

**PARENTS' EXPERIENCES OF THEIR CHILD BEING
DIAGNOSED WITH AN AUTISTIC SPECTRUM DISORDER**

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DECLARATION

Submitted in partial fulfilment of the requirements for the degree of Master of Arts, in
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I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Master of Arts (Educational Psychology) in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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Abstract

Autistic Spectrum Disorders (ASD's) represent some of the most common developmental disorders amongst children today (Rapin, 1994), yet knowledge and interventions for these disorders remain minimal. Access to resources for diagnosis and intervention for children with ASD's in South Africa appears to be limited to a few families. For this select population, many difficulties and much dissatisfaction with diagnostic processes remain. This study aimed to capture the experiences of parents whose children had received ASD diagnoses.

This study was qualitative in nature and took the form of semi structured interviews with a total of eight parents of ASD children (7 mothers and 1 father). These interviews highlighted key issues in the area of ASD's in South Africa, including: a lack of knowledge amongst professionals, an unwillingness to diagnose, and lack of available support and facilities. Data collected from this sample revealed that the average age of diagnosis of children was 6 years old, and the average number of years taken to reach diagnosis was 3 years 3 months. Although these figures correlate with international research, participants of this study revealed that it had taken on average 7.2 medical practitioners to diagnose their children with ASD's. This number is significantly higher in South Africa than research from other countries indicates.

These findings are discussed in this research study, with emphasis being placed on implications for early intervention in South Africa.

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Preliminary Comments

1. A note about terminology

A variety of terms are used to discuss Autism, the most popular of these being Autistic Spectrum Disorder (ASD). As ASD is the most recently favoured term in the field, this study will use the term ASD, except where authors have specifically referred to it as Autism.

The term 'neurotypical' is a common term used amongst caregivers of ASD children and refers to individuals who do not suffer from neurodevelopmental disorders such as ASD.

2. Use of pseudonyms

In order to protect the identities of participants taking part in this research study and their families, pseudonyms have been throughout this thesis.

Chapter 1

Rationale & Introduction

1.1 Rationale

Many quantitative studies and questionnaires have been done in the area of Autism diagnosis (Eikeseth, 1999; Goin-Kochel, Mackintosh & Myers, 2006; Howlin & Asgharian 1999; Mansell & Morris, 2004; Nissenbaum, Tollefson & Reese, 2002; Siklos & Kerns, 2005), however there is little qualitative research regarding diagnostic experiences. Much of the research to date has taken place in Europe and the United States of America, and there is need for qualitative insight into diagnostic experiences from a South African perspective. Children with special needs have not been a priority in South Africa; ASD is no exception in this regard. With the stress and difficulties that parents face without the certainty of a diagnosis, and the failure to know what interventions to use as a result, further studies into delayed diagnosis are certainly necessary. This qualitative study aims to provide a more empathic insight into the complex experience of these parents. One of the aims of the study was therefore to provide a rich descriptive picture that highlights where diagnosis can be enhanced and what interventions are required to improve early diagnosis for ASD children. As Mindence and O'Neill state, "very little research has been carried out using qualitative methods" (1999, p. 274) to investigate the diagnostic experience of ASD. The central aim of this study was therefore to describe the experiences of South African parents whose children have been diagnosed with an Autistic Spectrum Disorder.

The task of raising a child causes stress enough on its own for any parent. Research indicates that parenting children with severe medical or psychological difficulties causes even higher levels of stress (Beckman, 1991; Mallow & Bechtel, 1999; Trachtenberg & Batshaw, 1997). Having a child with any degree of special needs may leave a parent experiencing frustration,

remorse, bitterness and anger, and searching for answers to questions regarding their child's disability (Holmberg, 2007).

A diagnosis of an ASD has a profound effect on the entire family system. Parents are usually most affected, leaving them with tremendous emotional, psychological and economic burdens (Gray, 2000; Kohler 1999; Loynes, 2000; Shacar, 2006). Parents' high stress levels may be additionally compounded as they often have to wait for years before an accurate diagnosis of ASD is made (Layne, 2007; Siklos & Kerns, 2005). This is despite findings showing that the earlier the intervention with ASD diagnosed children, the better the prognosis for positive long-term outcomes (Acosta, 2006; Drew et al., 2002; Eikeseth, 1999; Kraft, 2006; Mooney, Gray & Tonge, 2006; Siklos & Kerns, 2005; Wetherby & Woods, 2006).

Children with special needs have not been a priority in South Africa; ASD is no exception in this regard. With the stress and problems that parents face without the certainty of a diagnosis, and the failure to know what interventions to use as a result of this, further studies into delayed diagnosis are certainly necessary. Although Autism is one of the most researched disorders, there is still much that needs to be addressed within the South African context; in particular, current practices being used by families and service providers across the country (Hays, 2007). This study will document the experiences that parents face in the time preceding and following an accurate diagnosis of Autistic Spectrum Disorder (ASD). It is hoped that the results of this study highlight where diagnosis can be enhanced and what interventions are required to improve early diagnosis for ASD children. The results of this study may be useful as a psycho educational tool for parents facing these emotional and practical difficulties, as well as for mental health and medical practitioners.

1.2 Introduction

Studies have shown how parents awaiting a diagnosis often feel stress and loneliness at the uncertainty of their child's disability (Layne, 2007; Siklos & Kerns, 2005). The additional stress on parents and siblings often causes family difficulties. This tension may be exacerbated by other children in the household exhibiting negative behaviours. There also appears to be an increased rate of alcoholism amongst parents with ASD children, as well as a considerable amount of marital conflict due to the pressures and frustrations faced by these parents (Layne, 2007). Mindence and O'Neill (1999, p.274) write "coping with Autism was a very difficult and demanding challenge, with parents reporting that lack of verbal communication, together with tantrums and violence, were the most difficult behaviours to deal with", reinforcing the loneliness and frustrations that parents deal with during the period before diagnosis.

Apart from this, there is the financial strain of many medical appointments and specialist visits (Kohler, 1999; Loynes, 2000). These burdens may include additional work, less income, and a variety of other obligations and responsibilities. Most ASD children are involved in a range of therapies for up to 40 hours per week (Kohler, 1999). The financial implications for many parents may thus be devastating, and a common solution is that the mother stays at home to care for the ASD child, while the father carries the family financially (Shacar, 2006). The wide range of stressors may contribute to further adverse effects on families as Siegal (1996) reports the divorce rate among couples with ASD children to be as high as 75-80%.

According to Howlin and Asgharian (1999) and Goin-Kochel, Mackintosh and Myers (2006), parents often find themselves in a frustrating period of doubt and concern trying to convince

their general practitioners that their concerns lie deeper than simply a phase of late development and that specialist assessment is necessary. It is possible to accurately diagnose Autism before the age of two (Goin-Kochel et al., 2006), yet research shows that parents have had to wait up to three years and see an average of four and a half professionals before they received ASD diagnosis (Siklos & Kerns, 2005).

The tendency for practitioners to dismiss parents' concerns and delay the diagnosis may be due to a number of reasons. Possible explanations include lack of information about ASD's and the fear that incorrect diagnosis will cause excess stress on families. Behavioural difficulties and speech delays are also common concerns in children aged one to three, and developmental screening tools are not used consistently by paediatricians to test for ASD's (Goin-Kochel et al., 2006). Whatever the reasons, studies indicate that delays in diagnosis add significantly to parents' levels of distress, and delay earlier intervention for ASD children (Goin-Kochel et al., 2006; Mansell & Morris, 2004). Amaral (2005 cited in Kraft, 2006, p.1) emphasizes that a delay "eliminates a valuable window of treatment opportunity when the brain is undergoing tremendous development".

This study adopted a qualitative design to gather information about parents' experiences on the road to diagnosis. An interpretive perspective was taken, allowing the researcher to interpret data with empathetic understanding (Terre Blanche, Durrheim & Painter, 2006). This involved taking people's subjective experiences seriously and making meaning of them by interacting and listening to them (Terre Blanche et al., 2006). This research consists of parents' subjective accounts in the years preceding and following their children's diagnosis of an Autistic Spectrum Disorder.

As this study investigated an area in which there has previously been little research from a qualitative perspective, it takes the form of an exploratory study that is descriptive in nature (Terre Blanche et al., 2006). The aim was to create a rich descriptive picture of parents' experiences. Data gathered for this research project was collected by means of individual interviews with parents whose children have been diagnosed with an ASD. This involved semi structured interviews with parents about their experiences relating to this topic. The sample consisted of parents whose children have had a diagnosis of ASD. A purposive and non random sample was therefore used, as the study requires a particular population that has been through the experience that is the subject of inquiry. Parents were recruited from local ASD support groups, organisations, and schools for children with ASD. Details of the research were provided to group leaders and educators who then invited interested parents to contact the researcher to volunteer for the study.

The data from recorded interviews was analysed using thematic analysis of the transcriptions. This method of transcription was deemed an appropriate technique for this study as it provided descriptive data and a rich picture of the experiences of the process of arriving at a diagnosis for parents of ASD children (Boyatzis, 1998). All participants were recruited on a voluntary basis and the purpose of the study was explained to them when they were first approached by the researcher. All participants and their children's names have been held in confidentiality and pseudonyms were used in the published reports.

In the chapters that follow, the literature review provides the context for the current study by describing ASD's and how they are currently diagnosed. The features of the disorders and the difficulties with early diagnosis are highlighted, and the importance and benefits of early

intervention are discussed. Previous studies in the area are reported on, with a particular focus on parents' experiences. The dearth of qualitative studies is noted.

The methodology chapter emphasises the exploratory nature of this study and the value of a qualitative perspective. It highlights the methodology used in conducting the research, as well as information regarding research design, procedure, sampling and analysis. Results have been reported via themes and excerpts from the transcriptions of the parents' interviews.

The discussion focuses on reporting and interpreting the major themes which emerged from the parent interviews. These are linked to the studies reported in the literature review, and highlight the unique contribution of a rich descriptive perspective, particularly in the South African context. The final section provides conclusions regarding the research questions, and potential implications for future research and practice. It also provides insight to the limitations of the study.

Chapter 2

Literature Review

This chapter reviews the history of Autism and the diverse definitions that have evolved over time. It explores some of the hypotheses regarding the aetiology of Autistic Spectrum Disorders. Prevalence figures of ASD's have risen sharply over the past decade, and these increased prevalence rates and possible causes are discussed. The five subcategories of Pervasive Developmental Disorder are described and defined, and the 'triad' of features that ASD individuals present with is explicated. The importance of early diagnosis is emphasised and potential diagnostic tools are presented. Prior research in this area is reviewed, with a particular focus on studies which have explored the experiences and emotions of parents relating to the process of receiving an ASD diagnosis for their child.

2.1 Autism: Definitions & Features

2.1.1 History of Autism

The word Autism is derived from the Greek word *autos* meaning self (Exkorn, 2005). Although the discovery of Autism is often attributed to Leo Kanner and Hans Asperger, from the 1940's, descriptions of behaviour resembling this disorder date back to publications from the eighteenth century. A Swiss Psychiatrist, Eugene Bleuer, first used the term Autism in 1911 in referring to patients he experienced as "isolated from the outside world and extremely self-absorbed" (Exkorn, 2005, p.6). Today's definition of the word, however, is usually accepted to embrace more of Kanner's classical definition, where he described Autism as "where children display symptoms of impaired social interaction, lack of imaginative play, and verbal communication problems" (Exkorn, 2005, p.6).

Hans Asperger described children with many traits similar to that of Autism. However, their intellectual functioning abilities appeared to be higher and they seemed to lack the degree of verbal communication and social difficulties of those labelled with classical Autism (Attwood, 2007; Prior, 2003). The term Asperger's Syndrome was first used in 1976 by Lorna Wing, who felt the need for a new diagnostic category to describe individuals with these particular traits (Attwood, 2007).

2.1.2 Definitions of Autism: Potential Problem Areas

Autism is generally understood as a life-long developmental disability, the onset thereof usually occurring between birth and three years (Relph, 2006; Sicile-Kira, 2003). There are various definitions of Autism, although all encompass largely a deficit in a triad of impairments (discussed in more detail in 2.2.2). Some specific definitions are discussed below.

The DSM-IV-TR (APA, 2000), defines Autism as follows:

299.00 AUTISTIC DISORDER

A. A total of 6 or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple non verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested in 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 or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make believe play or social imitative play appropriate to developmental level

(3) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, non functional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

(APA, 2000, p.75)

Over the last few years the notion of Autism has been expanded to Autistic Spectrum Disorder to convey the notion of a continuum of functioning, as 'Autistic' symptoms vary in severity and type. The definition of ASD includes five Pervasive Developmental Disorders: Autistic Disorders (also known as Classic Autism or Kanner's Autism and including High Functioning Autism), Rett's Syndrome, Childhood Disintegrative Disorder, Asperger's Syndrome and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS), otherwise known as Atypical Autism (Roberts, 2004). All individuals falling into these subtypes have some extent of social and communication difficulties; however the degree thereof differs (Sicile-Kira, 2003).

The DSM-IV-TR (APA, 2000) provides specific criteria for each of the five pervasive Developmental Disorders. The major difference between Autistic Disorder and Asperger's Disorder is that is a history of normal language development in the latter. This distinction is considered by many to be inappropriate as the only means of differentiation, and, according to some researchers, this leads to many children with Asperger's Syndrome being diagnosed with a milder form of Autism (Ozonoff, South & Miller, 2000; Szatmari, Archer, Fisman, Streiner & Wilson, 1995). Although researchers' opinions differ on the exact place of

Asperger's Disorder within the ASD spectrum, they do agree that current diagnostic guidelines need to be clarified and reconsidered (Ozonoff, South & Miller, 2000; Szatmari et al., 1995). According to Prior (2003), there is also often confusion between Asperger's Syndrome and Pervasive Developmental Disorder- NOS.

2.1.3 Subcategories of Autism

As stated above, Pervasive Developmental Disorders include five subtypes, which will be discussed in greater detail below.

Autistic Disorder is more commonly known as Autism, and in the past was referred to as Kanner's Syndrome or Infantile Autism. Children with Autistic disorder present with a range of difficulties in varying degrees, and many have some extent of mental retardation.

According to Exkorn (2005, p.17) the three most common early symptoms of this disorder are "a lack of eye contact, a lack of pointing, and a lack of responding." These children display difficulties in areas of social interaction, communication and language, and restricted repetitive play (Exkorn, 2005; Stone, 2006). Children with Autistic Disorder may commonly be diagnosed with Attention Deficit and Hyperactivity Disorder (ADHD), by clinicians inexperienced in ASD's (Exkorn, 2005). Attwood (2007) suggests that ASD children may also be incorrectly diagnosed with a language disorder, a movement disorder, a mood disorder, an eating disorder or a non-verbal learning disability.

Asperger's Syndrome was first described in 1944 by Hans Asperger, a Viennese physician (Attwood, 2007; Prior, 2003). It is often difficult to diagnose as individuals with this disorder commonly have average intelligence and do not initially have delays in language development. Their behaviours are typically described by parents as quirky, awkward, and

repetitive. Unlike the other ASD's, Asperger's Syndrome is usually only diagnosed after the child is five, and at school going age. The prevalence rates of girls to boys are considerably higher than other ASD's, with ratios ranging between 1:5 and 1:15. Asperger's Syndrome is often referred to as a social disability (Exkorn, 2005; Stone, 2006).

Childhood Disintegrative Disorder (CDD) is a rare and regressive disorder in which children who have developed typically for the first two years lose varying degrees of skills in communication, social interaction, motor skills and adaptive behaviours. Autistic traits such as repetitive behaviours may accompany the loss of these skills. CDD usually occurs between the ages of two and ten years, and many children suffer mental retardation and seizures. There is a higher occurrence of this disorder in boys than girls, while CDD is 100 times less common than Autistic Disorder (Exkorn, 2005; Sicile-Kira, 2003; Stone, 2006).

Rett's Disorder was named after an Austrian physician, Dr Andreas Rett, and was first described in 1966 (Sicile-Kira, 2003). It almost exclusively affects girls, and is extremely rare with prevalence rates placed at between 1: 10 000, and 1:23 000 females. Girls suffering from Rett's Disorder usually develop normally until six to eighteen months, when development either stagnates or regresses. Rett's Disorder affects communication skills, fine and gross motor skills and social skills. Individuals may also have seizures, sleep and breathing difficulties and mental retardation. This disorder is the only PDD that has an identifiable cause (being abnormality of the X chromosome) and can now be determined by a genetic blood test (Exkorn, 2005; Sicile-Kira, 2003; Stone, 2006).

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is often referred to as atypical Autism. A child in this category may fit some of the ASD criteria but not all;

specifically they may have impairments in either communication or social skills, and display repetitive, restricted behaviours. This subtype is also known as a diagnosis of exclusion (Exkorn, 2005; Stone, 2006).

2.1.4 Features of ASD Individuals

The Autism Association of South Africa defines Autism as a “life-long developmental disability that prevents individuals from properly understanding what they see, hear and otherwise sense” (Autism SA). An Autistic child generally has a normal appearance and life expectancy, and may be fit, healthy and physically appealing (Gillberg, 1991). However, Gillberg (1991, p.927) highlights the typical signs of Autism which are

withdrawal, isolation, aloofness, failure to develop language, preoccupation with inanimate objects- such as spinning tops or a light switch, bizarre ritualistic behaviours- such as hand-flapping or flicking the fingers in front of the eyes, and an intense aversion to the slightest change, so that even the most trivial disruption of an established routine, such as the route taken to the grocery store, can cause extreme anxiety and emotional turmoil (p.927).

The three primary areas that characterize people with ASD are referred to as a triad of impairments. These include the impairment of social relationships, impairment of social communication and impairment of imaginative thought (Sicile-Kira, 2003). Children with ASD’s battle to understand emotional aspects of communication, body language, and social cues, and so have difficulty maintaining friendships and in general are confused by the world they find themselves in.

The first feature in the triad of impairments is an impairment of social skills. Neurotypical children show an intense interest in their peers during times of social interaction; however children with ASD usually show intense interest in objects. Autistic Spectrum Disorders children may seem to be isolated and disconnected and lack the early social skills that typical children display. Symptoms involving impairment in social relationships can be seen from early infancy in how a child relates to his/her environment; eye contact with and emotional dependence on parents; imitation of adult actions; and interaction by means of smiling in the first few months. Autistic Spectrum Disorder children do not seem to need to interact socially and are not able to use or understand non verbal behaviour. They often appear to be unfriendly and detached from their environment (Exkorn, 2005; Sicile-Kira, 2003; Stone, 2006).

