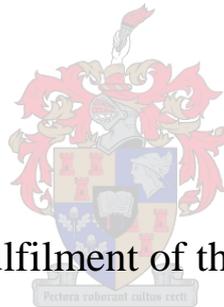


**RAISING A CHILD WITH AUTISM SPECTRUM DISORDER:
UNDERSTANDING PARENT SUPPORT SYSTEMS**

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Thesis presented in partial fulfilment of the requirements for the degree
of Master of Educational Support in the Faculty of Education at
Stellenbosch University

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction thereof by Stellenbosch University will not infringe any third-party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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April 2019

ABSTRACT

Autism Spectrum Disorder (ASD) is a developmental disorder that is currently being diagnosed in one in every 59 children worldwide. It is considered one of the most stressful childhood disorders for parents to cope with, and it has been associated with the escalation of economic-, social-, physical- and psychological strain on families, as well as a decrease in overall family well-being. Parents, who are faced with the challenges of raising a child with ASD, are often in great need of social support. Social support can be provided in various forms and come from a variety of sources. Research on parents' support needs for a child with ASD and the ways in which they perceive different support systems is important, as it could increase public understanding of effective support systems for such parents. This study on the support systems of parents of children with ASD is situated within the field of educational support, because parent support is an integral part of learner support.

This qualitative study explored the value that support systems have in the lives of South African parents who are raising a child with ASD. The individual lived experiences of four parents with regards to their support needs and –systems were researched as guided by the following research questions:

- What are the support needs of parents raising a child with ASD?
- What are the experiences of parents with the support systems that they use?
- Why do parents raising a child with ASD endorse some support systems over others?

With narrative inquiry as design, I sought to tell the stories of these parents. My understanding was that of multiple realities that are constructed by individuals who share similar, but also unique, life experiences. I positioned myself in the interpretive paradigm, as I wanted to understand the individual lived experiences of these parents with regards to their support needs and –systems. Data was collected by conducting individual in-depth interviews with the four purposively selected parents who are the primary caregivers of a child with ASD, for the rich and useful information they could provide.

What the study revealed was that such parents face many personal-, family- and social challenges that stem from their child's maladaptive behaviour and for which they need reliable support systems. The support these four parents relied on included personal resources, family support, friends, therapists and schools. The findings of this study have implications for how the learning-

support environment needs to engage with children with ASD and their parents. What the narratives of parents of children with ASD tell us, is that the support needs and valued support systems of each parent of a child with ASD are just as much on a spectrum as the children with ASD are. Therefore, there should exist an understanding that, though families of a child with ASD share similarities, each family's circumstances are unique, making it important to understand their specific needs and to support them and their child with ASD accordingly.

OPSOMMING

Outisme Spektrum Versteuring (OSV) is 'n ontwikkelingssteurnis wat tans by een in elke 59 kinders wêreldwyd gediagnoseer word. Dit word gereken as een van die mees veeleisende kinderverteurings vir ouers om mee om te gaan en dit word geassosieer met 'n toename in ekonomiese-, sosiale, fisieke- en sielkundige spanning binne gesinne asook 'n afname in die algemene welstand van gesinne. Ouers wat gekonfronteer word met die uitdagings daarvan om 'n kind met OSV groot te maak, het dikwels 'n groot behoefte aan sosiale ondersteuning. Sosiale ondersteuning kan in baie vorme en van 'n wye verskeidenheid bronne kom. Navorsing oor die ondersteuningsbehoefte en die wyses waarop hierdie ouers ondersteuning ervaar, is belangrik aangesien dit die publiek se verstaan van effektiewe ondersteuningsstelsels vir die ouers van kinders met OSV kan verhoog. Hierdie studie van die ondersteuningsstelsels van ouers met kinders met OSV is gesetel binne die veld van opvoedkundige ondersteuning omdat ouerondersteuning 'n integrale deel van leerderondersteuning is.

