autism and attending a touch therapy programme. *Child Care in Practise*, 8 (1), 35-45.
- Daley, T. (2002). The need for cross-cultural research on the pervasive developmental disorder. *Transcultural Psychiatry*, 39 (4), 531-550.
- Denzin, N., & Lincoln, Y. (2005). Handbook of qualitative research. Sage: London.
- Dissanayake, C., & Crossley, S. (1997). Autistic children's responses to separation and reunion with their mothers. *Journal of Developmental Disorders*, 27 (3), 295-312.
- Fairchild, S. (2006). Understanding attachment: Reliability and validity of selected attachment measures for preschoolers and children. *Child and Adolescent Social Work Journal*, 23(2), 235-261.

- Fiamenghi, G., Vedovato, A., Meirelles, M., & Shimoda, M. (2010). Mothers' interaction with their disabled infants: two case studies. *Journal of Reproductive and Infant Psychology*, 28(2), 191-199.
- Fonagy, P. (2001). Attachment theory and psychoanalysis. Other press: New York.
- Gervai, J. (2009). Environmental and genetic factors on early attachment. *Child and Adolescent Psychiatry and Mental Health*, 3, 25-36.
- Gravetter, F., & Forzano, L. (2003). *Research methods for the behavioural sciences*. Wadsworth.
- Goin-Kochel, R., Mackintosh, V., & Myers, B. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism*, 10 (5), 439-451.
- Goldfarb, C. & Roberts, W. (1996). Developmental monitoring in primary care. *Canadian Family Physician*, 42, 1527- 1536.
- Greenberg, M., Cicchetti, D. & Cummings, E. (1990). *Attachment in the Preschool years: Theory Research, and Intervention*. The University of Chicago Press: Chicago and London.
- Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9 (2), 125-137.
- Hoffman, C., Sweeney, D., Hodge, D., Lopez-Wagner, M., & Looney, L. (2009). Parenting Stress and Closeness: Mothers of Typically Developing Children and Mothers of Children with Autism. *Focus on Autism and Other Developmental Disabilities*. 24 (3), 178-187.
- Holmes, J. (1993). John Bowlby and attachment theory. Routledge.
- Howe, D., Brandon, M., Hinnings, D., & Schofield, G. (1999). *Attachment Theory, Child Maltreatment and Family Support: A Practise and Assessment Model*. PALGRAVE.
- Howe, D. (2006a). Disabled children, maltreatment and attachment. *British Journal of Social Work*, 36, 743-760.
- Howe, D. (2006b). Disabled children, parent-child interaction and attachment. *Child and Family Social Work*, 11, 95-106.
- Kazak, A. (1987). Families with disabled children: Stress and social networks in three samples. *Journal of Abnormal Child Psychology*, 15 (1), 137-146.
- Kearney, P., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-592.

- King, M., & Bearman, P. (2011). Socioeconomic status and the increased prevalence of autism in California. *American Sociological Review*, 76 (2), 320-346.
- Kobayashi, R. (2000). Affective communication of infants with autistic spectrum disorder and internal representation of their mothers. *Psychiatry and Clinical Neurosciences*, 54, 235-243.
- Kubeka, N. (2010). Autism South Africa. *aut;talk*, 16.
- Laxton-Kane, M., & Slade, P. (2002). The role of maternal prenatal attachment in a woman's experience of pregnancy and implications for the process of care. *Journal of Reproductive and Infant Psychology*, 20 (4), 253-266.
- Lyons, E. (2000). In G. Breakwell, S. Hammond., & C. Fife-Schaw (2000). *Research Methods in Psychology*. Sage: London.
- Lyons, E., & Coyle, A. (2007). *Analysing Qualitative data in Psychology*. Sage: Los Angeles.
- Marvin, R., & Pianta, R. (1996). Mothers reactions to their child's diagnosis: Relations with security of attachment. *Journal of Child Psychology*, 25(4), 436-445.
- Meirsschaut, M., Roeyers, H., & Warreyn, P. (2011). The social interactive behaviour of young children with autism spectrum disorder and their mothers: Is there an effect of familiarity of the interaction partner? *Autism*, 15(1), 43-64.
- Minde, K., Minde, R., & Vogel, W. (2006). Culturally sensitive assessment of attachment in children aged 18-40 months in a South African township. *Infant Mental Health Journal*, 27 (6), 544-558.
- Montes, G., & Halterman, J. (2007). Psychological functioning and coping among mothers of children with autism: a population based study. *Paediatrics*, 5, 1040-1046.
- Morgan, S. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18 (2), 263-280.
- Muller, M. (1996). Prenatal and postnatal attachment: A modest correlation. *Journal of Obstetric, Gynaecologic, and Neonatal Nursing*, 25 (2), 161-166.
- Oppenheim, D., & Goldsmith, D. (2007). *Attachment Theory in Clinical Work with Children: Bridging the Gap between Research and Practise*. The Guilford Press: New York.
- Ospina, M., Seida, J., Clark, B., Karkhaneh, M., Hartling, L., Tjosvold, L., Vandermeer, B., & Smith, V. (2008). Behavioural and developmental interventions for autism spectrum disorder: A clinical systematic review. *PloS ONE*, 3 (11).