Autistic Spectrum Disordered individuals also display impairments in communication and language skills. This impairment occurs in a variety of degrees, ranging between a complete absence of speech, delayed speech, repetitive, eccentric speech and the use of echolalia. According to Exkorn (2005) it has been estimated that 40% of children with an ASD have no speech at all, and communicate by non verbal means. These children have difficulty both initiating and responding to communication, while others seem not to understand the communication process at all (Exkorn, 2005; Sicile-Kira, 2003; Stone, 2006).

The third aspect in the triad is that of restricted and repetitive behaviours and activities. Autistic Spectrum Disorder children often have an overwhelming, all-consuming preoccupation with one interest area, and may display repetitive non functional routines and motor behaviours. These preoccupations are extreme in intensity, and may include fixations, routines or behaviours such as lining up toys or objects, flapping hands, spinning in circles,

rocking or self-stimulating, and injurious behaviour such as banging their heads. These repetitive actions are known as stereotypies. Any alteration to routine is frequently met by hysteria. ASD individuals are often highly sensitive to touch, taste, smell, sights and textures (Exkorn, 2005; Sicile-Kira, 2003; Stone, 2006).

Although not part of the triad of impairments, another common characteristic of ASD children is sleep difficulties. These children often have irregular sleep patterns and sleep only for short periods of time (Exkron, 2005; Sicile-Kira, 2003). The American Society of Autism (Harvard Mental Health Letter, 1997 cited in Taylor, 2006, p.10) further describes Autistic children as being unable to

maintain eye contact and seem barely able to distinguish their parents from strangers. They ignore other children and prefer repetitious, solitary play, such as staring at revolving objects or arranging things in meaningless patterns. They may repeatedly lay out objects in lines, sit quietly watching sand dribble through their hands for hours, or spin in an apparent trance-like state.

2.1.5 Prevalence of Autism

Autistic Spectrum Disorders, although once considered to be rare, seem to be increasing in prevalence (Sicile-Kira, 2003). The notion of a spectrum of Autistic disorders is one of the possible reasons for the increase in prevalence rates. Due to the idea of a continuum, more subtle displays of ASD can be seen within the triad of impairments, which may lead to an ASD diagnosis. Another possibility is that due to a greater awareness of Autistic Spectrum Disorders, many children previously diagnosed with mental retardation and learning disabilities have now more appropriately been diagnosed with an ASD. This possibility is

supported by a statistical decrease in these other areas of disability over the period of years that the prevalence of Autism has increased (Lillienfeld & Arkowitz, 2007).

The exact prevalence rate varies across studies, but more children are affected by an ASD than cancer, cystic fibrosis and multiple sclerosis combined (Dean, 1999). According to Rapin (1994, p.98), prevalence rates of Autism make it “one of the most common developmental disabilities”. Studies place the incidence rate of ASD at 15 to 40 per 10 000 births: “ASD’s have recently risen to epidemic proportions... Yet there still seems to be a lack of knowledge on this subject” (Sicile-Kira, 2003, p.xv). Research in America revealed that over the 10 year period from 1993-2003; there was a 657% increase in the nationwide rate of Autism (Lillienfeld & Arkowitz, 2007). As ASD is a disorder that knows no racial, economic, social or cultural boundaries, South African prevalence rates may be expected to be the same. These statistics have caused many educators and researchers to suggest that there may be an Autism epidemic (Lillienfeld & Arkowitz, 2007); however the reasons for this remain speculative. Although there are as yet no explanations for gender difference, the prevalence of this disorder is four times higher in boys than girls (Relph, 2006; Sicile-Kira, 2003).

2.1.6 Aetiology

There are a variety of theories regarding the aetiology of ASD’s. These range from concerns about the impact of MMR vaccines to notions of ‘Refrigerator Mothers’ (Sicile-Kira, 2003). These are outlined below.

Many parents have claimed that the first signs of an ASD in their child appeared after having the measles, mumps and rubella series of vaccine (MMR vaccine), or any vaccine containing

Thiomersal (Thimerosal in the United States), a preservative that contains traces of mercury (Lillienfeld & Arkowitz, 2007; Sicile-Kira, 2003). The link between Autistic Spectrum Disorders and the MMR vaccine was first investigated and published in 1998 by Andrew Wakefield, a British Gastroenterologist and his colleagues, and consisted of a study of 12 children who displayed symptoms of Autistic Spectrum Disorders shortly after the MMR vaccine was administered. (Lillienfeld & Arkowitz, 2007). Although public interest soared after these research findings, there is little evidence for this theory, and despite some governments prohibiting any vaccine with mercury traces, Autism statistics have continued to increase (Lillienfeld & Arkowitz, 2007). There remains much debate amongst medical practitioners concerning the validity of this theory; however it is agreed that more research is needed regarding the relationship between the MMR vaccine and Autism (Sicile-Kira, 2003).

Over the years other theories have emerged with regard to causation. One such theory was popularized by Brunno Bettelheim, a Hungarian psychotherapist, in the 1940's. According to Bettelheim, the cause of Autism could be linked to his 'Theory of Refrigerator Mothers' (Sicile-Kira, 2003). This theory alleged that the basis of Autism could be found in a mother's cold and detached nature, unresponsiveness and inability to connect with her baby.

Bettelheim also considered Autism to be a mental illness, not a developmental disability, and as a result many Autistic children were institutionalised and treatment options for these individuals remained limited (Bettelheim, 1967). The 'Refrigerator Mother' theory was widely accepted, but eventually placed into disrepute after two decades (Sicile-Kira, 2003).

Since these early theories, the preferred theory regarding ASD has been strongly associated with genetics. Autistic Spectrum Disorders are neurological disorders which present immense substantiation for linkage to a genetic basis. However, Sicile-Kira (2003, p.30)

argues against attributing the dramatic rise in ASDs to an increase in genetic anomalies, and instead contends that “it appears there is most likely a genetic predisposition to Autism Spectrum Disorders, interacting with environmental factors that may play a key role in affecting the gastrointestinal tract, the immune system, the sensory nervous system and the brain”.

2.2 Issues in Diagnosis

2.2.1 Early Diagnosis: Importance and Difficulties

Early diagnosis, intervention and treatment of Autism is crucial. Not only is this a time when “the brain is still significantly strengthening and pruning neural networks”(Kraft, 2006, p.15), but findings also show that intensive early intervention can improve the overall prognosis for children with ASD’s (Exkorn, 2005; Fenske, Zalenski, Krantz & McClannahan, 1985; Harris & Handelman, 2000). In his research concerning behavioural treatment of ASD’s, Eikeseth (1999, p.1) reports that “researchers recommend that to maximise the effectiveness of the program, treatment should be started before the child is four years old.” Outcomes in the later lives of most ASD children can be enhanced if there has been early diagnosis and suitable interventions (Bristol, 1987). There is thus a strong evidence base to support the correlation between early intervention and better prognosis.

“Autism is not a dead-end diagnosis; early intervention does improve outcomes” (Stone 2006, p.32). However, despite much research on the importance of early diagnosis and intervention, parents still often wait years for an accurate diagnosis of ASD (Acosta, 2006; Drew et al., 2002; Eikeseth, 1999; Kraft, 2006; Mooney et al., 2006; Siklos & Kerns, 2005; Wetherby & Woods, 2006). Even with so much emphasis being placed on the importance of

early intervention, many children are only being diagnosed well after the age of three or four years (Charwarska, Klin, Paul & Volkmar, 2007; Exkorn, 2005; Young & Brewer, 2002), with the average age of diagnosis occurring at the age of six years (Mooney et al., 2006). Despite an official diagnosis only being made later on, most parents raise concerns regarding their child's development before the age of two years, with half of those noticing abnormalities within the first year (Volkmar, Stier & Cohen, 1985).

A study on high risk infants revealed that the first symptoms of Autism may be noticeable as early as six months, and that by one year ASD children may be displaying impairments in visual attention, eye contact, delayed speech and communication, and restrictions in reciprocal smiling and imitation (Robins, Fein, Barton & Green, 2001; Zwaigenbaum et al., 2005). In the second year, the symptoms are even more prominent and include a loss of language and social interests by the age of eighteen to twenty-four months (Goldberg et al., 2003; Lord, Shulman & DiLavore, 2004; Siperstein & Volkmar, 2004; Werner & Dawson, 2005). Mooney et al. (2006, p.13) assert that "impairments in social and communication skills are probably the most reliable early features of Autism in children under 48 months of age." Acosta (2006) discovered an average delay of thirteen months between the first evaluation of a child and an official ASD diagnosis.

Given the importance of early diagnosis and intervention for improving longer term outcomes for children with ASD, there appears to be a critical void in current practice which allows multiple opportunities for interventions in these early years to be overlooked.

Reasons for the time delay are still unclear. However, Acosta (2006) maintains that paediatricians report being unfamiliar with existing evaluation tools and do not have time for

screening. She further reports that of the 225 doctors surveyed in her study, only 8% tested their patients for Autistic Spectrum Disorders. Although screening tools are relatively new measures for assessing the presence of an Autistic Spectrum Disorder (Acosta, 2006), Eaves and Ho (2004, p.112) contend that “specific screening tools may not matter as much as having professionals in the community who are capable of identifying developmental differences between these children and their typically developing peers”. Taylor (2006) highlights that as ASD’s have no pronounced physical symptoms, symptoms often do not become apparent until the child reaches an age where social interaction typically occurs, which adds to the delay of early interventions. Furthermore, the language and social skills (or deficits therein) necessary to determine whether a child is diagnosable with an ASD may not present or be able to be assessed in very young children (Mooney et al., 2006). Thus, although it seems that making an accurate diagnosis of an ASD in young children is difficult, there remains enough evidence that a stable and reliable diagnosis can be made in children under the age of 3 years (Goldberg, et al., 2003; Gray, 1995; Lord et al., 2004; Mooney et al., 2006; Schall, 2000; Siperstein & Volkmar, 2004; Werner & Dawson, 2005).

2.2.2 Early Diagnostic Tools

When considering diagnosis of an infant, there is no prototype personality to compare against. Some children are quiet, and considered by their parents to be ‘angels’, while others as infants are ‘screamers’. Still others behave as any neurotypical infant (Exkorn, 2005). Yet there are a handful of diagnostic tools which caregivers, parents and paediatricians are able to use to identify early warning signs. The National Institute of Mental Health (NIMH) proposed that some possible indicators include characteristics such as not speaking by 16 months of age, not responding to their names, avoiding eye contact and not smiling (Refer to

Appendix A). These are all behavioural and social signs that are likely to be picked up by parents of young children who have an ASD (Exkorn, 2005).

According to Exkorn (2005), additional signs to note may be young toddlers who are not able to imitate actions or later to follow simple instructions. A toddler may also possess echopraxia (imitating and repeating exact actions of others without having an understanding of what they are doing).

A more commonly known checklist used is the M-CHAT: Modified Checklist for Autism in Toddlers (Robins et al., 2001). This is a yes/no questionnaire for parents (Refer to Appendix B) which identifies common behavioural and social characteristics of ASD children. It is followed by scoring instructions, and parents are encouraged to seek further assistance from their doctors if they are concerned (Robins et al., 2001).

The above are two examples of a number of early checklists that illustrate the availability of diagnostic tools. However, in order for these tools to be effective, the education of doctors and parents regarding Autistic Spectrum Disorders is necessary. A thorough knowledge and awareness of ASD's may enable diagnosis to occur far sooner, thereby allowing the time for the valuable window of opportunity for intervening with ASD children. It may also assist in partially relieving parental stress felt during the months and years leading up to a diagnosis.

2.2.3 Research into Diagnostic Processes

Many quantitative studies have investigated the area of Autism diagnosis. Mansell and Morris (2004) conducted a postal survey in the United States of America (USA), investigating parents' attitudes toward, and the impact of, an ASD diagnosis. They

discovered that parents had both positive and negative experiences, but many were frustrated by the delays in diagnosis and the attitudes of public services such as health and education. Comparative studies in the USA have shown that ASD children who receive intervention earlier than peers have significantly better outcomes (Fenske et al., 1985; Harris & Handelman, 2000). In their multi-country survey (America, England/ Ireland, Canada and Australia/ New Zealand), Goin-Kochel et al. (2006) concluded that parental satisfaction increased with fewer professionals seen prior to diagnosis and the younger the age of the child at diagnosis. Other quantitative research conducted in British Columbia found that an ASD diagnosis was delayed for approximately three years, and that parents visited an average of 4.5 health practitioners before receiving an accurate diagnosis (Siklos & Kerns, 2005).

As described above, much of the research to date has taken place in Europe and the USA, and there is little qualitative research regarding diagnostic experiences. There is therefore a need for qualitative insight into the diagnostic experience from a South African perspective. A qualitative study may provide a more empathic insight into the complex experience of parents and could be used as a psycho educational tool for others facing a similar experience. The rich descriptive picture that emerges from a qualitative approach may highlight where diagnosis can be enhanced and what interventions are required to improve early diagnosis for ASD children.

2.3 Impact on Parents and Families

2.3.1 Parents' Experiences

Although few studies have had a qualitative focus, there have been some which have attempted to focus on the experience of parents. One such study was conducted by Glass

(2001) who interviewed six parents of Autistic children and used observational data. He reported that the effect of an Autistic child on a family can be an extremely stressful experience for many parents. Glass (2001, p.3) states with regards to this that

childhood is a demanding and challenging period for all parents, and when a child has a problem, the demands and challenges are magnified. When the problem is Autism, one of the most devastating and least understood mental disorders of childhood, it is hard to imagine how parents and siblings cope.

Shacar (2006) and Eaves and Ho (2004) conducted studies on the impact and experiences of families in the process of receiving ASD diagnoses. Shacar's study consisted of archival data collected from 85 parents during focus groups conducted in the USA. Although the original study was conducted with the aim of developing parent training programmes for ASD children, Shacar used the elicited information to research parents' experiences, and found that parents undergo a significant amount of stress during the diagnostic process. The Eaves and Ho (2004) study consisted of an eighteen question screening questionnaire, conducted on 49 children aged 2 years. The study was conducted in order to assess ASD screening tools for very young children. Layne (2007) reviewed this research and further discussed the impact of an ASD diagnosis on families. Research such as this indicates that valuable time in terms of early intervention is lost in the lengthy process of diagnosis of an ASD.

Another vital aspect for consideration is the impact of this time period on families, especially on parents. Families suspecting an abnormality with their child endure significant stress and anxiety awaiting a diagnosis, without any clear answers or indications of treatments to search for. During this time of uncertainty, they also undergo long periods of waiting for appointments with specialists, as well as often experiencing the stress of the financial burden

of medical assistance and testing which the child undergoes (Layne, 2007; Shacar, 2006). A supplementary stressor on the family may be the ASD child's behaviour, involving tantrums and aggressive, self-injurious, repetitive or other behaviour which, without a diagnosis, may be difficult for the family to understand (Layne, 2007). Research additionally indicates that there tend to be higher rates of alcoholism in families directly influenced by an Autistic individual (Miles, Takahashi, Haber, & Hadden, 2003). Furthermore, a study by Wolf, Noh, Fisman and Speechly (1989) reported that stress levels of parents with Autistic children were higher than those of neurotypical and even Down syndrome children. Studies on mothers of ASD children reveal that they often report "significantly higher amounts of stress, more depressive symptoms, higher feelings of incompetence as parents, and less marital satisfaction when compared with mothers of nonhandicapped children" (Rodrigue, Morgan, & Gelfken, 1990, p.371).

2.3.2 The Grieving Process

Many of the studies described above concur that parents of children who have an Autistic Spectrum Disorder experience a wide range of emotions following diagnosis, including anger, fear, frustration and guilt (Gray, 1994; Holmberg, 2007; Mindence & O'Neill, 1999; Nicoll, 2004a; Riddle, 1987). Riddle (1987) states that some parents even report experiencing the five stages of grief (Kübler-Ross, 1969) that typically follow death or loss of a loved one or thing.

According to Kübler-Ross (1969), these stages can apply to any form of loss in an individual's life, and include denial, anger, bargaining, depression, and finally acceptance. Closely linked to these emotions experienced during loss is a sense of helplessness and hopelessness (Kübler-Ross, 1969). Parents of a child diagnosed with an ASD experience

similar reactions to the process of bereavement, not systematically, but as a cycle, and they experience these emotions continually at different times (Sicile-Kira, 2003). Although parents may never completely reach acceptance, they tend to progressively spend greater amounts of time in this phase (Sicile-Kira, 2003). The emotional states that parents of ASD children seem to experience are depicted in the diagram below.

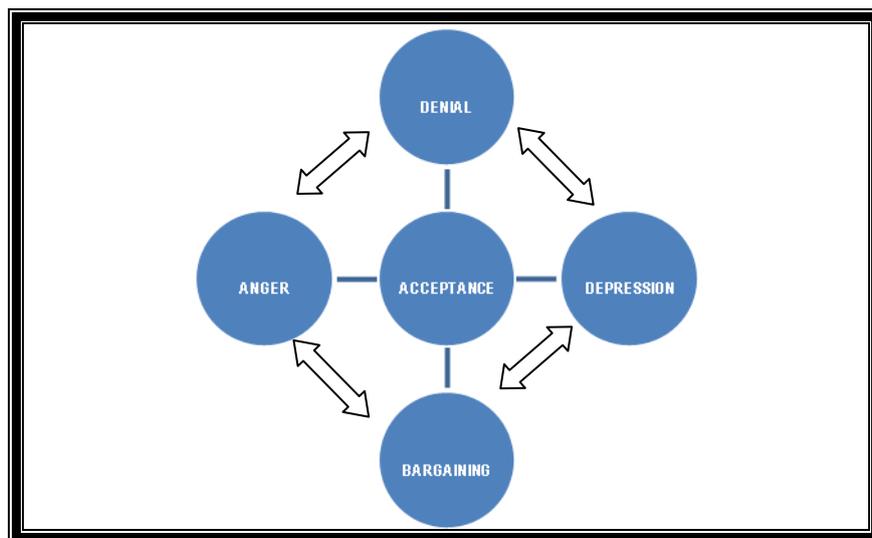


Figure 2.1: Emotional states experienced by parents during and after the process of diagnosis of an ASD

2.3.3 Depression and Stress

Research indicates that parents of children on the Autism spectrum may endure more stress than parents of children with any other disability (Schieve, Blumberg, Rice, Visser & Boyle, 2007).

Further research suggests that after an ASD diagnosis, parents’ “quality worlds collapse - they pictured healthy and full of life children in them and now these pictures are slowly being replaced by pictures of ‘disabled’, ‘Autistic’, ‘challenging’, ‘unmanageable’ children” (Trigonaki, 2002, p.13). Holmberg (2007) indicates that parents seem to find it difficult to cope with the stress involved in raising an ASD child as it affects numerous aspects of their

lives. Mothers in particular seem to experience a significant degree of guilt and depression following the diagnosis. Although sadness seems to be a common emotion experienced by most parents whose children are diagnosed with an ASD, some even become clinically depressed (Gray, 2003).