Hierdie kwalitatiewe studie het die waarde van ondersteuningsstelsels in die lewens van Suid-Afrikaanse ouers met kinders op die outisme spektrum verken. Die individuele lewenservarings van hierdie ouers, in terme van hulle ondersteuningsbehoefte en -stelsels, is ondersoek soos gelei deur die volgende navorsingsvrae:

- Wat is die ondersteuningsbehoefte van ouers wat kinders met OSV grootmaak?
- Hoe ervaar ouers die ondersteuningsstelsels waarvan hulle gebruik maak?
- Waarom verkies ouers wat kinders met OSV grootmaak sekere ondersteuningsstelsels bo ander?

Met narratiewe ondersoek as navorsingsontwerp, het ek gepoog om hierdie ouers se stories te vertel. My uitgangspunt was dat veelvuldige realiteite gekonstrueer word wanneer individue gelyksoortige, dog unieke, lewenservaringe deel. Ek het myself binne die interpretiewe paradigma geposisioneer omdat ek die individuele lewenservarings van hierdie ouers, in terme van hul ondersteuningsbehoefte en -stelsels, wou verstaan. Data is versamel deur individuele, in-diepte onderhouds te voer met vier ouers van kinders met OSV, wat doelgerig uitgekies is vir die ryk en bruikbare inligting wat hulle kon voorsien.

Wat die studie bevind het, was dat ouers van kinders met OSV ernstige persoonlike- familie- en sosiale uitdagings in die gesig staar as 'n direkte gevolg van hul kinders se wanaangepaste

gedragpatrone, en dat hulle betroubare ondersteuningsisteme benodig om hiervoor te kompenseer. Die ondersteuning waarop hierdie vier ouers staatgemaak het, het persoonlike hulpbronne, familie-ondersteuning, vriende, terapeute en skole ingesluit. Die bevindinge van hierdie studie het implikasies vir hoe die omgewing van leerondersteuning met kinders met OSV en hulle ouers moet omgaan. Wat die narratiewe van ouers met kinders met OSV vir ons sê, is dat die ondersteuningsbehoefte en gewaardeerde ondersteuningsisteme van elke ouer met 'n kind met OSV net soveel op 'n spektrum is as die kinders met OSV self. Daarom moet daar 'n verstaan wees van die feit dat, alhoewel die families van 'n kind met OSV ooreenkomste deel, elke familie se omstandighede uniek is, wat ons wys op die belangrikheid daarvan om hul spesifieke behoeftes te verstaan en hulle daarvolgens te ondersteun.

DEDICATION

I dedicate my work to every parent who is struggling to cope with the challenges of raising a child with ASD and to the four mothers who participated in this study: you are my heroes.

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CHAPTER 1

1.1 BACKGROUND AND MOTIVATION FOR THE STUDY

Autism Spectrum Disorder, referred to as ASD in this thesis, is considered one of the most stressful childhood disorders for parents to cope with (Fewster & Gurayah, 2016). This is because the disorder often disturbs the lives of the entire family. The presence of a family member with ASD has been associated with the escalation of economic-, social-, physical- and psychological strain in the family, high divorce-rates, time strains, and decreased overall family well-being. Research even shows that, in cases where a child in the family is diagnosed with ASD, it is not uncommon to find that the lives of all the family members are organised and structured around the child with ASD (Cappe, Wolff, Bobet, & Adrien, 2011; Karst & Van Hecke, 2012).

ASD is a developmental disorder that can currently be diagnosed in one in every 59 children worldwide (Centre for Disease Control, 2018). According to the Fifth Edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-V), children with ASD always experience and display difficulty with social interaction and communication. They would, for example, often display anti-social behaviour, such as responding inappropriately in conversations or misreading nonverbal clues. As such, children living with ASD have difficulty building age-appropriate friendships. Other typical behaviour for such children includes being overly focused on specific objects, engaging in excessively repetitive behaviour, being resistant to change and hyper- or hypo-reactivity to sensory stimuli (American Psychiatric Association, 2013).