- Pajulo, M., Savonlahti, E., Sourander, A., Pih, J., & Helenius, H. (2001). Prenatal maternal representations: Mothers at psychological risk. *Infant Mental Health Journal*, 22, 592-544.
- Rugters, A., IJzendoorn, M., Bakermans-Kranenburg, M., Swinkels, van Daalen, E., Dietz, C., Naber, F., Buitelaar, J., & van Engeland, H. (2007). Autism, Attachment and Parenting: A Comparison of Children with Autism Spectrum Disorder, Mental Retardation, Language Disorder, and Non-clinical Children. *Journal of Abnormal Child Psychology*, 35, 859-870.
- Rutter, M. (1978). Diagnosis and definition of childhood autism. *Journal of Autism and Developmental Disorders*, 8(2), 139-161.
- Ryan, S. (2005). 'People don't do odd, do they? Mothers making sense of the reactions of others towards their learning disabled children in public places. *Children's Geographies*, 3 (3), 291-305.
- Sadock, B., & Sadock, V. (2007). *Synopsis of Psychiatry: Behavioural Sciences/Clinical Psychiatry*. (10th ed). Lippincott Williams & Wilkins.
- Schwartz, C. (2003). Parents of children with chronic disabilities: the gratification of caregiving. *Families in Society*, 84(4), 576-584.
- Seskin, L., Feliciano, E., Tippy, G., Yedloutschnig, R., Sossin, K., & Yasik, A. (2010). Attachment and autism: Parental attachment representations and relational behaviours in the parent-child dyad. *Journal of Abnormal Child Psychology*. May, 1-12.
- Stace, H. (2010). Mother blaming; or autism, gender and science. *Woman's Studies Journal*, 24(2), 66-70.
- Statistics South Africa (2011). Statistical release (P0302): Midyear population estimates. Retrieved on 2nd November, 2011 from <http://www.statssa.gov.za/publications/P0302/P03022011.pdf>
- Sousa, A. (2011). From refrigerator mothers to warrior-heroes: The cultural identity transformation of mothers raising children with intellectual disabilities. *Symbolic Interaction*, 32(2), p. 220-243.
- Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). *Quality in Qualitative Evaluation: A framework for assessing research evidence*. Crown.
- Terre Blanche, M., Durrheim, K., Painter, D. (2006). *Research in practise*. Cape Town: University of Cape Town Press.