2.3.4 Broader Family Impact

There is much evidence that an ASD child significantly impacts upon neurotypical siblings (Bagenholm & Gillberg, 1991; Hastings, 2003; Kaminsky & Dewey, 2002). Rivers and Stoneman (2003) conducted a study on the connection between sibling relationships, marital stress, and coping in families where there had been an ASD diagnosis. Their study took the form of self report inventories and questionnaires completed by both the neurotypical sibling and a parent from each family in order to capture multiple perspectives of these relationships. Fifty families were involved in this study. The study revealed that amongst families where there is an ASD diagnosis there is a diverse variety of sibling relationships. They hypothesized that this diversity could possibly be understood in terms of the Family Systems Theory (Minuchin, 1974). According to this theory, children form a part of certain systems, including their family and other possible support sources, such as their school, church, community etc. Each individual within the system is interconnected and interdependent, and the family is seen as one emotional unit, with each part affecting the other. This theory presupposes that the functioning of the systems in a child's life directly impact upon each other and the child (Broderick & Smith, 1979; Bronfenbrenner, 1979). Thus, if a family is able to cope effectively with the stress of having an ASD child and the process of diagnosis, the impact upon a sibling will be less severe. If additional support is received from other systems outside of the family, the effect upon a neurotypical sibling may even be experienced as positive.

Cohen (1998) indicates that families cope better when their support networks are stronger. This support may come from a variety of sources, including grandparents, friends, extended family, support groups or social services. According to Lazarus and Folkman (1984) accessing social support in fact becomes a focused coping strategy of many families. Much research has indicated that it is social support that determines positive outcomes for all families with children with disabilities, including Autistic Spectrum Disorders (Bristol, 1987; Bristol, Gallagher & Schopler, 1988; Dunst, Trivette & Cornwell, 1989; Factor, Perry & Freeman, 1990; Henderson & Van der Berg, 1992; Nissenbaum, Tollefson & Reese 2002; Roeyers & Mycke, 1995). The study by Rivers and Stoneman (2003, p.390), substantiated the hypothesis that “family stress originating in the marriage relationship was an important factor in the quality of sibling relationship”, once again confirming that the Family Systems Model can be an important means by which to view relationships between family members where there is an ASD child. It has also been suggested that in families where children have disabilities such as ASD, siblings of these children may be especially sensitive to conflict within the home (Nixon & Cummings, 1999).

2.4 Conclusion

The above section has given an overview of definitions and characteristics relating to Autistic Spectrum Disorders. It has discussed difficulties and delays in the diagnosis of an ASD, and the impact that these have on parents and families with ASD children. It is hypothesized that reasons for delays may be due to lack of knowledge of ASD's and early diagnostic tools available. Although the importance of early intervention is emphasized in the literature, it is evident that there remains a dearth of research on diagnostic issues and intervention. In particular, there is an absence of qualitative studies tapping into the unique experiences of

parents in learning about and managing a diagnosis of ASD in their child. This study aims to address this gap by qualitatively exploring parents' experiences within the South African context.

Chapter 3 **Research Design and Methodology**

This chapter outlines the aims and design of the study, sampling techniques and data collection methods. It highlights ethical issues and discusses difficulties encountered in data collection.

3.1 Research Questions

The main research question in this study was: “What is the experience of South African parents of obtaining a diagnosis of ASD for their child?”

The study focused on the following questions in order to obtain a detailed picture of this experience:

- How did the family cope before the diagnosis?
- What was the time delay between when parents first had concerns and when a diagnosis was made?
- What was the process by which parents came to learn that their child had an ASD?
- How was a diagnosis made?
- Who made the diagnosis?
- How did the family cope after a diagnosis had been made?
- How has the diagnosis/lack of diagnosis affected the siblings?
- How has the diagnosis/lack of diagnosis affected the marital relationship, from the parents’ perspective?
- What advice do parents of ASD children have for other parents regarding the diagnostic process?

3.2 Research Design and Aim of Study

This study aimed to gain an understanding of and insight into the subjective experiences of the process of diagnosis of parents who had an ASD child. As the study was descriptive and exploratory in nature, aiming to tap the richness of parents' experiences, a qualitative interpretive design was therefore considered most appropriate. The qualitative design utilized in this study employed individual interviews which were used to gather information about parents' experiences on the road to diagnosis.

According to Mouton (2003) the researcher using qualitative research attempts to understand people through their own definition of the world. Participants' experiences are understood in terms of subjective means, and this understanding is sensitive to unique frameworks within which individuals may function.

Data were studied from an interpretive perspective, which enabled the researcher to interpret with empathetic understanding (Terre Blanche et al., 2006). This method of interpretation involved taking people's subjective experiences seriously and making meaning of them by interacting and listening to them (Terre Blanche et al., 2006). Using an interpretive perspective, the researcher worked towards finding meaning and uniqueness by engaging in the intricate networks of relationships within the experience of an ASD diagnosis. The data gathered consisted of parents' subjective accounts in the years preceding and following their children's diagnosis of an Autistic Spectrum Disorder.

3.3 Research Methodology

3.3.1 Sample

The sample for this study consisted of parents of children who have a diagnosis of ASD. A purposive and a non-random sample was used. Non-probability purposive sampling was used because the study required a particular population that has been through the experience that is the subject of inquiry. Therefore parents who have a child who has received a diagnosis of ASD in the last five years were eligible to participate. In some instances, snowball sampling was used to locate participants, as parents of ASD children are often not easily accessible without a contact person. Five of the participants were recruited in this manner, beginning with a mother who ran a support group. Parents were recruited from Durban-based ASD support groups, and a local home-run educational facility in Pietermaritzburg. Details of the research were provided to group leaders, who then invited interested parents to contact the researcher to volunteer for the study. A total of seven parents were recruited for the study. One father chose to join in on the interview process, bringing the total number of participants to eight. Participant details are illustrated in table 3.1.

The process of sampling to saturation was employed in this study. According to Terre Blanche et al. (2006, p.372), saturation refers to “the condition of an interpretive account where the account is richly fed by the material that has been collected”. This point occurs when the researcher feels that the data has been carefully explored and that they have a reasonable idea of the topic being researched and its processes. The decision was thus made to end the sample after interviews with seven mothers and one father, when information extracted from interviews with the participants was, apart from minor differences, being repeated and reiterated.

Table 3.1: Participants' details

Pseudonyms Parents	Pseudonym Child	ASD diagnosis	Child's age	Marital Status	Siblings
Sandra & Peter	Martin	Autism	9 yrs	Married	Older brother
Kirsten & Adam	Tammy	Autism	4 yrs	Married	Older Brother
Joanne & Chris	Gary	Asperger's	12 yrs	Married	Younger brother
Michelle & Dave	Timothy	Autism	9 yrs	Married	Older brother (Asperger's)
Julia & Glen	Patrick	Autism	8 yrs	Married	Only child
Carmen	Bryce	Asperger's	9yrs	Divorced	Older brother
Lydia	Gavin	Asperger's	7yrs	Married	Older brother

3.3.2 Procedure

Data were collected by means of interviews with parents of children who had been diagnosed with an ASD in the past five years. These ASD's ranged from Asperger's Syndrome to various degrees of Autism. Seven of the eight ASD children whose parents participated were boys. A total of eight parents were interviewed, all of whom were between the ages of 30 and 45 years old. Mothers readily volunteered for the interviews; however one father chose to be involved and answered questions alongside his wife. Interviews took place during January and February 2008.

Appointments were made telephonically with parents two weeks prior to the scheduled interview dates. An explanation of the research study and the participant's role in the study was explained telephonically before the appointment times. Individual interviews took place at participants' homes and were recorded by a digital dictaphone.

Before the interviews began, an informed consent process was explained and participants signed consent forms (Refer to Appendix C). Aspects of beneficence, confidentiality and nonmaleficence were explained to them. Open ended questions were used within the interview process. The decision to use open ended questions was based on this study being exploratory in nature, as this kind of questioning "allows respondents to communicate their experiences or opinions about a specific issue in their own words, without any restrictions" (Terre Blanche et al., 2006, p.486). Due to the diversity and sensitivity of the nature of this research topic, open ended questioning also allowed the participants to regulate the details and depth of experiences they shared. The interviews lasted 50 to 70 minutes. The interview schedule is attached in Appendix D.

During one of the interviews, technical difficulties were encountered with the recording device. Notes were jotted down immediately after the interview, detailing as much information as possible.

3.4 Data Analysis

The recorded interviews were transcribed and the data were analysed using thematic analysis of the transcriptions. Thematic analysis was an appropriate technique for this study as it provided descriptive data (Boyatzis, 1998) and a rich picture of the experiences of the process

of arriving at a diagnosis for parents of ASD children. The steps followed in the interpretive data analysis for this study were those laid out in Terre Blanche et al. (2006).

3.4.1 Data Management

The initial stage of data analysis involved the verbatim transcription of interviews from the recordings. On completion of data collection, transcripts were saved electronically in a single data base.

3.4.2 Familiarisation and Immersion

The second stage involved familiarisation with the data. This was achieved within the transcription process, by further reading and re-reading of transcriptions, and reflecting on the interviews. The aim was to become immersed in the data, and through the process of immersion to reach a deeper understanding of the text and language usage. During the familiarisation stage, memos were recorded, key ideas were highlighted, and emerging codes were noted.

3.4.3 Inducing Themes and Coding

The coding process was finalised through immersion in the data. Emerging themes were identified and recorded. Through working so closely with the data, unexpected themes and key ideas were elicited. An example of the colour coded thematic excerpts is provided in Table 3.2.

Table 3.2: A worked example of the generation of themes from the data

Initial code	Raw data	Emerging theme
<ul style="list-style-type: none"> • Early signs • Concerns dismissed • Developmental 	<p>“we knew there might be something wrong but everyone said, oh when he goes to school he’ll be fine, don’t worry about it, he’ll be fine. ...no don’t worry, it’s cause he’s an only child, he doesn’t really need to speak because if he points to that, you know he wants juice, or wants milk. Once he goes to school, he will speak, so don’t worry about it, he’ll be fine”.</p>	<ul style="list-style-type: none"> • Misdiagnosis- Global developmental Delay
<ul style="list-style-type: none"> • Developmental • Terminology 	<p>“He said, mum, he’s going to grow out of it. It’s a developmental delay and he’ll be fine by the time he’s five. There was a delay, and they call it a global developmental delay for quite a long time, and then I noticed on the Physiotherapists report she’d put PDD, and I didn’t know PDD, and I didn’t know that PDD is Autism”</p>	<ul style="list-style-type: none"> • Unwillingness of professionals to give diagnoses • Misdiagnosis- Global developmental Delay
<ul style="list-style-type: none"> • Developmental • Early signs • Intuition 	<p>“A lot of people said to me, “They’re all different, they all reach their milestones at different stages” but as a mother you have a gut feel, and that’s when I started asking questions”</p>	<ul style="list-style-type: none"> • Misdiagnosis- Global developmental Delay • Early signs
<ul style="list-style-type: none"> • Concerns dismissed • Developmental 	<p>“No there’s nothing wrong, there’s nothing wrong. He’s got all his milestones, he’s fine. A slight global delay perhaps but nothing to worry about”.</p>	<ul style="list-style-type: none"> • Misdiagnosis- Global developmental Delay

3.4.4 Elaboration

The codes identified were organised into emerging themes, which encapsulated the codes.

These themes were elaborated on through re-reading the data for other ways in which this theme may have been raised; deviant cases were also identified or explored.

3.4.5 Interpretation and Checking

The themes were organised into a conceptual map, which ultimately illustrated the chronology of the process of obtaining a diagnosis. These themes were checked against the existing literature and new emerging themes from this study were identified.

3.5 Credibility and Trustworthiness

Accusations of poor reliability and validity are often levelled at qualitative research studies. According to Lincoln and Guba (1985), there are four criteria of design validity and reliability to take into account when doing qualitative research. These criteria are further highlighted by Trochim (2006) and are: credibility, transferability, dependability and confirmability.

3.5.1 Credibility

Credibility involves establishing whether or not the results of qualitative research are believable. As the research objective was to understand experiences from the participants' perspective, and the method allowed the emergence of these experiences from the participants' point of view, credibility of the study was attained. Furthermore the results of this study were consistent with those of other researchers, both from quantitative and qualitative perspectives.

3.5.2 Transferability

This aspect refers to the extent to which the results of the research can be transferred to other situations. The possibility of transferability is enhanced by the researcher thoroughly describing the research situation and the suppositions that were fundamental to the research.

These are clearly highlighted in this study such that the design used in this study could be transferable to other contexts and yield similar results. There are some concerns regarding the nature of the sample selected and these are discussed in the limitations section of the study.

3.5.3 Dependability

Dependability relies on the researcher to thoroughly document each change that may have occurred within the research setting and how these may have affected the research material. Difficulties in the research process and changes within the data collection settings were taken into account by the researcher in the analysis phase of the study. Aspects such as interferences by children, quietness of setting, atmosphere of setting etc. may all have impacted upon material and these factors were considered by the researcher.

3.5.4 Confirmability

Confirmability refers to the degree to which other researchers would be able to apply the same methods and confirm the research results. This can be enhanced by the researcher thoroughly documenting all processes for interacting with the data. The researcher can also check for contradictory information within the research material, and conduct a data audit. A data audit would examine methods of data collection and analysis for partiality or misrepresentation (Trochim, 2006).

In terms of an audit trail for this study: the research procedure, methods and data analysis process have been explicitly described. The excerpts quoted in this thesis were all extracted from a digital dictaphone recorder and repeated verbatim. Transcripts used were coded in

terms of participants' pseudonyms and line numbers of the transcripts. E.g. Sandra, line 45-52. Transcripts were stored in computer files coded with passwords.

In considering the credibility and trustworthiness of this study, it should additionally be noted that rapport was established with participants through in-depth, detailed interviews. The use of open ended questions allowed the participants to contribute as much as they felt able to, and share their experiences in a comfortable and open manner. There were no time limits to interviews. It is anticipated that this may have added to the creation of a relaxed environment where the possibility of the credibility and trustworthiness of data collected may have been increased.

3.6 Ethical Considerations

Due to the sensitive nature of this research topic, ethical considerations were deemed of particular importance. According to Wassenaar (2006), there are four ethical principles which guide research. These principles were upheld and followed during the process of data collection.

3.6.1 Informed Consent

All participants were recruited on a voluntary basis. The purpose of the study was explained to them when they were first approached, during the initial contact telephone call. According to Gregory (2003) one of the main ethical concerns of research is that of informed consent. Each participant signed consent before the interview, which included consent to record the interview.

3.6.2 Confidentiality

All participants and their children's names have been held in confidentiality and pseudonyms are used in this thesis. This was clearly explained to each participant before the interviews were held. In order to protect the anonymity of participants, codes were assigned to electronic data files and unlinked to identifying information. These files are stored on a password protected computer. They will be kept for a period of five years and thereafter will be destroyed.

3.6.3 Beneficence

Although this study did not directly benefit the participants, it was hoped that the study would highlight where diagnosis can be enhanced and what interventions are required to improve early diagnosis for ASD children. The lack of potential direct benefit was explained to the participants as part of the informed consent procedure.

3.6.4 Nonmaleficence

Although it was unlikely that the nature of the study would harm the participants in any way, the subject matter of the data collected was potentially of a sensitive and painful nature, and it was anticipated that some emotional distress or discomfort could occur. The researcher, being a trainee psychologist under the supervision of a registered psychologist was sensitive to and aware of these issues. Although it was not required, should it have been necessary, participants would have been directed to available support and counselling services after the interview. They were provided with contact details for the above. Interviews were conducted in participants' homes, where they were able to feel more relaxed and contained while sharing experiences.

3.7 Conclusion

The aim of this chapter was to discuss the methodology of this study. It has addressed the decision to conduct a qualitative and exploratory study, which enabled a more in depth and sensitive look at parents' experiences of the diagnostic process. This chapter further details the process of data collection and analysis. It discusses the research design, sample and all ethical issues relating to this study.

Chapter 4

Results

This chapter presents the results of the study. Demographic information has been presented first, followed by details of diagnostic issues. Themes and sub-themes from these issues, which emerged during the course of the interview process and the analysis of data collected via transcripts, are presented in a chronological manner, i.e. what parents reported they experienced prior to learning the diagnosis, the diagnostic process and finally the aftermath of learning the diagnosis. During the interviews the participants also made recommendations for how the system could be improved, these are also provided below.

4.1 Demographic Information

Table 3.1 represents pseudonyms for the participants and their children involved in this study. Pseudonyms for participants' husbands have been provided for those who have been made reference to in the study. The table also provides the children's diagnoses, and their current ages. Only one child in this study was below the age of five, and the majority fell in the middle childhood age bracket from 7 to 12 yrs of age.

The marital status of the parents is also listed, as well as details of any siblings in the family. Six of the seven participants had one other child, besides the ASD child, and one of the children in this research study was an only child. Of the six siblings, five were older, and only one sibling was younger. Five of the siblings were neurotypical, with one sibling having been diagnosed with Asperger's Syndrome.

Table 3.1 (Repeat): Participants' details

Pseudonyms Parents	Pseudonym Child	ASD diagnosis	Child's age	Marital Status	Siblings
Sandra & Peter	Martin	Autism	9 yrs	Married	Older brother
Kirsten & Adam	Tammy	Autism	4 yrs	Married	Older Brother
Joanne & Chris	Gary	Asperger's	12 yrs	Married	Younger brother
Michelle & Dave	Timothy	Autism	9 yrs	Married	Older brother (Asperger's)
Julia & Glen	Patrick	Autism	8 yrs	Married	Only child
Carmen	Bryce	Asperger's	9yrs	Divorced	Older brother
Lydia	Gavin	Asperger's	7yrs	Married	Older brother

4.2 Experiences Leading up to Diagnosis: Quantitative Findings

4.2.1 Number of years and medical professionals required to make a diagnosis

Figures 4.1 and 4.2 represent the number of years that were taken before a diagnosis of ASD was made, and the number of professionals involved in the diagnostic process for each child.

Participants involved in the research revealed that on average it had taken 7.2 medical practitioners and 3 years 3 months to reach an accurate ASD diagnosis.

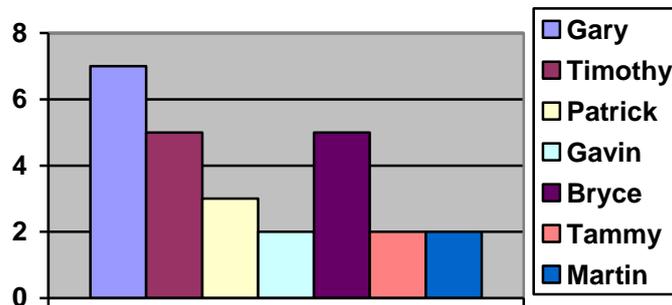


Figure 4.1: Number of years taken to make an ASD diagnosis

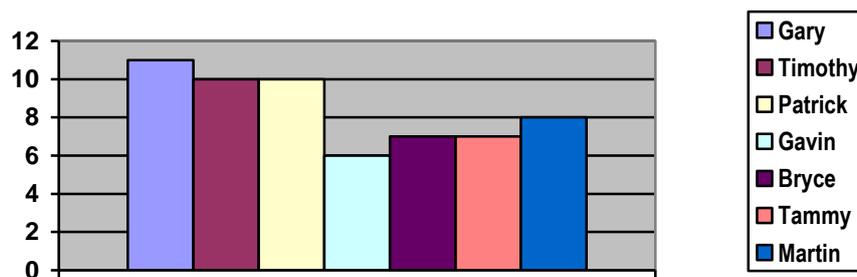


Figure 4.2: Number of medical professionals taken to make an ASD diagnosis

Although these numbers seem to be consistent with research from the USA and Europe, it remains unclear as to why these figures are so high. Many participants highlighted the need to educate medical practitioners as a possible means of reducing these figures.

After Michelle’s extensive search for information, which led her as far as Texas and the United Kingdom (UK), she received many enquiries from companies, concerned parents, and even doctors on issues relating to ASD. Julia’s General Practitioner admitted to her that ASD’s are not an area sufficiently covered in a doctor’s education. She also advised parents

who were concerned about their children, not just to go to a doctor, but rather a specialist in the field, who may have more knowledge. Kirsten disclosed that her paediatrician still does not have an adequate enough knowledge of ASD's to diagnose her daughter's condition.

“But to this day (the paediatrician) will not say she is Autistic, he doesn't know what it is. None of them will really put their head on a block and say this is exactly what it is. ”

For Sandra's paediatrician, the immediate answer was to refer to another paediatrician, as he was unable to diagnose her son's condition. This in turn led to a number of referrals, as the lack of certainty amongst paediatricians seemed to be great.

4.2.2 Types of professionals consulted

Table 4.3 indicates the types of medical practitioners and the number that the participants consulted in the course of their child's ASD diagnosis. These ranged from Neuro-Physiotherapists, to assessment inspectors, with the most frequent assistance being sought from paediatricians, closely followed by Speech and Language Therapists and Educational Psychologists.

This study indicated that the journey of diagnosis for most participants began with their general practitioners or paediatricians. From there it was a constant referral of 'hit and miss' situation, until a diagnosis was eventually given. All of the participants, at some stage of the diagnosis, consulted with Educational Psychologists. Speech therapists were also employed by all participants. Out of the seven, four had received Occupational Therapy for their ASD children. Some participants felt that it was worthwhile seeking the services of specialized Neuro-Physiotherapists and Neuro-Paediatricians.

Table 4.3: Medical professionals consulted

	Martin	Timothy	Patrick	Gary	Tammy	Bryce	Gavin	Total
Paediatrician	3	1	1	1	2	1	2	11
Speech & Language Therapist	1	1	2	3	1	1	1	10
Educational Psychologist	1	2	1	3	1		1	9
General Practitioners			2	2				4
Occupational Therapist	1		1	1	1			4
Audiologists		1			1	1	1	4
Neuro-Paediatrician	1	1				1		3
Unspecified Psychologist		1	1			1		3
Neuro-Physiotherapist					1	1		2
Physiotherapist	1			1				2
Assessment Centres			1			1		2
Optometrists		1						1
Remedial Teachers			1					1
Psychiatrists							1	1
Assessment Inspectors		1						1
Sports Psychologist		1						1

4.2.3 Types of medical procedures used in the diagnostic process

Along the journey to diagnosis, all participants reported that their ASD children had undergone other types of medical assessments as well. These included Computed Tomography Scans (CT Scans), Magnetic Resonance Imaging's (MRI's), various blood and urine tests, Electroencephalography's (EEG's), and chemical tests. Joanne insisted that metabolic and chemical tests be done on her son, which proved to be of vital importance as he was then diagnosed with a rare metabolic disturbance known as LCAD (Long Chain Acyl-CoA Dehydrogenase), on top of his Asperger's diagnosis. LCAD can prove to be fatal if it is not controlled by strict diet. The most common medical assessments, involving four of the seven participants, were CT Scans and blood tests. Table 4.4 below provides details of medical procedures that ASD children in this study underwent.

Table 4.4: Medical assessments undergone during diagnostic the process

	Martin	Timothy	Patrick	Gary	Tammy	Bryce	Gavin
EEG					√	√	√
CT Scan	√	√		√	√		
MRI Scan			√	√			√
Blood	√		√	√			√
Urine			√	√			√
Chemical/ Metabolic				√			

4.3 Experiences Preceding, During & Following Diagnosis: Qualitative Findings

The themes that emerged during the interview process have, for the sake of ease of presentation of results, been classified according to pre diagnostic, diagnostic and post diagnostic stages of the discovery of participant children's ASD. These are summarized in a table at the end of this chapter.

4.3.1 Pre Diagnosis Experiences

“Extremely demanding, extremely needy, extremely frustrating”

Michelle

i. Early signs and other concerns

During the interviews many of the participants reflected that in retrospect, they should have noticed obvious signs in their children from a much younger age. However, due to their lack of knowledge on ASD's, they did not know any better. Kirsten noticed a lack of eye contact and shared attention, and Sandra reported early stereotypies in her child, as expressed in the excerpt below:

“Now that I know Autism we should have picked it up a lot earlier, when he was a toddler, or even a little baby- the way he'd sit, and pick for ants in the grass, or he'd pick blades of grass or he'd pick leaves off bushes one by one. I used to think he was such a good baby, he'd just sit there. But he's doing all these repetitive, having all these stims.”

Three participants reported that their child had or still has difficulties with sleeping; the resultant sleep deprivation had consequences in terms of their mood and their capacity to

cope. Although Julia's son is nine years old, he still sleeps erratically at night and wakes his parents up. She shared how this is a very tiring experience for both her and her husband.

"Even though it does put a strain on it because he sleeps so badly. Most children with Autism I know they have, so they sleep for two hours then he wakes up, then he comes to our bed, then its back again, wake up again, you get a bit tired, and still to this day he doesn't sleep through the night. He's nine years old and still can't go to sleep at night. ...it's exhausting."

Sandra's lack of sleep diminished her ability to cope and she became severely depressed, as revealed in the following extract:

"He was a shocking baby, he didn't sleep so he was up all night, and I didn't sleep because of that so I became quite severely depressed. So I don't remember a lot of it. I think mainly because for the first couple of years he didn't sleep at night and he just screamed the whole time, and I was so run down."

ii. Age of first concern

Although all but one of the participants' children were diagnosed after the age of seven, initial warning signs were far earlier. These were sometimes dismissed by the participants. However, for many, once the children began attending school, signs were immediately picked up.

Kirsten initially noticed signs immediately following the birth of her daughter, as she was battling to latch on during breast feeding. She became further concerned when her daughter seemed to have low muscle tone. Her investigation into a diagnosis began during the first few months of her daughter's life.

Sandra's husband first noted signs of concern in their son, Martin, around the age of one year. He became concerned at Martin's late development of babbling, and then walking. He also noted some 'strange behaviours'.

Carmen, Joanne and Julia all began to be concerned when their sons were around the age of three years. Julia realized that her son was not integrating with other children and that he had delayed speech. Joanne and Carmen became acutely aware of their sons' difficulties when they began attending preschool. Gary, Joanne's son, displayed strange behaviours of withdrawing when entering the classroom, and had a significant relapse in his speech at times. Recalling Gary's speech difficulties, Joanne commented,

"He'd speak English beautifully, and then he'd speak Greek, literally a foreign language. It was like garbled, totally garbled."

Carmen knew that there was a problem on Bryce's third birthday. She relayed that she had given both her sons the exact same birthday party, being 'The Menagerie'. This is made up of two women who bring interesting animals and talk to the children about them. Carmen watched both video recordings afterwards, and noticed how her oldest son had been completely engaged and interactive, yet Bryce had spent the afternoon caught up in his own world.

"... all he was doing was looking in his chip packet and eating his chips. That's when I knew something was very, very wrong."

iii. Unwillingness of professionals to give diagnoses

All of the participants interviewed in this study disclosed that, during the journey of diagnosis, there had been medical practitioners who had been unwilling to provide an absolute diagnosis of ASD.

Sandra and her husband proceeded along the diagnostic journey in confusion and uncertainty. She felt that if a medical professional could have given a diagnosis at an earlier stage, the process, including applying correct interventions, would have been far easier for the family.

*“What there isn’t available is that person to say, ‘OK, this is what your child seems to have.’
...Whereas if they’d said to us right at the beginning, we could have started hammering it straight away. Not one of those professionals will turn around to you and say, ‘Your child is Autistic’, because only a psychiatrist can give that official diagnosis and no one says to you, ‘I think you should take your child to a psychiatrist’. So it makes it harder.”*

Kirsten’s daughter, who is four years old and has all the signs of Autism, including no speech, is still unable to receive an official diagnosis from her doctor.

*“But to this day (the doctor) will not say she is Autistic, he doesn’t know what it is.
None of them will really put their head on a block and say this is exactly what it is.”*

Joanne experienced frustration in professionals’ unwillingness to provide a diagnosis. She felt that diagnosis really helped her understand her son and assisted with putting correct interventions in place, and would have valued this diagnosis at an earlier age. She felt that the first Educational Psychologist she went to was unhelpful in this regard.

“And they’re too slow in giving diagnosis and trying to help.”

Carmen reiterated the unwillingness and delay in professionals diagnosing her son with Asperger's, even though she felt they may have known.

"I think they knew, but they didn't know where on the spectrum he was, and no one was willing to say, 'this is a definite diagnosis'. No one wanted to say... 'This is a definite diagnosis', until he'd been undergoing therapy for a year, two years. It had to unfold, but the thought was there."

Julia and her husband, Glen, investigated Autism for two years on their own, believing that it was the correct diagnosis for their son, before a medical professional finally diagnosed him.

"...they didn't say anything about Autism, anything like that...in the meantime Glen and I started doing research on Autism on the internet, and thought, 'Well it definitely is', but nobody said anything...But it took us almost two years finally before somebody said, 'I think he does have Autism'."

iv. Misdiagnosis

Mothers' initial concerns were often thrown aside by medical practitioners, friends or family, and put down to a global developmental delay. Many participants were assured that their children would 'grow out of it', and encouraged not to compare as children were all different. Unfortunately, as mothers reflected later, this initial 'brushing aside of concerns' may have caused delayed diagnosis, which affected earlier intervention.

Julia's concerns were passed off as delays due to her son being an only child.

“...we knew there might be something wrong but everyone said, ‘Oh when he goes to school he’ll be fine, don’t worry about it, he’ll be fine...’ ‘No don’t worry, it’s ‘cause he’s an only child, he doesn’t really need to speak because if he points to that, you know he wants juice, or wants milk. Once he goes to school, he will speak, so don’t worry about it, he’ll be fine’.”

Sandra was initially told by one of the paediatricians with whom she consulted that her son was only experiencing a global delay. The physiotherapist noted ‘Pervasive Developmental Disorder’ (PDD) on a report a few years later, but did not mention or explain this to Sandra, prolonging the diagnosis further.

“...he said, ‘Mum, he’s going to grow out of it. It’s a developmental delay and he’ll be fine by the time he’s five’. There was a delay, and they called it a global developmental delay for quite a long time, and then I noticed on the Physiotherapists report she’d put PDD, and I didn’t know PDD, and I didn’t know that PDD is Autism.”

Kirsten felt all along that something was different in her daughter’s development; however she was told by friends and family to bear in mind children’s unique development.

“A lot of people said to me, ‘They’re all different, they all reach their milestones at different stages’ but as a mother you have a gut feel, and that’s when I started asking questions.”

Joanne was told during numerous visits to paediatricians that her son would outgrow his difficulties, and that she had no reason for concern.

“No there’s nothing wrong, there’s nothing wrong. He’s got all his milestones, he’s fine. A slight global delay perhaps but nothing to worry about.”

On numerous occasions Michelle was told by therapists, teachers and psychologists that her child had a severe behaviour problem, and it was recommended that he be placed on Ritalin.

Regarding the diagnoses offered, Michelle stated:

“...she felt he was a very angry and frustrated child... We then moved onto a Speech and Language therapist who said to Dave and I ‘No he’s ADHD’... So they recommended that he go on Ritalin, and I said ‘No’.”

Many ASD children experience sensory difficulties and Central Auditory processing difficulties. These diagnoses were offered to some participants as explanations for their child’s behaviours. Carmen was told that her son had Central Auditory Processing Disability. Julia was told by professionals that they expected that her son had a cleft pallet, many sensory problems and general delays. Joanne was also given the diagnosis of Sensory Integration Disorder and a slight Global Developmental Delay.

v. Perceptions of ASD and the lack of knowledge

Michelle and Sandra felt that society’s first thought about ASD’s was ‘Rain Man’, the movie where Dustin Hoffman plays a remarkably gifted Autistic man.

“You know as everyone will tell you, they’ve seen Rain Man and that’s the extent of it.”

Another myth experienced by participants, perhaps also arising from ‘Rain Man’, is the belief that every ASD person has a highly specialized talent or gift, and exhibits genius qualities.

This was acknowledged by Julia.

“...when you say to people your child has Autism and they can be highly intelligent and educated people and they say, ‘What is that again?’, or ‘Oh is he a genius, or does he rock all the time’.”

A lack of knowledge and understanding of ASD’s among individuals in society at times created difficult situations for participants. Julia felt that she was often ‘frowned upon’ by people who mistook her son’s ASD for bad behaviour. According to her, Patrick was:

“...classed as being naughty, ‘Just give him a smack, that’s all he needs is a good smack’...Then people look at you funny because your child is behaving differently and it was not easy...A lot of people don’t understand what it is, but they realize ‘OK there’s something, he’s not the same as the other kid’ s.”

Like Julia, Joanne also experienced people’s lack of understanding of her son’s behaviour. She found experiences, such as shopping, were particularly stressful for her.

Sandra had an unpleasant time when trying to board an overseas flight, and experienced staff as being very unsupportive due to a lack of knowledge of ASD’s. Michelle, like Sandra, also experienced a difficult time from a staff member on board an airplane. This experience highlighted the lack of knowledge of ASD’s amongst individuals in society.

“We had a flight recently where a steward asked my son if he would like something to drink and ...looks at me and goes ‘Ma’, and I looked up and said he would like such and such. ‘Why can’t your child tell me?’ I said because he doesn’t want to speak to you. So he says to my child, ‘Look at me’. He won’t look at him. He says, ‘Is he being rude to me?’ I said ‘The child is Autistic’. ‘Huh?’ And that’s the basis of a lot of people unfortunately.”

Kirsten reported a lack of understanding of ASD's was demonstrated in people's inability to know how to react to these children.

“Some think that if they ignore her, she'll go away and the other thing when you say Autism, you assume they know what you're talking about and they're too embarrassed to say, 'What's that'.”

4.3.2 Diagnosis Experiences

“At the time it was the end of the world”

Carmen

i. Average age of diagnosis

Information from this study indicated that the average age of participants' children when they received an ASD diagnosis was 6 years 3 months, ranging from 3 to 9 years of age.

Reflecting on the age of her son's eventual diagnosis, Julia stated:

“I wish it had been sooner but I just think people don't know enough about it in this country.”

ii. Advantage of a label

Although denial offers a protective function for many parents, all participants agreed that there were great benefits in knowing the diagnosis and having a label (The role of denial is discussed in more detail below). They were able to understand their children's behaviour and explain it to others. Some felt as if the diagnosis had brought enlightenment for them, and were overwhelmed with the relief that it brought.

Julia felt that not only did a diagnosis help her to explain her son's behaviour, but it also helped her and her husband know what the best therapies were to put in place. Since they have done this, Patrick has shown great improvement.

"We were happy to know what we were dealing with, because when you're in the dark you don't know. And that's more scary, at least you can be proactive..."

"And then from that moment, we started putting in all the right, go to ABA therapy, and all that type of thing, so we started with all of that. And I think once he had the diagnosis it was just easier because when you went somewhere and he did something strange then you could say, 'Sorry, but you know my child has Autism'."

Sandra reinforced the importance of having a name for the behaviours and delays her son had displayed in the years before diagnosis, and how this had made coping easier for her.

"And a lot of people say but you don't need a name. But you do, as a parent you do need a name. We were told a lot of times it's not necessary to have that name but it really, really is. It makes it a lot easier too, to explain to people, he has Autism."

For Kirsten, diagnosis brought clarity and understanding.

"You're not floundering in the dark thinking, 'What do I do, where do I go?' It's easier to be upfront with people and say, 'This is what she is, she's Autistic'."

Before the diagnosis, Joanne did not know how to deal with the behaviour that her son was displaying. The lack of understanding of what she was dealing with and what he was experiencing was a difficult situation for her.

“And I mean that for me was probably one of the worst because I mean people look at your child, meanwhile he was actually just out of control, this was long before diagnosis and I didn’t actually know how to deal with it so I just used to actually get him out of the shop. And it was terrible. But at least we got a diagnosis...”

She felt that without a diagnosis, her son would have been placed in a home for mentally disabled individuals. She shared how as a result of a correct diagnosis, she and her husband had been able to provide the correct educational stimulation and environment for him, in order that he could progress to the level he is at presently.

“...without that I think he would have regressed and regressed and regressed...But at least we got a diagnosis...We didn’t want to be hiding in the dark we wanted to know...”

Joanne felt extreme gratitude to the Educational Psychologist who eventually was able to give them a diagnosis, as it gave clarity and a sense of completion to all their unanswered questions.

Michelle was another mother who emphasized the importance of understanding that diagnosis brought.

“Everyone says to you ‘Oh, but he’s somewhere on the spectrum’, and you know you don’t tell a parent ‘He’s somewhere on the spectrum’, it means sweet nothing. You need to have, well we

needed to have, some parents probably don't want to know, but we had to know what we were dealing with and it's made the world of difference."

iii. Early intervention

Two of the participants in this research study, Julia and Sandra shared the importance of early intervention.