- Theran, S., Levendosky, A., Bogat, A., & Huth-Bocks, A. (2005). Stability and change in mother's representations of their infants over time. *Attachment and Human Development*, 7(3), 253-268.
- Thurmond, V. (2001). The point of triangulation. *Journal of Nursing Scholarship*, 33 (3), 253-258.
- Travis, L., & Sigman, M. (1998). Social Deficits and interpersonal relationships in autism. *Mental Retardation and Developmental Disabilities*, 4, 65-72.
- Trevarthen, C., Aitken, K., Papoudi, D., & Robarts, J. (1999). *Children with autism: Diagnosis and interventions to meet their needs*. (2nd ed). Jessica Kinsley: London
- Turpin, G., Barley, V., Beail, N., Scaif, J., Slade, P., Smith, J. & Walsh, S (1997). In Lyons, E., & Coyle, A. (2007). *Analysing Qualitative data in Psychology*. Sage: Los Angeles.
- Wachtel, K., & Carter, S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASD's. *Autism*, 12(5), 575-594.
- Waters, E., Kondo-Ikemura, K., Posada, G., & Richters, J. (1991). Learning to love: Mechanisms and milestones. Self processes and development. The Minnesota symposia on child psychology, Vol. 23 (pp. 217-255). Hillsdale: England:
- Whitaker, P. (2001). *Challenging behaviour and Autism*. London: The National Autistic Society.
- World Health Association. (1993). The ICD-10 classification of mental behavioural disorders: Diagnostic criteria for research. Geneva: World Health Organisation.
- Zeanah, C., Benoit, D., & Barton, M. (1995). Clinical applications of a parent perception interview in infant mental health. *Child and Adolescent Psychiatric Clinics of North America*, 4, 539-554.
- Zimmerman, A. (2003). Prenatal attachment, empathy, and cognitive adaption to pregnancy subsequent to having a child with Down's syndrome. *Journal of Developmental Disabilities*, 10 (1), 141-148.

APPENDICES

Appendix A: Medical Ethics Certificate

Appendix B: Organisation Information Letter

Appendix C: Organisation Consent Form

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Appendix I: Consent Letter from Chris Hani Baragwanath Hospital

Appendix A: Medical Ethics Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Lorin Wortman

CLEARANCE CERTIFICATE

M110511

PROJECT

Diverse

The Effects of Autistic Spectrum Disorders (ASD)
on Attachment: Experiences of Mothers from

South African Socio-Economic Groups

INVESTIGATORS

Ms Lorin Wortman.

DEPARTMENT

Department of Psychology/SHCD

DATE CONSIDERED

27/05/2011

DECISION OF THE COMMITTEE*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 15/07/2011

CHAIRPERSON
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr Charmaine Gordon

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix B: Organisation Information Letter

School of Human & Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559



Dear _____

My name is Lorin Wortmann, and I am conducting research for the purpose of obtaining my Masters in Educational Psychology at the University of the Witwatersrand, Gauteng. My area of focus is mothers' experiences of the effects of Autistic Spectrum Disorders (ASD's) on the attachment relationship with their child. This research aims to explore this relationship between a mother and her child, who has a diagnosis of an ASD, taking into consideration the role socio-economic factors play in creating these experiences. As attachment and the relationship between a mother and her child are so important in the child's overall development, and there is such a paucity of information of this nature in South Africa, it is a very important area to investigate. Being an organisation that has accessibility to mothers of ASD children, I would like to ask permission to conduct this research at your organisation.

If permission is granted to use your organisation, and ethical clearance has been granted by the ethical committee of the University of the Witwatersrand, I will submit participant information letters and consent forms for all the mothers with an ASD child that attend your school/support groups, inviting them to participate in the study. Once the forms have been returned I will contact each mother that is interested to participate in the study telephonically to set up an interview date and time that is suitable for the participant and the organisation.

Participation in this research will entail being interviewed by me, and the interview will last approximately an hour. All of the responses will be kept confidential and no information that could identify the participant's will be included in the report. With each participant's permission, this interview will be tape recorded in order to ensure accuracy. Participation is voluntary, and no persons will be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study. Results may include direct quotes from the

participants' answers but these will remain completely confidential. The interview material (tapes and transcripts) will not be seen or heard by anyone in the organisation, and will only be processed by myself and an interpreter if one is required. The records will be kept in a locked filing cabinet in the researcher's home. If the research is published the interview material will be destroyed after two years, and if the research is not published, the interview material will be destroyed after six years.

The participants may refuse to answer any questions they would prefer not to, and they may choose to withdraw from the study at any point with no negative consequences. If your organisation or the participants in the research, would like to access the research results, they can contact the researcher directly and the researcher will provide individual participants with a summary of the results. Alternatively the research project will be held in the library at the University of the Witwatersrand if you wish to view the whole document.

Your participation in this study would be greatly appreciated. This research will contribute to a larger body of knowledge on mother's perceptions on the effects of disability on attachment.

Kind Regards

Lorin Wortmann (Researcher)
Department of Psychology
University of the Witwatersrand
Tel: 084 757 3983
E-mail: lolwortmann@yahoo.com

Dr. Charmaine Gordon (Research Supervisor)
Department of Psychology
University of the Witwatersrand
Tel: 011 717 4527
Email: Charmaine.gordon@wits.ac.za

Appendix C: Organisation Consent Form

Dear _____

Please can you fill out the Organisation Consent Form to consent to your organisation being used as a research location.

I, _____ (name and surname), consent to
_____ (Organisations name)
being used as a research location for the purpose of Lorin Wortmann's research on mothers' experiences of the effects of ASD on attachment'. I have read the organisation information letter and I am aware of the details of the research.

I understand that:

- Participant interviews will be conducted onsite
- Participation in interviews is voluntary
- Withdrawal from the research can occur at any time
- No information that may identify participants will be included in the research report, and participants responses will remain confidential
- If the research is published the interview material will be destroyed after two years, and if the research is not published, the interview material will be destroyed after six years.
- Results may include direct quotes from participants answers but these will remain completely anonymous
- Should the organisation request the results of this study, these will be made available after the completion of the research report
- There are no risks or benefits attached to the organisations participation in this research
- The results may be published in an academic journal

Signed: _____

Date: _____

Kind Regards

Lorin Wortmann

Appendix D: Participant Information Letter

School of Human & Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559



Good day, my name is Lorin Wortmann, and I am conducting research for the purpose of obtaining my Masters in Educational Psychology at the University of the Witwatersrand, Gauteng. My area of focus will be of mothers' experiences of attachment with their child who has an ASD. This research aims to explore this extraordinary relationship between a mother and child who has a diagnosis of autism, living in diverse socioeconomic contexts in South Africa. I am interested in finding out more about your personal experiences regarding your relationship with your ASD child and I would therefore like to invite you to participate in this study.

Participation in this research will entail being interviewed by me, and the interview will last approximately an hour. All of the responses will be kept confidential and no information that could identify you will be included in the report. With your permission, this interview will be tape recorded in order to ensure accuracy. Participation is voluntary, and no person will be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study. Results may include direct quotes from your answers but these will remain completely confidential. The interview material (tapes and transcripts) will not be seen or heard by anyone in your organisation, and will only be processed by myself and an interpreter if required. The interview material will be kept in a locked filing cabinet in the researcher's home. If the research is published the interview material will be destroyed after two years, and if the research is not published, the interview material will be destroyed after six years.

You may refuse to answer any questions that you would prefer not to and you may choose to withdraw from the study at any point with no negative consequences. If you would like to access the research results, you can contact the researcher directly and the researcher will provide individual participants with a summary of the results. Alternatively the research project will be held in the library at the University of the Witwatersrand if you wish to view the whole document.

Although this research may not be of direct benefit to you, it could be a valuable source of information used to assist others in understanding mother's experiences of attachment with their child with autism. Such research could be used to inform future parental programmes as a means of support to mothers of ASD children as well as used by multidisciplinary professionals to inform intervention programmes and to promote wellbeing.

Some of the material elicited during the interview maybe of a sensitive nature and the contact details of parent support groups and nearby counselling services shall be provided should it be necessary to talk to someone further.

If you would like to participate in this research, please can you fill out the attached consent form and return in to your child's school/parental support group at the earliest convenience and you shall be contacted to arrange an interview date and time.

Thank you for your time and I look forward to hearing from you.