Julia emphasized this in the excerpt below:

"I think if we'd had a diagnosis sooner, we would have put a facilitator in sooner, because the minute we found our facilitator..., it was like day and night, like a switch was switched on. He suddenly was coping at school, he suddenly was talking at school, he was doing the work at school, and I think you know two years ago we could have done that. His whole Pre School he hardly did anything, he just sat there and when the teacher could help him she did. I wish it had been sooner...I feel if we had a facilitator in place then, and everyone knew what they were dealing with we could have made his Preschool a bit happier for him and not such a terrible experience everyday of his life, just dreading being there, and all the rest of it."

iv. Controversy of the MMR vaccine

One participant raised the issue of the much debated and controversial MMR vaccine. Julia believes that this may have been the trigger for her son's Autism. She reported that on his first birthday he still interacted with children at his party, had a large quantity of speech, and was able to tolerate loud noises. It was only after he had the MMR vaccine that regression began.

“He was fine on his first birthday. He had the MMR vaccine. I didn’t know all the controversy, none of us did, the sister said this is the best thing you must have it done, so we had it done. Cause he did have quite a lot of speech, and then it disappeared. I watched the video of his first birthday and he was very much involved. The nephews were there and he was jumping up and down and he was bashing away on this little bike he got and it was shrieking and squeaking. Now you go into a toyshop and he always asks, ‘Does this toy squeak?’, then you mustn’t squeak it. If he does it then its fine, but don’t you suddenly squeak it.”

4.3.3 Post Diagnosis Experiences

“It’s got to be a mistake...but it always comes back to the same thing”

Kirsten

i. Stages of grief

This study found that the diagnosis of an ASD leaves parents experiencing stages of grief and other powerful emotions before accepting their child’s condition. The researcher discovered that due to the significant effects of an ASD diagnosis, the journey of parents’ experiences does not end with a diagnosis, but continues for a great length of time thereafter, carrying with it many emotions and difficult stages for parents whose children have received such a diagnosis. Typical themes of bereavement and loss were revealed to the researcher during interviews with caregivers of ASD children. While discussing the emotions she experienced regarding her son’s ASD, Julia related the following:

“There are certain times when you see other people’s children doing certain things like playing in a cricket or soccer team. It’s almost sad in a way because you think well he won’t be doing that because we won’t be going off to watch him play cricket or soccer. You feel sad for him, almost for yourself, because he’s not going to go off and do that type of thing.”

Sandra experienced the process of bereavement significantly, and described her cycle of emotions as follows:

“I suppose I went through it worse than some other people. You see there’s always still that hope that it’s going to turn around. ..I still get angry; I get angry with people because they don’t realize what it’s all about. I get angry with people who come to me and say, and it happens a lot, ‘You were given this child for a special reason, God gave you this child for a special reason’.”

Sandra further described her feelings of loss, in the following statement:

“I’d like to do some travelling. You know friends of ours went to Belgium; we can’t do things like that. That we find very, very hard. We’ve lost a lot because it’s affected our whole family.”

In relation to the stages of bereavement, Kirsten described her experience and range of emotions as the following:

“...those phases of grief, denial is the first thing you go to. And then it was, there’s been a lot of anger towards it, I mean ‘Why? Why do we have to have a daughter like this? We took five years to have her, and she’s Autistic’. And that was a bit of a slap in the face. You get given these things in life and you don’t have a choice, she’s our child, no one else is going to care for her like us.”

- *Denial*

In this study, interviews with mothers revealed that denial was a common defence mechanism. Most mothers experienced denial for a prolonged period of time and it seemed to be a common defence strategy used by participants. This sense of denial is captured in the statements by Kirsten and Sandra.

Kirsten hoped that her daughter's diagnosis would somehow change or disappear.

"We were still in the state of denial, where it's something that will go away. And we felt that if we put her in this little school we felt that maybe the interaction with kids of her own age, would snap her out of it. But of course it didn't...you know you do go into a denial situation, so there was this niggle but I didn't ever think it was something that was going to be a permanent thing. I thought it was something that we could work at and it would go away. And maybe it is a protective mechanism, it's just something you do as a mother, as a human response to any kind of trauma, those phases of grief, denial is the first thing you go to."

Sandra felt that her period of denial had lasted four years.

"There's a lot of denial that goes on because first of all you don't think it will ever happen to you and secondly you don't understand it. It took me from three until he was about seven, until I started going, 'He's Autistic'."

- *Depression and stress*

A common response of mothers in particular in dealing with an ASD diagnosis and an ASD child's behaviour, is significant stress and even depression. Although all participants in this study experienced sadness at some point during the diagnostic process, two were diagnosed with clinical depression due to the stress involved in having an ASD child, and were placed on medication. Mothers in particular seemed to experience feelings of hopelessness and helplessness, closely linked to depression and powerlessness.

Sandra was one such parent who developed clinical depression and described how she initially fell apart under the overwhelming stress and the impact of having an ASD child:

“I didn’t sleep because of that so I became quite severely depressed. I just became severely depressed and I ended up going on anti depressants, I ended up going to a psychologist, and she was amazing, she really helped. But I don’t really remember it all because I was a wreck, an absolute wreck and just getting through day to day and the pressure of sorting out this child who was just crying all the time and had all these needs, and having my older son as well who was very vulnerable and trying to give him time as well.”

Carmen, like Sandra, was also placed on medication and diagnosed with anxiety and depression.

“I remember standing there and thinking, ‘Why are all these people standing there and having such fun, doesn’t everyone know that were all going to die?’ Then I thought ‘Shit, Carmen, you’re not well’. Of course one of the things of a depressive episode is these overwhelming thoughts of death. And it was overwhelming. I couldn’t talk to my husband because what would he have understood.”

Although Kirsten was never diagnosed with clinical depression, she still suffered with some of the symptoms.

“Initially I couldn’t talk about it, I used to cry, and that’s why I didn’t want to talk about it because I’d end up like a gibbering idiot, all tearful. It got easier, and then it got easier. You get better at being able to talk without being emotional about it.”

- *Anger*

Four of the seven participants expressed that they had experienced anger; be it towards medical professionals, educators or God. Carmen experienced a tremendous sense of anger

towards the professionals involved in assessing her son during the diagnostic process. She expressed this frustration and resentment in the following statements:

“I hated every minute of it. I hated the teacher.”

“And I thought ‘Fuck you, you bitch, don’t talk to me like that about my child. Don’t tell me that. I don’t need this’. There’s an incredible anger, an incredible anger against people who dare to suggest that everything is hopeless, and that this is a complete an utter nightmare. Just the experience is... you can’t believe this is happening to you, this is your worst nightmare, and there could be something seriously wrong with your child.”

“Sometimes you’re angry at your child too.”

- *Acceptance*

For some parents, acceptance may be a longer and harder destination to reach than for others. All participants interviewed felt that although they had reached the stage of acceptance, for all but one it had been a difficult phase to attain. Many felt that they still experienced days of anger and frustration, and that emotions tended to flow like ‘roller coasters’. Sandra shared the difficulty of her journey in reaching the acceptance stage in the following words:

“You know it takes a long time to get that acceptance of ‘this is it’, and you’ve got to deal with it for the rest of your life. And the acceptance of Autism has really only come in the last couple of years. Yes we know he is Autistic but the acceptance, only in the last couple of years.”

Kirsten described her experience as follows:

“So you just deal with it, you haven’t got a choice. Once you’ve worked through the initial anger and initial ‘Why us?’, and ‘Poor me’ and shattered dreams and all those sorts of things then accept what it is.”

Carmen described her emotions involved in the phases of grief, and how she eventually reached acceptance, and a sense of relief along with it.

“Denial stage, I think that’s huge, the anger, and that’s usually directed at the therapist, the depression, yes, I think I did, then I got to the acceptance phase. You do go through that mourning process. It does sort of follow... then you get to that point of acceptance and it’s quite a relief really. Humour helped a lot. If I can’t laugh at it I’ll go mad.”

Sandra shared how the process had also been a difficult one for her husband, and how he felt that acceptance was out of his reach.

“I think for Peter too it’s taken longer. He says he’ll never get over it and I don’t think he ever will. You reach that level of acceptance but you still have those moments of feeling really blue and why me. Then you pick yourself up and run again.”

Michelle felt that although she grieved, acceptance came immediately following her son’s ASD diagnosis, as the suffering he had endured due to uncertainty of his condition was immense.

“I accepted immediately, only because of the frustration of watching this poor child go through a misery. I mean he was beaten up at school, he was bullied, he cried at school, he found life very

frustrating, and I got concerned more than anything else...but I was happy with the Autistic diagnosis, for some unknown reason that didn't trouble me at all...I did have that one moment when I literally just sobbed myself silly, but I think that was the grieving process. It was a matter of 'Ok, this is what I've got and this is what I need to deal with. I need to find out as much information as possible to help the child as much as possible'. So I didn't go through all the five stages, I would say it was very much the accepting and very much the grieving."

ii. Family responses to an ASD diagnosis

Participants revealed a variety of responses to receiving an ASD diagnosis. These ranged from relief to shock, and differed in intensity and diversity from family to family.

- *Isolation*

Two participants felt that they had initially isolated themselves and their families as methods of coping with the diagnosis. This feeling is especially emphasized in the following statement by Kirsten:

"(It's) easier to stay at home, stay in a little box, and you don't have to think about it."

- *Other emotions*

A number of other emotions were mentioned by the participants. Julia mentioned varying levels of sadness and strain throughout the process of diagnosis. Sandra seemed to find the journey a particularly difficult one, as seen in the following excerpts from the interview conducted with her:

"It's been a pretty horrific journey, I must say..."

Basically it is a horrible road to travel and you wouldn't want to wish it on anyone, and the future is very daunting for us..."

Joanne commented on the stress that she felt before her son's diagnosis of ASD had been made however, for her the diagnosis was a relief and had a positive impact on the family, as she shared the direction that it seemed to give them, and sense of empowerment that her and her husband felt once they had received an ASD diagnosis for their son.

"So for us it was relief that we knew we could work on it, and it's been positive, we've never been negative about it, ever."

Many participants also reported feelings of uncertainty, doubt and confusion during the initial investigation phases before diagnosis was made.

iii. Financial implications

The financial implications of having a child with ASD were discussed by many of the participants. Six of the mothers interviewed were not working at all, due to the amount of time and input necessary for adequate supportive therapeutic needs of a child diagnosed with an ASD. The seventh mother had a part time, flexible job from home. All participants felt that this enabled them to focus all their time and energies on their ASD children and transporting them to and from various therapeutic interventions.

Carmen, a single mother, was able to rely on her parents for financial support, and spoke of the tremendous reassurance she felt by her father's offer of financial assistance.

Kirsten shared her appreciation in having the financial means to afford all the necessary therapies and extra help required at home, in order for her to cope with her ASD daughter.

“The expense - it’s frightening. And I always think to myself I feel sorry for people who have a child like this and can barely make ends meet, because what happens to them and the child, it’s ridiculous. Because it affects your whole life, you need to have extra help.”

Sandra dissected the tremendous costs involved in caring for her son’s needs, which also allow her to spend some time with her other son, and feel a degree of normality in her life.

“We’ve had to employ people to come in and look after him, so it gives us a bit of our life back. A lot of people can’t afford that. We have speech therapy twice a week for two hours, at R300 an hour, physio every two weeks, OT every week, school fees, facilitator fees, aupair fees, that’s huge. Medication, Risperdol is R400 a month, and he’s on an anti depressant as well for anxiety. Which is not really working. That’s also another R100 or so. It’s horrific.”

After some time, Julia realized that she was unable to work and cope with the demanding needs that an ASD diagnosis of her son brought.

“I’ve stopped working now to do all the things I want to do so that’s my time, and then he comes home, then I’m 100% his. He has a full afternoon every afternoon. He does play ball the one afternoon, then its swimming, then speech, then RDI programme, always something.”

iv. Marital relationships

Many participants felt that the diagnosis of ASD strengthened their marital relationships. However, two of the seven mothers shared the overwhelming negative effects on their

marriages. The diagnosis of Carmen's son with an ASD led to her divorce from her husband. She shared how they grew apart, and inevitably, soon had no marriage left to salvage.

"Well my marriage has broken up. I think, it's hard to say, I think an issue like this, it calls into question your deepest values regarding family life, and where your priorities lie. Some people I think can live together with different priorities as long as there is no crisis. It all depends how deep the crisis is and how different you are. It also depends on... I took it very, very seriously. His father said, 'Life's a jol, I want to jol, I want to have fun. Having fun is my priority. Don't worry so much about him, he'll be fine. There's nothing wrong with him'. It was a quick unravelling of a situation where there were perhaps different priorities."

"By then there was no marriage left. I'd just gone on a different path."

Although Sandra and her husband are still together, she shared with the researcher the profound impact and near divorce situation she felt her marriage had been through following her son's diagnosis.

"I'm sure Peter wanted to divorce me. I'm sure. But I don't really remember it all because I was a wreck, an absolute wreck and just getting through day to day and the pressure of sorting out this child who was just crying all the time and had all these needs, and having my older son as well who was very vulnerable and trying to give him time as well, and then. So you do tend to forget your main relationship. But it's come back on track now. And I know the instances of divorce of people with children with Autism is very, very high...I think, you know my husband is not an affectionate man, and I think it would have made a big difference if he'd come to me and given me a big hug. But he never did. He didn't know how to react to my depression, having hissy fits and bla, bla, bla."

Kirsten felt that the diagnosis had in fact been the instrument that strengthened her marriage, but recognized the potential it has to affect the marital relationship.

“Fortunately, and I know that the stats are very high on divorces that occur within families with children with special needs, and they say particularly Autism. Fortunately for Adam and I, it’s gone the opposite way, it’s actually strengthened our marriage rather than pull us apart which again is a bit strange that it has to be an Autistic child. I think there are a lot of men who would run from it.”

Michelle and Joanne both felt that their marriages had been strong from the beginning, and thus did not feel that the diagnosis had had any effect on their relationships with their husbands. Joanne felt that being an older parent had definitely been beneficial.

“Well I think, we’ve always been very strong, actually great. I think being older it certainly helped, if I’d been in my twenty’s I think the wheels would have fallen off horrifically. Being older and also having waited for our precious babies to come, you know we’d waited, it didn’t happen over night, we’d waited a couple of years for them to arrive and when they did it was magic, so, no, um, it’s been a long road, but it’s had so many positive things.”

Michelle expressed the strength of the partnership that she and Dave share.

“Dave and I have a very strong marriage, we are very fortunate to have a very strong marriage. Our marriage is based on a huge amount of communication because we see only about 40% of each other. So there’s a tremendous amount of verbal, telephonic sort of thing so there’s a lot of time for discussion. He does his research, I do my research, we come together, we discuss it, and we discuss ways of how to deal with it. I unfortunately have put a tremendous amount, 24/7 into the children and have very little time of my own, so stress wise, it has had its repercussions on me, but as a couple we’ve dealt with it pretty well I think.”

Julia felt that although the diagnosis had not affected her marriage, due to the nature of ASD certain aspects of the marital relationship had suffered, such as the ability to have a quiet, undisturbed evening, and a good nights sleep.

“No, I don’t think so, because we both knew that it was going to be that, and we thought, well this is it, and we’ll deal with it and get on with it and give him whatever he needs, put whatever he needs in place, that type of thing, it’s not like ‘Oh gosh we’re devastated now. It was your fault or my fault’. No nothing ever like that at all. Even though it does put a strain on it because he sleeps so badly...”

v. Impact on siblings

- *Coping*

Six of the seven parents interviewed, had other children apart from the ASD child.

Participants shared how the impact of an ASD child had seemed to affect their other children in a variety of ways. Two of the participants felt that the neurotypical child had grown up as if they were an ‘only child’, reinforcing the loneliness experienced by these siblings. Kirsten and Sandra shared the following extracts on their neurotypical sons:

“...he doesn’t interact with his brother...he’s still not an interactive brother, he’s like an only child.”

“It’s almost as though he’s grown up like an only child. For us it’s sad that he doesn’t have a sibling that can interact with him as a sibling of her age should be able to do by now.”

Five out of the six participants felt that their children had coped well with having an ASD sibling, and that they had grown emotionally from the experience. The majority of participants felt that the diagnosis of ASD had brought out the best in their other children. Kirsten and her husband shared the following excerpts relating to their son's response to his sister's Autism:

"It hasn't affected him like I know of some siblings, they hate the other one, not at all, nothing, it's almost as though she's enriched his life in some ways because there's that lovely bond. He's like a little mini dad to her, so we explain to him, he understands."

"...if there is such a thing, Jonathan has got a particularly appropriate personality to have a sister like this. He adores this child, and strange as it seems, he absolutely loves her. He never kind of questioned. He's never been a 'poor me' or 'Why couldn't I have a normal sister?' He's got a very appropriate personality type for dealing with this sort of situation."

Carmen acknowledged her son's positive attitude and input into his ASD brother's life, but also recognized the difficult journey that it has been for him.

"Sean has had to be so good and so patient with his brother... It's been frustrating and hard for him but he knows that we know, and we try to make up for it in other things, me and my family."

Joanne felt that the experience had been a positive one for her younger son, but she acknowledged his occasional frustration at the limits of having a sibling with an ASD.

"I think that James has got a lot more compassion, and he's probably grown up a bit faster, maybe a little bit faster in certain areas, but they're very close, and even though there's a four year gap its more like two. So it hasn't really been a negative thing with James. He sometimes

shows a little bit of frustration, like once or twice he said, 'Why can't my brother be like other brothers?' But that's when his brother has driven him up the wall. Generally they're tolerant; they're pretty good with each other."

Michelle has two sons on the ASD spectrum. One has been diagnosed with having Asperger's Syndrome, and the other, Autism. In the extract below, she revealed the level of understanding and patience that her Asperger son has for her Autistic son.

"...he is very good with Timothy, in fact if Timothy thinks he's going to have a problem with us he says to us, I'm going to Mark, Mark will really understand what's going on here. He seems to have that ability I think because he is Asperger that he can deal with the situation well."

- *Peer relationships*

Two of the six participants who had sibling children felt that their neurotypical son's friendships had been impacted upon due to the ASD diagnosis. Both of these children sought the help of a psychologist in relation to these difficulties.

Carmen shared how difficult having an ASD sibling had been for her son, Peter.

"...it has affected him. When he was in about Grade four, when Bryce was six, the kids at school would say, 'What's the matter with your brother; is he a retard?'... It's been very frustrating for him. It's affected his peer relationships in terms of inviting boy's home, having boys over. We have to be very careful that whoever is here understands Bryce's difficulties. It has affected Sean. I hope that good comes out of it, but he's been able to express his emotions."

Sandra's oldest son has experienced a particularly difficult time, and although she feels that he cares for his ASD brother, he has struggled to cope and deal with his emotions of anger and frustration.

"...he really, really battled and it was affecting his relationships at school. So he really, really battled in Grade four, he had a horrible, horrible year. He was taking his anger and frustrations out on the children at school, they were in turn ostracizing him, and hating him and he was very, very unhappy."

Sandra took her son to an Educational Psychologist, in the hope of providing an outlet for his emotions. She felt that this had resulted in positive outcomes from a very difficult situation.

"He loves his brother, he's very protective of his brother but he doesn't interact with his brother. And he was also under the care of an Educational Psychologist. Last year a couple of sessions, he's in Grade six now, in Grade four he went to her a lotHe started going to..., sorted him out, and he's also matured now. But he's still not an interactive brother...."

The researcher noted that in families where the mothers were particularly stressed and had suffered from depression, siblings were able to cope less effectively with the ASD child, and also had more difficulties with peer relationships.

vi. Extended family

Participants reported varying reactions from extended family members, including denying, ignoring, and supporting. The majority of extended family members of participants seemed to have great difficulty accepting the ASD diagnosis. Most participants agreed that the diagnosis, however difficult, did seem to help the extended family members to understand

some of their child's behaviour, and thus make things slightly easier and less stressful. Michelle reported that many of the extended family members seemed to be in denial, and refused to accept the situation as this would mean they were accepting that they were part of a genetic fault.

"The extended family was shocked. They continued to tell me that the child was normal with strange behaviour. I have had reactions such as, 'He should be on Ritalin because he's fat', and 'Just leave him alone, he's just being peculiar', 'he's being stupid', 'he's manipulative', 'he's just being demanding', 'he's trying to get his own way'...I think the family don't want to know that there's a weak link or 'Gosh, now we need to look at ourselves and look back on our family history and try find where the problem might exist'."

Sandra's father-in-law attempted to find a cure for Autism until the day he died. Although her mother loves her son, she still seems to be unable to accept it.

"Peter's father died this year, and we went two years ago, strange man, he kept trying to find the cure for Autism. My mother, she loves Martin dearly and she's fine with Autism, she'll say every now and then, 'It's so sad', and I'll say, 'It is sad but get over it'."

Julia's extended family seemed to have adjusted what they needed to and helped where they could to make things easier for the family and for her ASD son. Her mother-in-law still shows evidence of denial, not wanting to believe that her grandson could be 'defective' in any way.

Most of Joanne's extended family live far away, and thus have not really been affected by Gary's diagnosis of Asperger's. Her experiences thus far have been very positive, and the family seems to have been understanding and accepting.

Kirsten experienced support to varying degrees from both sides of the family.

“We then had to tell family, and my folks have been very, very supportive, very accepting. Adam’s family, have never been as close to the kids as my family, but they weren’t as supportive towards us, they were quite sweet with her.”

Although Carmen lost the support of a husband during the diagnosis process, her parents have played a tremendous supportive and encouraging role in her life.

vii. Coping post diagnosis

The diagnosis of an ASD seemed to affect each of the participant’s families in a different way. Michelle felt great relief that, after many years of searching, they were finally able to receive a diagnosis and begin to actively do what they could. Prior to this there had been a tremendous amount of uncertainty, and a variety of explanations for Timothy’s behaviour. Up to the point of diagnosis, Michelle had not been convinced of any of the diagnoses she had received. When the family finally received the correct diagnosis, the relief for Michelle and her husband was overwhelming.

“Dave and I were very relieved. We had spent a lot of time going around to doctors and assessments. He was frustrated by it and very tearful by it, we were at our wits end because nothing concrete had come out of it. So we were very, very relieved.”

Initially Kirsten and her husband, Adam, struggled to cope with their daughter’s diagnosis. It was a profound shock for them to be told that her condition was not something that ‘she

would grow out of. They both experienced tremendous sadness and denial during the initial stages of coping with the diagnosis.

“With difficulty. I remember the day that ...said she had Asperger's, Adam was the one that went to pieces, absolute pieces, we had to go up to a 40th, I think he sat in the garden crying the whole party. It was a bad weekend. I was OK, but I shut it off, I was in denial. So Adam dealt with it, well that was his reaction to it. Jonathan kept coming to me and saying, 'Mommy, daddy's crying the whole time, what's wrong?' He didn't really understand. It wasn't easy at all. I don't think people actually know how to react. We struggled, we did, we had a very difficult year that year. And it was constantly searching for other answers in the hope that it's going to take you off that initial diagnosis. It's got to be a mistake; you keep sort of feeling he had to have made a mistake. But it always comes back to the same thing.”

Sandra immediately threw herself into gaining as much knowledge as possible, and did much research into her son's ASD condition. She acknowledged that part of the coping, came with acceptance, which for her was especially difficult to achieve.

Carmen, who was left to cope as a single mother, found a diagnosis of ASD an extremely difficult burden to bear alone. Joanne however felt that her family had coped well, based on a strength that she felt had always existed amongst them.

viii. Empowerment

Many of the participants who were interviewed immediately found as much information about their child's ASD as they could. Use of the internet proved to be particularly useful to some, and having knowledge of the disorder seemed to give participants a sense of power over it.

After many confusing and incorrect suggestions of diagnoses for Michelle's son, Timothy, her older son Mark, eventually thought he had found the difficulty. Mark had been reading the book, 'The curious incident of the dog in the night time', by Mark Haddon, for a school report, and came home one day telling his mother to read it, as he felt that this was what his brother had. Once Michelle had read it, she knew he was right, and with this knowledge, she and her husband, Dave, read all the information they could find and even travelled all over the world looking for information and solutions, and assisting others in similar situations as much as they were able to.

Michelle also realized the lack of knowledge of ASD's of both professionals and other people. When she began speaking about them, she discovered how little is known about these disorders.

Julia found the internet to be her greatest source of information, from where she was able to confirm and understand her son's Autistic diagnosis more.

"...we went onto the internet and looked at all the different signs and things that he, like no eye contact, lining up toys in a straight line, and memorizing books, and those type of things, and then flapping and the jumping up and down, all those type of things, and this is exactly what the child is doing, you know. All off the internet, lots of stuff off the internet, and then from there, seeing different books and reading the books, and then I realized this is huge. There's just so much. There's a lot of information on the internet if you just keep going into it and into it and that."

Sandra immediately read every book and source of information that she could find, desperate to be as well informed about her son's diagnosis as possible. She also stated that the internet was a tremendous source of information for her.

Carmen discovered that her son had Asperger's at a time when many books were being written and workshops were being held on the topic. She empowered herself with as much knowledge as she could. Apart from the sense of empowerment this gave her, she reported that she appreciated knowing that she was not alone, and that other parents were experiencing similar emotions and difficulties.

ix. Future concerns

Once parents had received the ASD diagnosis and were able to palate the information regarding their child's diagnosis, many indicated concerns for the future. A common concern was the care and support that their child would need throughout their lives, and how parents could best provide for this. Most of the participants had financial provisions in place for their ASD child's care should anything happen to them.

Julia's greatest concern was that there would be no one to look after her son as well as she and her husband would, should anything happen to them. She also had concerns about Patrick's future in terms of work, coping in society, and relationships.

"The biggest worry is, and still is today, what will happen to him when he is grown up? When he's finished school, out of that structured environment, will he be able to cope. We don't know, because as he gets older we'll be able to see, will he be able to cope in society, will he be able to get a job of some sort, I think those are the biggest things. As he gets older, will he be OK?"

Cause he didn't have any brothers or sisters, so there's no one to really look out for him. Now I'm in tears. That is my biggest concern. Who will care for him like I do? We've put everything in place so he will always be well cared for, all our policies in place should anything happen, will he be OK? Will he ever have a relationship with anyone?, that side of things."

Sandra felt concern at the future of her son as a whole. It worried her that there are no family members in South Africa who would be able to take care of Martin should anything happen to her and her husband. She finds it helpful not to look into the future, but rather to concentrate on dealing with the present.

Kirsten's concerns focused on her daughter's education, career prospects, dependence on Kirsten and her husband, and future care for her.

"Well it was basically where to from here, where does she go to school, how is she going to be educated, is she ever going to live a normal life, is she ever going to have a job and earn her own money, is she going to be dependent on us? There are all sorts of things. Are we going to be able to continue to support her forever and a day? What if something happens to us, whose going to take care of her? All that sort of thing."

Joanne felt that the future emphasis had been on planning for the future of their son and making financial provisions for him, but also indicated that this was something which she would also have done for any neurotypical child.

The initial concerns felt by Carmen after the diagnosis centred around her son's ability to have a job and be involved in relationships. She was concerned about the life experiences he may not be able to have, given his ASD diagnosis.

Michelle was concerned about the elevated rates of depression and suicide that may be found amongst ASD populations. She was concerned that her son would be alone, and not be understood by society. Another concern was that, due to her son's inability to express frustrations and anger, he may physically injure another person. She is however hopeful that he will cope well.

x. Lack of facilities and support

Participants from this study all highlighted the significant shortage of facilities and support for ASD children in South Africa. Many opted to employ personal facilitators and form their own educational support facilities for their children.

After Julia's realization that there was a significant shortage of appropriate facilities, she employed a full time facilitator to assist her son daily at school. She spends her afternoons taking him to all the necessary therapies.

"...you suddenly realize, 'hey, this child's not capable of being main streamed', and then what are your options? There's not a lot out there...In this country, there's no where for children to go into care, or if there are they're not keen on taking children or young adults with Autism, and there are more kids being diagnosed as well."

Although Sandra's son is now attending a small private school for ASD children, which she established due to a lack of facilities, one of her initial concerns was a higher education placement for her son.

"One of my concerns was High School. What happens when High school comes along, cause can you imagine putting a child with Autism into a boy's high school?"

Joanne initially attempted to educate her son in special education and small private schools, due to a lack of facilities and suitable educational environments for him, she began home schooling him with the assistance of remedial teachers. She has experienced this decision as a tremendously successful one, and her son has made remarkable progress in this home schooling environment.

She further highlighted the lack of support that they as a family have experienced, and how the family has needed to create their own.

“For this particular condition there is no support, you have to find your own support. It’s not the end of the road, it’s a new journey starting all the time, because you kind of get to the end of one stage, and you have to readjust. You have to keep rolling with it and changing. We’ve had to educate our own doctors, they’ve learnt from us.”

xi. Need to increase awareness (amongst professionals and society)

All research participants believed that both medical professionals and the general public had a very limited knowledge of ASD’s. They considered education of people regarding ASD’s to be of vital importance.

Julia’s doctor admitted that his education in the field of ASD’s was very limited. She felt that more knowledge may lead to earlier diagnosis, and subsequently earlier intervention, which she considered would have been very beneficial in her son’s case.

“So I just think, if there was more knowledge out there. Also when I was speaking to the doctor the one day, he said to me, after all the years of studying to be a doctor, they don’t cover it. Or it’s a like a paragraph, so they don’t really know much about it either. Of course that’s a

problem, because if they knew more they may be able to say, look your child's not speaking, or your child."

As mentioned previously, the initial paediatrician that Sandra requested assistance from referred her to another paediatrician as he felt his knowledge in the area was not enough. She also felt that if she had been more aware of ASD's, she may have noticed the signs earlier.

Due to a lack of knowledge of the medical professionals that Joanne dealt with, her son's difficulties were often misdiagnosed. When they eventually did have a diagnosis, it was not understood by many professionals.

"...they did their best and they were very sweet, but I don't think they really understood what he was all about. They couldn't really fathom, once again it wasn't like it was a diagnosis at that stage, we were busy sorting out the diagnosis. And when we did get the diagnosis they didn't understand it because they'd never come across it before."

Joanne and her husband were told on numerous occasions that they had nothing to be concerned about. Only after much persistence did the couple receive a diagnosis.

"...we were like hound dogs, we actually fought with doctors, we actually had fights, because they kept flogging it off as nothing, slight global delay, 'Ag don't worry it will come right', and not actually getting to the bottom of it. And they were shocked themselves when they got the feedback, then it was out of their league so we had to go to the next level."

She went on to state that they have had to educate their doctors with information from their personal research of the LCAD and Asperger's diagnosis.

Sandra experienced great frustration in medical professionals' inability to diagnose, and in their lack of knowledge and certainty of ASD conditions.

"...you know you don't know the word Autism, and you are 'What's wrong?' and they say 'Well we don't know', that is frustrating."

4.4 Advice to Other Parents

As indicated in this research study, the road to an ASD diagnosis is, for many parents, a long, frustrating and stressful time. Participants shared their advice to parents who are experiencing similar journeys.

Julia's advice was to act on first suspicions immediately, as this was beneficial to both the functioning of the child and family unit.

"...the minute they suspect something, it might be nothing, I would tell them to go and see someone immediately. Maybe not a medical doctor as such, but maybe more a psychologist or someone specifically working in that field...Don't leave it because the sooner you can start with the right therapies and that, it only benefits a your child, and then it actually makes your life easier too. It makes everyone's life easier if you are doing your bit and you've got the right therapist and the right people working with your child...Some people find it difficult to accept. You'd be surprised how many people there are out there with children with Autism. You think you're the only one, and no body else out there. Then you start going to the shopping centres and you see certain things and you think 'Ya well my child is not the only one, you know.' So the sooner the better."

Sandra felt that the most important advice was not to become overwhelmed by thoughts of the future, and to take things one day at a time. She also recommended keeping track of work that therapists may be doing with ASD children.

“...take it step by step. Just don't think beyond the year, and do your homework. Research Autism, and if you are going to a therapist, follow through on what they're doing.”

Kirsten and her husband felt that acceptance was a vital part of dealing with the process. They believed that too much information on the topic of ASD's would cause confusion and may become overwhelming. They considered it to be important to maintain a 'normal' life as far as possible.

“You can't allow it to become all consuming of your life. You just have to accept that it is what it is, there is so much you can do, you try your best, you do whatever you can, we're not therapists, we don't have special insight that you don't have, and we're just ordinary people trying to make a reasonable life for ourselves. There's no use in ruining your whole family, your marriage, and everyone else's life for something that you can't actually do anything about. So we've taken the route that we're doing the best we can, we try offer Tammy the best we can, we do as much with her as we possibly can, but she is what she is, and inside of that, we have to try and live as normal a life as possible. We've got to get something out of this life as well. To allow it to become all consuming and destroy what's good in your life, those rocks that kind of, you put your own foundations down on; it's just not worth it.”

Joanne believed that it is of crucial importance to insist upon a correct diagnosis, and not to have concerns put aside by medical professionals. She felt strongly that if she and her husband had not fought for a diagnosis for their son, his future would have looked very different to the prospects it now holds.

“I would be like a bull dog, I would go in and keep asking and change doctors if you have to. ...just keep going, don't just be fobbed off, don't, and I was lucky having Chris because he's more of a scientific mind and he says 'There's a reason for everything'. 'Don't come with me and say this global delay what, why is there a global delay?' There are reasons for global delays, he hasn't been knocked on his head or fallen out of his chair, he's not cerebral palsied, and he's not epileptic, he's not ADD, and I can go on. So then why is this healthy beautiful boy experiencing speech problems, and fixations and all these other things, why? So fight, fight, fight. I'm very much for fighting.”

Carmen emphasized the importance of working with knowledgeable, optimistic medical professionals. She also felt that having a team of supportive medical professionals provided necessary support and assistance. Carmen believed that there are also great benefits to finding support with other individuals and families experiencing a similar diagnosis.

“Find a good language therapist who understands Autism. Find somebody who might say to you, 'I'm not necessarily saying he is Autistic, but I've worked with a lot of children who've got his problem to a greater or lesser degree.' Find somebody who knows what they're doing, who doesn't buy into your denial, that is quite important, but someone who is compassionate. Seek as much, get a whole team together, I don't know that I handled it that well. If you're lucky enough to have a supportive family... Find other women who have children like yours, very important. Find someone who's going through what you are going through. And when you are hysterical and they are two years down the process then that helps because they say, 'Yes I know I was there, but this helps and this can be done'. Find someone who gives you hope. Find good skilled therapists. Because without help what's the point. You always have a hope that somehow you'll make things better for your child.”

Michelle advised that a medical professional such as a Neuro-Paediatrician or Educational Psychologist who has a good knowledge of ASD's, was the correct place to seek assistance.

“Go to the right specialist. If you have any inclination or anyone has made any mention of the fact that the child is on the Autistic Spectrum Disorder or you are unsure or unhappy with the diagnosis made by someone else, go to a specialist, and probably a Neuro paediatrician or somebody who, you get Educational Psychologists who are incredibly clued up on it.”

4.5 Conclusion

The aim of this chapter was to document the results of this study. Participants in this study experienced the diagnostic process as a frustrating and lengthy process, and found that few medical practitioners were able to diagnose their children at an early age. An ASD child seems to impact significantly upon many aspects of a family, including siblings and the marital relationship. Degrees of impact varied from family to family. Results of this study indicated that the experience of diagnosis does not end in a label but is a life long process. The process includes a wide range of emotions and certain stages of grief, including depression, anger, denial and acceptance. Participants also highlighted a lack of resources and facilities to support ASD children and their families in South Africa.

Major themes discussed in this chapter have been divided into pre diagnosis, diagnosis and post diagnosis experiences, as indicated in Table 4.5 below. These themes, including their broader impact within the South African context will be discussed in further detail in the following chapter.

Table 4.5: Themes emerging during interviews

PRE DIAGNOSIS	1. Early Signs
“Niggles and frustrations”	2. Age of first concern
	3. Unwillingness of professionals to diagnose
	4. Misdiagnosis
	5. Perceptions of ASD and a lack of knowledge
DIAGNOSIS	1. Average age of diagnosis
“Finally- the truth”	2. Number of years and medical practitioners
	3. Types of professionals consulted
	4. Advantages of a label
	5. Early intervention
	6. Controversy of the MMR Vaccine
POST DIAGNOSIS	1. Stages of Grief
“Where to from here?”	2. Family responses to an ASD diagnosis
	3. Effect on the marital relationship
	4. Effect on the sibling relationship
	5. Empowerment
	6. Coping post diagnosis
	7. Future concerns
	8. Lack of facilities and support
	9. The need to increase awareness of ASD’s
	10. Advice to parents

This research aimed to gain an understanding of parents' experiences of receiving a diagnosis of an ASD child. Qualitative methodology using in depth interviews allowed for the depth of their experience to be captured.

The small sample of participants interviewed for the purpose of this research revealed that on average it had taken 7.2 medical practitioners and 3 years 3 months to reach an accurate ASD diagnosis. There also seemed to be a considerable diversity of professionals who parents sought assistance from in terms of a diagnosis, yet only a handful who were willing to officially diagnose. The lack of knowledge surrounding ASD's in South Africa was also noted by participants. These aspects are further discussed in the chapter below.