Kind Regards

Lorin Wortmann (Researcher)
Department of Psychology
University of the Witwatersrand
Tel: 084 757 3983
E-mail: lolwortmann@yahoo.com

Dr. Charmaine Gordon (Research Supervisor)
Department of Psychology
University of the Witwatersrand
Tel: 011 717 4527
Email: Charmaine.gordon@wits.ac

Support and counselling centres

- Life Line
(011) 715-2000
- Emthonjeni Centre (University of the Witwatersrand)
(011) 717 4513
- Autism South Africa
(011) 484-9909
- Chris Hani Baragwanath Hospital
Speech and Language Department
ASD Parental support groups
Tel: (011) 933-8000

Appendix E: Participant Informed Consent Form

School of Human & Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559



I, _____ (name and surname), consent to being interviewed by Lorin Wortmann, for her study on mothers experiences of the effects of ASD on attachment, across diverse socioeconomic contexts in South Africa.

I understand that:

- Participation in this interview is voluntary
- I can choose not to answer questions if I would prefer not to
- I may withdraw from the research at any time
- No information that may identify me will be included in the research report, and my responses will remain confidential
- Data will be kept in a safe place and if the research is published the interview material will be destroyed after two years, and if the research is not published, the interview material will be destroyed after six years.
- Results may include direct quotes from participants answers but these will remain completely confidential
- Should I request the results of this study, I can contact the researcher after the completion of the research report
- Should I require contact details of parental support groups or counselling services, these shall be made available by the researcher on request
- There are no risks or benefits attached to my participation in this research
- The results may be published in an academic journal

Signature of Participant

Date

Appendix F: Consent Form (Recording)

School of Human & Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559



I _____ (Name and Surname), consent to an interview with Lorin Wortmann for her study on mothers' experiences of the effects of ASD on attachment, across diverse socio-economic contexts in South Africa, being tape recorded for accuracy.

I understand that:

- The tapes and transcripts will not be seen or heard by any persons in this organisation at any time, and will only be processed by the researcher
- All tape recordings will be kept in a safe locked cabinet at the researchers home
- If the research is published the interview material will be destroyed after two years, and if the research is not published, the interview material will be destroyed after six years.
- No identifying information will be used in the transcripts or the research report

Signature of Participant

Date

Appendix G: Interview Schedule

Demographic Details of Mother:

Name: _____

Age: _____

First Language: _____

Other Languages: _____

Employment: _____

Average family income _____

Residing area _____

Marital Status _____

Number of children: _____

Age of child with ASD: _____

Child's position in the family _____ (e.g. first born)

When was your child diagnosed with ASD: _____

Who gave your child the diagnosis? _____

Does your child have any other difficulties? _____

Question 1: I'd like you to begin by telling me about your child's development

- a) Let's start with your pregnancy - planned or unplanned, how you felt physically and emotionally?
- b) Tell me about your labour and delivery. How did you feel and react at the time? What was your first reaction when you saw the baby? What was your reaction to having a boy/girl? How did your family react? (husband, siblings, grandparents, community)
- c) Did your baby have any problems in the first few days after birth?
- d) How would you describe the first few weeks at home in terms of feeding, sleeping, crying ect.
- e) Tell me about your baby's developmental milestones such as sitting up, crawling, walking, talking, smiling, and talking
- f) Did your baby seem to have a regular routine? What happened if you didn't stay in the routine?
- g) How did your baby react to separations from you? How did the baby react? How was it for you? How did you feel? What did you do?
- h) How did your baby respond to being soothed and comforted? What were your baby's responses to touch and physical affection?

Question 2: Does your baby/child get upset often? What do you do at these times? What do you feel like doing when this happens? What do you feel like at these times?

Question 3: Describe your impression of your child's personality.

Question 4: What do you feel is unique or different about your child compared to other children?

Question 5: What about your child's behaviour now is most difficult to handle

- a) How often does this occur? What do you feel like doing when your child reacts that way? What do you actually do?
- b) What does the child do after you respond to the difficult behaviour in the way you described, how do you imagine the child feels when you respond this way?
- c) What do you imagine will happen to this behaviour as your child grows older?