5.1 Difficulties with Diagnosis

5.1.1 Average number of years and medical practitioners for diagnosis

The average age of diagnosis for the children of participants from this study was six years old. This figure is supported in research by Mooney et al. (2006) that indicated that the average age of diagnosis is six years old. However, Young and Brewer (2002) found that it was possible to accurately diagnose Autism before the age of two.

Findings from this study also correlate with research in other countries, but the number of medical practitioners that participants in this study consulted was almost double that of other studies. A Canadian study, for instance, reports that the average number of years to diagnosis is three, and the average number of medical practitioners consulted before diagnosis is 4.5

(Siklos & Kerns, 2005). This may indicate that South African medical practitioners have less experience and knowledge about Autistic Spectrum Disorders.

Joanne felt that because Gary appeared to be such a healthy young child, medical professionals saw no need for concern.

“When we started asking questions, they weren’t concerned. At all. They weren’t concerned because he looked big, strong and healthy, he wasn’t underweight, he wasn’t sickly looking...eventually we said ‘Look, there is something’.”

She went on to describe that she and her husband,

“... were like hound dogs, we actually fought with doctors, we actually had fights, because they kept flogging it off as nothing, slight global delay, ‘ag, don’t worry it will come right’, and not actually getting to the bottom of it.”

Results from the current study seem to indicate that an even greater number of professionals are involved in the diagnostic process in South Africa than in other countries such as the USA and UK. The great diversity of professionals that were consulted during the diagnostic process of the participants was notable. These ranged from assessment inspectors to Sports Psychologists. Thus parents went to great lengths and consulted many professionals from a range of disciplines in order to receive an ASD diagnosis.

Due to the difficulty of diagnosis and the number of professionals consulted in the process of diagnosis, it is possible that many South African children may remain undiagnosed. This is

of great concern as specific and purposeful interventions are required in order to assist these children adequately.

5.1.2 Misdiagnosis

Participants in this study reported that an initial difficulty in distinguishing ASD's from other developmental delays may have added to the delay in diagnosis. This is consistent with findings from Mooney et al. (2006). According to Howlin and Asgharian (1999, p.834), "parents' anxieties may be dismissed by professionals as being without foundation". In many cases, practitioners seemed to offer the 'safer' and more generalized diagnosis of 'Global Developmental Delay'. This misdiagnosis may have affected earlier intervention and was most likely influenced by the lack of awareness of professionals of ASD's and the availability of early diagnostic tools. If there was a greater knowledge and understanding of ASD's and a willingness to use early diagnostic tools, there is a significant possibility that experiences of parents in the process of diagnosis of an ASD would be different. Howlin and Asgharian (1999) found that many professionals may diagnose ASD as behavioural problems, Attention Deficit Disorder, minimal brain damage or other emotional and behavioural problems.

Some participants in this study were told that their children had Central Auditory processing difficulties. However, it is important to note that a significant number of ASD children experience sensory difficulties as part of the disorder, and not as an isolated diagnosis.

The lack of knowledge amongst professionals was highlighted by Michelle when she began to question professionals' familiarity of ASD's.

"I started asking around and no one had heard of it; not even GP's, not even doctors. They were absolutely blank when I mentioned it."

The training and knowledge of medical professionals on the content of ASD's is an area which needs to be addressed at a higher level of medical practitioner curriculum planning, especially as ASD's are now being referred to by some researchers in the field as an epidemic (Sicile-Kira, 2003).

It is unfortunate that years of valuable intervention time seem to be lost because of misdiagnosis of ASD's. During these years, correct practices and interventions could be implemented, saving time, money, and a great deal of distress, both for ASD children and their families. The extent of the distress experienced during the lengthy process of diagnosis was clearly indicated in this study.

5.1.3 Early diagnostic tools

Despite the availability and accessibility of tools for early diagnosis, participants in this study felt that professionals had been unwilling to make a diagnosis too early. There was also no evidence of the available tools having been used in any of the diagnoses. If practitioners were willing to utilize the available early diagnostic tools, earlier intervention could mean a better prognosis for the ASD child, and as research indicates, this intervention may even enable some ASD children to return to mainstream education at a later stage (Fenske, et al., 1985; Harris & Handelman, 2000). Julia expressed how her son's world changed from a misery to a success when they were able to implement the correct strategies in order to facilitate him. His earlier years may have been far happier had they had a diagnosis and been able to apply appropriate interventions with an understanding of the disorder.

Many studies have indicated that professionals seem to dismiss parents' concerns about their children's delays and behaviours, and attempt to persuade parents that their children will grow out of these (Gray, 1995; Schall, 2000). Research by Goin- Kochel et al. (2006) indicates that a possible reason for this may be a lack of professional knowledge of ASD's. A second hypothesis is that due to the commonality of speech delays and behavioural difficulties as developmental concerns in children, professionals are cautious of misdiagnosing, as this may add additional stress and apprehension to a family. However, as Layne (2007) indicates, the delay in diagnosis and lack of understanding of their child's condition may also exacerbate parents' anxieties.

5.1.4 Early diagnosis

Researchers have indicated that in order for early diagnosis to occur, there are certain signs and behaviours that children present with that should be looked out for. Parents in this study recognised that these signs of ASD were evident from a young age in their children. However, due to lack of their own and professionals' knowledge on ASD's, the importance of these was downplayed, and further steps to diagnose and intervene were not taken. Some of these signs included behaviours noted in research by Robins et al. (2001), such as lack of eye contact, smiling and limited attentive engagement.

Mothers in this study felt that had they had knowledge of ASD's and been aware of early warning signs, earlier interventions could have been put into place for their children. Joanne found that even specialist educators were baffled by Gary's difficulties.

"...the head there said she'd never known a child like this. She couldn't put her finger on it."

The awareness of these signs seems to remain limited to select professionals. There is an urgent need for this to change.

According to Mooney et al (2006), there is sufficient evidence that a reliable diagnosis of an ASD can be made in children under the age of three years, and that earlier diagnosis correlates with better developmental outcomes. Siklos and Kerns (2005, p.11) confirmed this finding, stating that “parents typically are aware of some problems sometime before their child’s first or second birthday, but on average must wait until the child is between 5 or 6 years of age to obtain a formal diagnosis”. The parents in this study reported having early concerns about their child’s functioning, which were generally dismissed by the professionals consulted. Joanne confirmed this in her experiences of medical professionals along the path to diagnosis.

“No, there’s nothing wrong...and again they said ‘No, No, No, you don’t have to worry’.”

Siklos and Kerns (2005) suggested that further possible reasons for the delay in diagnosis could be due to factors such as lack of specialized services and focused training of professionals. Parents in the current study reported similar frustrations. Siklos and Kerns (2005) also hypothesized that limitations of assessment tools and lack of knowledge of them may exacerbate the above delays. Furthermore, their study documents that parents of children with ASD’s “experience significant hardships in attempting to obtain a diagnosis for their child” (Siklos & Kerns, 2005, p.10). It is hypothesized that these reasons are intensified in South Africa, where there is an even greater lack of knowledge and specialization in ASD’s. Many participants mentioned the need to educate medical practitioners.

Although there seems to be relatively little information on sleeping difficulties amongst ASD children, results of this study indicate that it seems to be a common concern for parents of ASD children. Although not a symptom of ASD, many parents raised the issue of sleep difficulties as having been a concern from a young age. Parents seem to experience a significant amount of stress and many have sleepless nights as a result of a child who has difficulty establishing sleeping patterns. Exkorn (2005) emphasizes that a common element of ASD children is their sleeping difficulties. These place a tremendous amount of additional stress on mothers in particular, who due to this have limited sleep themselves which in turn makes it harder for them to cope, often exacerbating negative emotions.

An understanding and awareness of the difficulties of raising an ASD child may provide a greater supportive and facilitative environment for parents. There is not only a lack of facilities for the educational stimulation of ASD children, but also a lack of support groups for parents. There is a need for greater external support for families who have ASD children and a significant need for an increase in public awareness of ASD's.

The results of this study also seem to indicate that there are a few experts in the field of ASD's, who were often referred to and who were most often willing to provide a final diagnosis. There seems to be a lack of specialized professionals in this field of expertise who are aware of early signs and symptoms and who have a good knowledge of Autistic Spectrum Disorders. This clearly points to the need for more specialists, and again emphasizes the need for a greater awareness amongst practitioners in general, perhaps more specifically an awareness of the tools available for use in early diagnosis.

5.1.5 Importance of early intervention

Early interventions have a noteworthy effect on the prognosis of an ASD child, and as participants reported, made a great deal of difference to the emotional state of both the child and the family. Although research has indicated that proportions of ASD children are sharply on the incline (Lillienfeld & Arkowitz, 2007; Sicile-Kira, 2003), there seems to be little work done in terms of public awareness drives and information accessibility of ASD's. Public awareness of Autistic Spectrum Disorders and their symptoms definitely seems to be an area in which South Africa needs to focus, as it is the first step in the process of diagnosis. Apart from potentially encouraging early intervention and improving long term prognosis, it may be a vital step in the reduction of stress and frustration that this study has shown many families experience.

As discussed previously, studies indicate that the average age of diagnosis of Autism is six years old; however, earlier diagnosis is preferable as it enables earlier intervention. Layne (2007, p.110) states that ASD's can be diagnosed by the age of two years, as it "impairs language, social interactions, and play skills, as well as cognitive and adaptive functioning". This research was confirmed by Eaves and Ho (2004), whose study determined that ASD should be able to be identified between 20 and 30 months by practitioners experienced to assess behaviours such as poor eye contact, lack of interest and attention and limited responsiveness to their names. A study by Mooney et al. (2006) indicated that if intervention can occur between the ages of 2 and 4 yrs, there is a better prospective for development and progress.

Parental responses in the current study indicate that the issues of early diagnosis and intervention seem to be a significant problem in South Africa. Valuable intervention time is being lost and reasons for this need to be addressed with urgency.

5.1.6 Importance of diagnosis

Participants in this study all felt that a label of ASD had provided them with an understanding of their child's condition and enabled them to implement structures in order to facilitate enhanced all round functioning. A label also seemed to relieve a degree of stress that the participants were facing in already stressful circumstances. The ability of participants to understand a diagnosis through the means of a label enabled them to be proactive in assisting their ASD children. As mentioned above, practitioners seem to be afraid to label an ASD child. However, with the knowledge of the advantage of labels, perhaps more thorough investigations, use of tools, and provision of diagnoses needs to be encouraged amongst medical practitioners.

Although in this study a diagnosis led to relief for all the participants, research by Mansell and Morris (2004) indicated that an ASD diagnosis may lead to mixed reactions from parents. They state that some parents may be "relieved that someone else has collaborated what they had initially suspected" (Mansell & Morris, 2004, p.388), and see a label as a way of explaining behaviour to themselves and others. A label also opens support opportunities and resources which may be open to them following an ASD diagnosis. They go on to report that some parents, however, are not accepting, and experience distress, disbelief and shock at the diagnostic label of ASD.

5.2 Parents' & Families' Reactions to Diagnosis

5.2.1 Parents' experiences

Participants revealed that a diagnosis was only part of a life long journey, involving many stages and a variety of emotions. These are of valuable importance in understanding the comprehensive diagnostic experience of parents' whose children have been diagnosed with an ASD.

i. A grieving process

Although for ease of results, the process of grief as experienced by parents has been placed in the post-diagnosis category, aspects of it seem to occur during the pre-stages as well, and extend throughout the lifelong process of the journey of having an ASD child. The grief that participants in this study experienced highlighted the need for greater support facilities for parents whose children have received an ASD diagnosis. This support needs to have an ongoing focus, which extends into years of a diagnosis. As indicated below, aspects such as denial may be present for many years. Parents also highlighted the difficulty of reaching acceptance. Support facilities and groups need to consider the grieving process when dealing with families experiencing an ASD diagnosis.

Grief experienced by parents whose children have an ASD diagnosis results from feelings of loss related to hopes and dreams for the child, and opportunities that they will never experience. This sadness was aptly expressed by Michelle in the following excerpt.

“There are certain times when you see other people’s children doing certain things like playing in a cricket or soccer team. It’s almost sad in a way because you think, ‘Well he won’t be doing that because we won’t be going off to watch him play cricket or soccer’. You feel sad for him, almost for yourself, because he’s not going to go off and do that type of thing.”

Sicile-Kira (2003) explicates the mourning that is described by parents in this study, as they endure the loss of a child they will never have and a shattering of future expectations and aspirations for their child and family.

- *Denial*

Interviews with mothers in this study revealed that denial was a common defence experienced, with most mothers experiencing denial for a prolonged period of time.

Denial is known as a primitive yet effective defence mechanism by which individuals put distance between themselves and their experiences, refusing to acknowledge the existence or severity of these unpleasant realities, thoughts or feelings (Nicoll, 2004b). In the case of a diagnosis of a severe disability, or ASD, denial may be present in a parent for many years (Nicoll, 2004b).

- *Anger*

“I still get angry; I get angry with people because they don’t realize what it’s all about. I get angry with people who come to me and say and it happens a lot, you were given this child for a special reason, God gave you this child for a special reason.

With Autism you don’t have an easy life...

It’s been a pretty horrific journey, I must say...

Basically it is a horrible road to travel and you wouldn't want to wish it on anyone, and the future is very daunting for us..."

The journey of many parents whose children have received an ASD diagnosis is a very difficult one, causing feelings of tremendous anger and resentment in some, as indicated in the above statement by Sandra. A common reaction following initial feelings of denial is one of rage and anger. Parents may feel anger toward professionals involved in the diagnostic process, towards God, their ASD child or even a neurotypical sibling (Nissenbaum et al., 2002; Sicile-Kira, 2003). This points to the necessity of ongoing support for parents involved in this process, which seems to be severely lacking in South Africa.

- *Acceptance*

Parents in this study only seemed to be able to accept their child's diagnosis after experiencing and dealing with some of the other emotions involved, as those mentioned above. When parents realize that they will be able to cope, and are able to regain a sense of power and control over a previously helpless situation, they are able to begin accepting (Sicile-Kira, 2003). Although acceptance is an extremely difficult state to reach, according to Nicoll (2004c), it is one that is vital for parents of children with disabilities to reach if long term happiness is to be gained. The process of an ASD diagnosis is an extremely difficult one for parents to experience. Responses from participants emphasized the importance of support and understanding from external facilities in order to assist parents in gaining acceptance.

- *Isolation*

The need for a support network has been emphasized and discussed repeatedly during this study. Sicile-Kira (2003) supports this in her discussion on how certain parents of children with ASD tend to isolate themselves from friends and family. She suggests that one reason

may be as a result of parents viewing neurotypical children of others as a painful reminder of their own children's disabilities. Nicoll (2004d) also indicates that another reason parents may tend to isolate themselves is as a result of the overwhelming challenges of parenting a child with disabilities. They may merely be too exhausted to interact socially or feel that the logistical requirements of social interaction are too much for them. It is, however, of vital importance that parents have a support network, consisting of both families with children with disabilities, and those with neurotypical children (Sicile-Kira, 2003).

- *Other emotions*

Participants in this study revealed a wide range of reactions from shock and rejection, to support and concern. Although reactions to diagnosis and having an ASD child vary from family to family, research indicates that the impact of such a diagnosis is significant (Gray, 2003; Nicoll, 2004a; Nissenbaum et al., 2002; Sicile-Kira, 2003).

Cassandra, experiencing a significant lack of support during and after the diagnosis, relayed the following feelings that she experienced.

"I felt I couldn't breathe. I couldn't sleep for the first eight months when we picked up the problem. I was wired."

A sense of desperation and exhaustion is appropriately captured in this quote from Kirsten.

"I said to Adam, 'She's going to make me very old, very quickly'."

This emphasizes the importance of greater awareness of ASD's, as more knowledge surrounding these disorders may enable family members to feel a greater sense of

empowerment and understanding at a time when the family desperately needs support from one another.

ii. Marital relationship

Although there was only one incidence of divorce out of the seven participants in this study, many parents emphasized the strain that their marriages experienced.

Autistic Spectrum disorders are thought to have more of a psychological impact and greater stress on parents than neurotypical or children with any other disability (Bristol, 1987; Gray 2002; Wolf, et al., 1989). Although reasons for this vary, more evidence of the above may be in the high divorce rate of parents of ASD children. According to Siegel (1996), this rate is reported to be 75-80%.

Nicoll (2004d, p.124), in discussing marriage break ups in families where there are children with special needs, states that “While the child is seldom the key factor in the decision for parents to divorce, the additional strain of meeting the child’s special needs often plays some role in marital breakdowns”.

Again the need for greater support facilities for families during the process of diagnosis and in the years thereafter is highlighted.

5.2.2 Siblings' experiences

- *Coping*

Responses from participants of this study indicate that, during the process of an ASD diagnosis, the focus centres on the ASD child, and the emotional and psychological well being of siblings may take second place. The difficulties experienced by neurotypical siblings emphasize the importance and need for specific support for them during this time.

The results discussed previously in this study indicate that a mother's depression seems to directly impact upon the coping abilities of a neurotypical sibling. This finding was supported in research by Rivers and Stoneman (2003, p.391), which states that "...findings are reflective of studies of siblings of children with Autism where marital and parental stress have been related to lower sibling self esteem and higher depression".

As mothers' emotions seem to directly affect the well being of other family members, their emotional and psychological well being needs to be a top priority of intervention during and following the diagnostic process.

Participants expressed a wide range of effects that they felt an ASD child had had upon a neurotypical sibling, ranging from various degrees of difficulties to positive influences. A significant amount of research has been done on the impact of an ASD child on his/her siblings which supports findings from the current study (Bagenholm & Gillberg, 1991; Hastings, 2003; Howling & Yates, 1990; Kaminsky & Dewey, 2002; Miller, 2001; Rivers & Stoneman, 2003). Research has been inconsistent in reporting the effects of an ASD on a neurotypical sibling. While some research has reported negative outcomes such as loneliness and isolation, others studies have indicated that having a sibling with ASD may have no

impact, and even a positive impact on neurotypical children in these families (Bagenholm & Gillberg, 1991; Roeyers & Mycke, 1995).

Behaviours and responses of an ASD child may be difficult for a sibling to handle. Rivers and Stoneman (2003) state that a sibling relationship may be particularly difficult because a disorder such as ASD involves numerous social deficits which may affect it. An ASD child may display “a limited repertoire of play and social/affective behaviour, tend to have poor eye contact, show communication deficits, and may not be socially responsive” (Rivers & Stoneman, 2003, p.383). This response of the sibling to the ASD child may be better understood applying the Family Systems Theory, as explained in the literature review.

- *Peer Relationships*

Some of the siblings of children from this study had a particularly difficult time in their relationships with peers, and participants acknowledged difficulties their children had experienced. Cassandra’s oldest son had to endure much criticism from peers, with comments such as the one below being offered to him on a regular basis.