Question 6: How would you describe your relationship to your child?

Question 7: What pleases you most about your relationship with your child?

Question 8: How do you feel your relationship with your child has affected your child's personality?

Question 9: How has your relationship to your child changed over time (since birth)?
What are your feelings about this change?

Question 10: Which parent is your child closest to now?
How can you tell?
Has it always been this way?

Question 11: As you know the first few months/years can be difficult at times- what is your worst memory?

Question 12: Are there any experiences which your child has had which you feel have been a setback for him/her? Why do you think so?

- a) Do you have any regrets about the way you have raised your child so far?
- b) If you could start all over again, knowing what you know now, what would you do differently

Question 13: What worries you the most about your child?

Question 14: As you look ahead, what do you think will be the most difficult time in your child's development?

Question 15: Think for a moment of your child as an adult. What hopes and fears do you have about that time?

Question 16: What has been the hardest thing about raising a child diagnosed with an ASD?

Question 17: What are the effects of your own circumstances on the relationship with your ASD child?

Question 18: Is there anything else you would like to share?

Appendix H: Consent from Support and Counselling Organisations



autism south africa
children's memorial institute
gate 13. cnr joubert street ext and empire road
braamfontein. 2001
p.o. box 84209 greenside. 2034
tel: + 27 11 484 9909
fax: +27 11 484 3171
e-mail: info@autismsouthafrica.org
web page: www.autismsouthafrica.org

Attn: To whom it may concern
7 July 2011

Re: Services at Autism South Africa

I, Jill Stacey as National Director of Autism South Africa, hereby give Lorin Wortmann permission to recommend Autism South Africa to the participants of her Masters in Educational Psychology research project if they require any support as a result of the interviews conducted for the purpose of her research project on 'The effects of Autistic Spectrum Disorders (ASD) on attachment: Experiences of mothers from diverse South African socio-economic groups'.

The participants are free to contact Binwell Keshi on 011 484 6448.

Yours sincerely

A handwritten signature in black ink that reads 'Jill Stacey'.

JILL STACEY



The National Lottery Distribution Trust Fund enhances outcomes for those with
autism in South Africa

Appendix H: Consent from Support and Counselling Organisations



Emthonjeni Centre (EC)
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4513 Fax: (011) 717 8324



27 June 2011

To whom it may concern

Re: Services at the Emthonjeni Centre (EC)

I, Sharon Moonsamy, as the Acting Director of the Emthonjeni Centre, hereby give Lorin Wortmann permission to recommend the EC at the University of the Witwatersrand to the participants of her Masters in Educational Psychology research project if they require any support as a result of the interviews conducted for the purpose of her research project on ‘The effects of Autistic Spectrum Disorders (ASD) on attachment: Experiences of mothers from diverse South African socio-economic groups’.

The participants are free to contact Nthabiseng Modikoane as required on 011 717 4513.

Yours sincerely

Sharon Moonsamy
Acting Director: EC
School of Human & Community Development
University of the Witwatersrand

Appendix I: Consent from Chris Hani Baragwanath Hospital



Chris Hani Baragwanath Hospital
Department of Speech Therapy and Audiology
P. O. Box 2013
Bertsham
2013
Tel: (011) 933 9263/4/5
Fax: 086 631 3984
E-mail: hansspeechtherapy@webmail.co.za
5/07/2011

Ms Lorin Wortman

Regarding Study:

The Effects of Autistic Spectrum Disorders (ASD) on
Attachment: Experiences of Mothers from Diverse South African
Socio- Economic Groups

Please note that provisional permission is provided for you to conduct your study at Chris Hani Baragwanath Academic Hospital pending your ethical clearance. Permission is also granted that results will be shared with the department of Speech Therapy /Audiology .

Yours Sincerely

A handwritten signature in black ink, appearing to read 'Sadna Balton'.

Dr Sadna Balton
Speech Therapist & Audiologist
(HOD)
(011) 933 9265/3