“What’s the matter with your brother? Is he a retard?”

Roeyers and Mycke (1995) discovered in their research that although there seemed to be more acceptance among siblings of ASD children, there was also more embarrassment, supporting findings in this study. Behaviour of an ASD child may cause embarrassment for the sibling in social situations (Exkorn, 2005) thus limiting the opportunities in which the sibling can interact freely with peers. Studies done on the siblings of ASD children found that these siblings experience loneliness and difficulties with peers. The sense of loneliness

may be due to a lack of support and understanding of the siblings' peers (Gillberg, 1991; Kaminsky & Dewey, 2002).

5.2.3 Financial implications

Participants in this study highlighted the tremendous financial burden that is involved when having an ASD child. Due to various means of financial support; all of the participants were able to afford therapies, doctors, medication and facilitators necessary for their ASD child. However, they still acknowledged the financial strain. Kohler (1999) notes that the additional burdens often accompanying a diagnosis are financial strain, added work, loss of personal time, and an extensive range of other sacrifices made by parents. A study by Loynes (2000) found the financial strain of having an ASD child to be a profound burden for families. Due to the extensive range of therapies needed by an ASD child, the financial strain on parents is often overwhelming. This may be exacerbated by a lack of income from the mother, who places all her time and energy into support for her ASD child, and the father who may need to work more in order to provide adequately for the family's extended financial needs (Shacar, 2006).

If parents with the financial means (as in this study) have felt the difficulties involved in recruiting and employing adequate support for their ASD child, how possible is adequate support for the average South African, whose income is far less? This is a profound concern, and there is a great need in South Africa for the implementation of resources which will facilitate ASD children and be affordable to all South Africans. Financial implications of a diagnosis place adequate interventions for the average South African out of reach, possibly leaving many children undiagnosed and misunderstood in terms of their disability.

5.3 Aetiology

Only two notions of aetiology of ASD were highlighted and discussed by participants. One related to the MMR (Measles, Mumps and Rubella) vaccine, and the other to genetic predisposition.

The literature review discusses the many theories surrounding the causation of ASD's. These have developed over time from the theory of 'Refrigerator Mothers', to genetics. ASD's are neurological disorders, but it seems they are most likely caused by a combination of genetic predispositions towards these disorders, and environmental factors (Sicile-Kira, 2003). Members of Michelle's extended family suggested that their grandson's ASD was an indication of weak genes, and were concerned at the reflection this may have on the family line.

"...he should be castrated so that he doesn't continue the line of Autism in the family."

Although the MMR controversy seems to be highly debated in the USA and UK, only one participant in this study highlighted that it remained a concern for her in terms of her son's development of an ASD. The connection between ASD's and the MMR vaccine has become a highly debated and controversial topic in recent years. Although it is not believed that the vaccine causes ASD's, the question remains whether it affects children who may already be genetically predisposed to an ASD. It is believed that Thimerosal, a preservative in this vaccine that contains mercury, may be responsible for regressive Autism. This is seen in children who develop neurotypically until about eighteen months, and then show symptoms of regression (Lillienfeld & Arkowitz, 2007; Sicile-Kira, 2003). Thinking of the MMR vaccine as a possible cause of ASD's seems to be less prevalent in South Africa than in other countries.

5.4 Lack of Facilities & Support

In South Africa in particular, there seems to be a lack of available facilities for ASD children as they require highly specialized interventions. Most of the participants involved in this study had implemented their own measures in order to provide adequate educational environments for their ASD children.

Sandra emphasized this as an area of concern, especially as the prevalence of ASD's seems to be rising to great proportions.

“In this country, there's nowhere for children to go into care, or if there are, they are not keen on taking children or young adults with Autism. And there are more kids being diagnosed as well.”

The empowerment of a parent whose child has an ASD diagnosis is an important part of coping and acceptance. However, due to a lack of facilities and support, this is extremely difficult. Many doctors and specialists only have limited information about ASD's, and therefore seldom explain diagnoses in a way that is palatable to parents. Schall's study of family perspectives on raising a child with Autism supports the importance of a diagnosis as was emphasized by participants of this study. She found that “for all the families, the diagnosis gave them a sense of empowerment. Finally, they had information to learn, experts to find, and an explanation for their child's difference” (Schall, 2000, p.415).

When ASD's were first distinguished as disorders, the standard care for children with this diagnosis was institutionalization (Shacar, 2006). A consistent concern of participants in this study was that, although there are limited services and support systems available for families

today, there do not appear to be enough facilities for children with ASD's. This is also highlighted by Fujiura (1998), who found that, in many instances, families have become the single greatest support providers for their children with ASD's, and are in numerous cases an "integral part of the treatment of their children" (Shacar, 2006, p.5). Numerous studies conducted in the USA and the UK also mirror these concerns, and emphasise that one of the most common complaints of parents is the lack of availability and accessibility of quality facilities and services for ASD children (Shacar, 2006).

The above information highlights a significant need in South Africa for greater educational facilities and support structures regarding ASD to be implemented and established in South Africa.

5.5 Prevalence

The group of participants of this study were all in the middle to high income bracket, and thus were able to access specialised medical assistance over a number of years in order to gain a diagnosis. Not only is there a lack of facilities and services available to the South African population for diagnostic purposes, but only a minimal percentage has the financial means to access these in order to gain an ASD diagnosis.

Cassandra expressed significant concern for less fortunate people who did not have access to the limited support and facilities that are available.

"I feel desperate for people who are living in the townships who have these kids, I mean, God, you just want to create facilities where they can get some kind of relief, or just know they are not alone."

South African statistics of the prevalence of ASD's are expected to be in line with that of Europe and the USA, that is, at 15 to 40 per 10 000 births. It is presumed that a very small proportion of South African individuals with ASD have actually been diagnosed due to the significant lack of access the majority of the population have to diagnostic services.

5.6 Broader Importance of an ASD Diagnosis

Results from the current study indicate that there is broad-spectrum ignorance regarding ASD's in South Africa, both by medical practitioners and the general population.

Sicile-Kira (2003) highlights some of the many myths of perceptions of people with ASD's. Participants in this study mentioned some of these misconceptions regarding this disorder, for example, the "Rain man" myth, and the "Genius" myth. This again indicates that there seems to be a great need for public awareness drives on ASD. An understanding of ASD's may create more tolerance for families and provide a more supportive and understanding environment.

The lack of diagnostic services and facilities emphasizes the importance of information regarding ASD's being work-shopped at ground level so that the general public can increase their awareness. Support and adequate facilities should also be made available for ASD children from all walks of life. Due to the perceived rising proportions of this disorder, and the lack of knowledge about it, it seems necessary that future policies which address the serious nature of Autistic Spectrum Disorders in South Africa be implemented at a national level.

5.7 Existing Research & Contribution of this Study

Although the sample used in this study had limitations in terms of its small size, qualitative semi structured interviews allowed for a great depth and insight into the experiences of parents with an ASD child. The nature of the design allowed close interaction with and insight into the lives and emotions of parents whose children have an ASD. Many quantitative studies, taking the form of postal surveys and questionnaires, have been conducted in the field of ASD, yet the number of qualitative studies remains small (Fenske et al., 1985; Goin-Kochel et al., 2006; Harris & Handelman, 2000; Mansell & Morris, 2004).

Few studies highlighting the nature of South African parents experiences have been done, with the majority of research studies on ASD's done in the USA and UK. The results of this study concur with many European and American studies done, although figures seem to indicate an even a greater need for support and awareness of ASD's in South Africa.

5.8 Conclusions and Implications for South Africa

The results of this study highlight several important implications for consideration within the South African context.

Department of Health policies regarding developmentally based disorders need to be clarified, and steps to transform policies into practice need to be designed to ensure that, at a practice level, these disorders are recognized and that treatment can begin. Some suggestions are as follows:

1. The capacity of Government Health sites (from provincial hospitals to rural clinics) need to be enhanced through training professionals and upgrading facilities to be able to diagnose ASD's. Free and immediate access to Speech and Language therapists, Physiotherapists and Occupational Therapists should also be made available for children with a diagnosis of this condition. Access to health information on this disorder should also be available to parents, and should be translated into all official languages to ensure complete understanding of these disorders.
2. Campaigns of public awareness on Autistic Spectrum Disorders are necessary in urban, peri-urban and rural areas. A public awareness of ASD's will not only create more understanding and support for families of children with these disorders, but may also allow for the earlier recognition of symptoms, and thus earlier interventions leading to better prognosis.
3. There seems to be a need for the South African medical curriculum to include training around developmental disorders, so that medical practitioners are exposed to ASD's during their years of tertiary training. This training should include the development of an awareness of the early diagnostic tools available for use in diagnosing young children. It is plausible that this step will have far reaching consequences in terms of earlier diagnosis, less cost and frustration involved in lengthy diagnostic processes for parents, and also allow for earlier intervention for ASD children.

4. Much of this study has pointed to the lack of facilities available for ASD children in South Africa. Participants of this study had the financial means to access any suitable facilities, yet found very few. How much more so the need for suitable facilities to be created and made accessible to disadvantaged members of our society.

5. There seems to be a need for further support and understanding of families with ASD children, as the impact upon them has in many cases had far reaching effects on the lives of siblings, parents, and marital relationships. This support may be created by increasing public knowledge of these disorders, and the creation of more specialized and accessible facilities for ASD children.

Chapter 6

Conclusion

The aim of this chapter is to provide an overview of the study, and to present a summary of the main findings. It will highlight the limitations of this study, and will make recommendations for further study.

6.1 Overview of Study

The present study was a response to the concerning figures of the number of years and medical practitioners taken to receive an ASD diagnosis revealed in research conducted in the UK and the USA. Parents in these studies indicated great dissatisfaction with the diagnostic process, including emotions such as stress and frustration. This qualitative study aimed to research South African parents' experiences of the diagnostic process, interventions and facilities available. Results indicated an urgent need for intervention and policy changes regarding ASD's, on a variety of levels.

6.2 Limitations of this Study

Due to the nature of this research problem, the sample size used was small. Efforts were made to ensure that the lessons gained from this small group could be useful in other contexts and remain reliable. The data that emerged recurred throughout the interviews, indicating that similar issues and difficulties were experienced by all participants. As this research was qualitative by nature, it also allowed for a greater depth of insight into participants lives and experiences with ASD children.

The sample of research participants in this study is not representative of the South Africa population at a number of levels, such as racially and economically, thus further research is required to gain insight into more diverse experiences. This is discussed below.

All the participants were in a similar financial income bracket, allowing them access to a range of medical professionals, services and facilities. This study excluded financially disadvantaged participants, partly because this population was difficult to access. This is likely due to lack of diagnosis amongst financially disadvantaged communities, as the process of diagnosis has been shown to be such a lengthy and expensive one. This makes a diagnosis of ASD inaccessible and extremely difficult for the majority of the South African population. It is probable that the prevalence of ASD children is equally dispersed at all levels of society; however, many population groups still do not have equal access to medical facilities necessary to make specialised diagnoses such as ASD's. It should therefore be noted that the generalisability of this study to the broader South African population is limited.

6.3 Considerations for Future Research

From the information elicited in this study, there seems to be a need for this study to be replicated using a representative sample of the South African population. Studies could include the establishment of rates of diagnosis at paediatric clinics, and the number of diagnoses per geographic region. This would allow access for both qualitative and quantitative research to be undertaken in broader population groups. It is presumed that a study of this nature would further highlight the urgent need for greater knowledge and awareness of ASD's, the critical need to equip medical practitioners for diagnosis and use of diagnostic tools, and would prioritise the need for the creation of facilities and support in terms of ASD's.

In order to establish the optimal methods of empowering medical practitioners with knowledge of ASD's it is recommended that research be conducted into the knowledge that they possess of ASD's, their capacity to diagnose ASD's, and their familiarity and willingness to use early diagnostic tools. In this way loopholes in the diagnostic process in terms of medical professionals could be addressed further.

This study has identified some imperative areas of need in South Africa regarding Autistic Spectrum Disorders. These include health policy, medical curriculum, support and facilities for ASD families, public knowledge and awareness of developmental disorders, and the critical need for equal access to diagnostic procedures and interventions by all population groups in South Africa.

As mentioned previously in this study, the prevalence of ASD's seems to be increasing and, whatever the reasons for the rising numbers, the urgency for diagnosis and effective intervention escalates with this prevalence.

6.4. Final Comments

The initial aim of this research study was to capture the parents' experiential journey of their children's ASD diagnoses. Findings revealed these experiences included years of searching for diagnoses through various medical assessments, and added a tremendous amount of strain on parents and neurotypical siblings. Parents expressed the variety of emotions they had experienced, including stages of grief, frustration and acceptance. These experiences have demonstrated the great need for initiatives at the levels of policy development, education

(from public awareness through medical practitioner training), research and practice. In particular, a lack of knowledge on all levels has been highlighted, as well as a significant need for more research. Participants in this study drew particular attention to the challenges and difficulties involved in managing and having an ASD child. It is hoped that this study will be able to assist in the development of further research and serve as a guide for parents embarking on similar journeys.

“It’s not the end of the road; it’s a new journey starting all the time...”

Michelle, January 2008.

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Appendices

APPENDIX A

National Institute of Mental Health (NIMH) indicators for ASD's

- Does not babble, point, or make meaningful gestures by one year of age
- Does not speak one word by sixteen months
- Does not combine two words by two years of age
- Does not respond to his or her name
- Loses language or social skills
- Avoids eye contact
- Doesn't seem to know how to play with toys
- Excessively lines up toys or other objects
- Is attached to one particular toy or object
- Does not smile
- At time times seems to be hearing impaired

(Retrieved from Exkorn, 2005, p.8)

APPENDIX B

M-CHAT: Modified Checklist for Autism in Toddlers

1. Does your child enjoy being swung, bounced on your knee, etc?
2. Does your child take an interest in other children?
3. Does your child like climbing on things, such as up stairs?
4. Does your child enjoy playing peek-a-boo/ hide-and-seek?
5. Does your child ever pretend, for example, to talk on the phone or take care of dolls or pretend other things?
6. Does your child ever use his or her index finger to point, to ask you for something?
7. Does your child ever use his or her index finger to indicate something of interest?
8. Can your child play properly with small toys (e.g., cars or bricks) without just mouthing, fiddling or dropping them?
9. Does your child ever bring objects over to you (parent) to show you something?
10. Does your child look you in the eye for more than a second or two?
11. Does your child seem oversensitive to noise? (e.g. plugging ears)
12. Does your child smile in response to your face or your smile?
13. Does your child imitate you? (e.g., you make a face; will your child imitate it?)
14. Does your child respond to his/ her name when you call?
15. If you point to a toy across the room, does your child look at it?
16. Does your child walk?
17. Does your child look at things you are looking at?
18. Does your child make unusual finger movements near his/her face?
19. Does your child try to attract your attention to his/her own activity?
20. Have you ever wondered if your child is deaf?
21. Does your child understand what people say?
22. Does your child sometimes stare at nothing or wander with no purpose?
23. Does your child look at your face to check your reaction when faced with something unfamiliar?

(Robins, Fein, Barton & Green, 2001)

APPENDIX C

Participant Consent Form

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PIETERMARITZBURG, 3209
South Africa
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Consent Form

I am Naomi Holdt, a Psychology Masters Student from UKZN, doing research on parents' experiences on the road to diagnosis of an ASD in their children. I am conducting this research to provide a psycho educational and accessible tool for parents battling to come to terms with a child facing a life long developmental disability. This study may provide easier access to an understanding of the traumatic emotions being experienced by parents and may be used to assist others facing a similar struggle.

I am interested in finding out more about your personal experiences regarding your child's ASD diagnosis in the years and months preceding this. The results of this study will be released in a thesis. No personally identifiable details will be released and pseudonyms will be used for both your and your children's names in order to protect your identity. Any significantly identifiable information will also be changed.

You have been asked to volunteer for this interview, in which we will specifically be discussing your experiences of diagnosis. I will also be conducting interviews with other parents whose children have been diagnosed with an ASD.

Your participation in this study is voluntary. Although your input will be greatly valued and appreciated, should you wish to withdraw at any stage, you are free to do so. Only my supervisor, Carol Mitchell, and I will have access to your and your children's names. These will be changed in the thesis to protect your identities. Although this study will not be of any

direct benefit to you, it could be a valuable source of information used to assist South African parents facing a diagnosis.

The interview will last about 60 minutes. The discussion will be focused and led by your unique experiences, although I will ask some open ended questions. I am interested in your personal experience and emotions involved in the process which led up to the eventual ASD diagnosis of your child. Should an issue be raised which upsets you, you will be de-briefed after the interview, and directed to nearby counselling services or parent support group in the area, should it be necessary. If you need to speak to a professional after I have left, _____ can be contacted at _____. If you have any other questions regarding this study, you can contact Carol Mitchell, at the UKZN Psychology Department at 033 2606054.

If you have any complaints regarding this study you may contact the ethics committee of UKZN at _____

CONSENT

I hereby agree to participate in research regarding parents' experiences on the road to diagnosis of their ASD child. I understand that my participation is voluntary and I can leave the interview at any time and that this decision will in no way affect me negatively.

The purpose and nature of this study has been explained to me, and I understand that my participation will mean discussing my personal experiences of my child's intervention model. I understand that this participation will not benefit me directly.

I have received the telephone number of a contact person should I have any issues or questions relating to this study.

I understand that my participation and name will remain confidential, as well as that of my child's.

I understand that should I request the results of this thesis, they will be made available to me after its completion.

Signature of participant

Date

In addition to the above, I agree to an audio recording of this interview so that data can be accurately captured. I understand that no personally identifiable information will be released in any form and that this audio recording will be kept locked in a secure environment and destroyed or erased once data capture and analysis are complete.

Signature of participant

Date

APPENDIX D

Semi-structured interview guide for parents

What was it like before your child was diagnosed?

Please can you relate some specific experiences that happened during this time?

How did your family cope before the diagnosis?

Please describe your experience of discovering you child had ASD. How did it begin?

When did you first begin to suspect that his/her development was unusual? Please describe the factors surrounding this.

What were the first steps that you took after you first became concerned?

Please tell me more about the doctors/ specialists that you took your child to and what their recommendations and initial diagnoses were?

How was the diagnosis made?

Who made the diagnosis?

How did the family cope after a diagnosis had been made?

How did the diagnosis affect your marital relationship?

Who else in the family was affected and how?

How long was the entire process before an ASD was officially diagnosed, from the time you became concerned about your child's development?

What were your feelings once the diagnosis had been made? (probe: concerns, fears, thoughts)

If you were to advise parents about the diagnostic process, what would you say to them?