Beyond the diagnostic criteria defined in the DSM-V, ASD is also associated with a wide variety of socially unacceptable behaviours, which in the literature is also referred to as maladaptive behaviours. Some of these behaviours manifest as difficulty in feeding and toilet training, emotional outbursts, violence, aggression, self-injury, and screaming. These maladaptive behaviours of children with ASD often cause parents and caregivers of children with ASD to experience distress, anxiety, depression and even guilt. Due to the way society responds to the, sometimes, antisocial behaviours of children with ASD, parents could find themselves being socially isolated and eventually experience a general exclusion from society (Hall & Graff, 2012).

Research has repeatedly shown that parents of children with ASD experience more anxiety, chronic stress, physical- and mental illness and present more depressive symptoms than parents of typically developing children, and even those of children with other developmental disorders such as Down's syndrome (Costa, Steffgen & Ferring, 2017; Dykens, Fisher, Taylor, Lambert, Miodrag, 2014; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Weiss, Wingsiong & Lunsy, 2014; Keenan, Newman, Gray, & Rinehart, 2016; Vasilopoulou & Nisbet, 2016). They are more prone to serious mental health problems and an overall decrease in well-being and physical health. It is very common for the parents of children with ASD to suffer feelings of isolation and exhaustion resulting from society's lack of understanding and the stigmatization of their children's antisocial behaviour (Costa et al., 2017; Dykens et al., 2014). From the perspective of educational support, this is cause for concern, because highly stressed parents are likely to be less effective in their parenting roles. This could lead to poor outcomes in the child with ASD, especially since current policies and practices generally serve the child with ASD and neglect to do the same for the parents (Dykens et al., 2014).

Parents who are faced with the challenges of raising a child with ASD, are often in great need of emotional- and social support. Cobb (1976, as cited in Siklos & Kerns, 2006, p. 921) explains the concept of social support as "information leading the person to believe that he is cared for and loved, valued and esteemed, and is important in a network of mutual obligation and communication". Research shows that this kind of support can help to moderate the stress levels of parents who are raising a child with ASD (Carrol, 2013).

Social support can come in various forms and from a variety of sources. Individuals, such as a spouse, family, friends and professionals, as well as groups such as community programmes and specialist services, could be service providers. According to research, support groups can be very helpful for many parents of children with ASD. Parents can be members of groups that meet in person on a regular basis or of virtual groups that communicate through online forums. Irrespective of the format, these groups have been found to be especially useful as a platform for parents to share their experiences and ideas and to encourage parents to support one another. They also help facilitate the parents' acceptance of the ASD diagnosis (Banach, Ludice, Conway & Couse, 2010). Participation in such groups is associated with lower levels of stress and a more positive mood. Membership to such groups also provides a relatively cost-effective way for parents raising a child with ASD to perceive support (Clifford & Minnes, 2012).

This study was interested in understanding the value that support systems have in the lives of South African parents who are raising a child with ASD. One of the most important considerations in the provision of support is the parents' belief of the specific support they need and their perceptions of whether or not their needs are being adequately met (Siklos & Kerns, 2006). My ontological stance is that the support needs of each parent who is raising a child with ASD are unique, and that the perceptions and beliefs regarding the support needs of every family, and therefore every parent, are different. This stance is also informed by an understanding of significant ethnic and racial differences in the way parents perceive and experience support (Benivedes, Carretta & Mandell, 2015). Research on parents' support needs, and the ways in which they perceive different support systems, is important as it could increase public understanding of effective support systems for parents raising a child with ASD. This is of specific interest within the field of educational support as support in education and learning goes beyond learner support, to include the support systems available to those who work with children in need of support. New knowledge could shift existent ways of thinking about the types of support available at various levels such as support to teachers by fellow teachers, specialist teachers and other professionals; as well as support to any of the other role players within the system, including parents (Department of Basic Education, 2014).

As part of my research module in this MEd programme, I conducted a pilot study on the challenges and support needs of parents who are raising a child with ASD. The findings of my pilot study prompted me to conduct scientific research on the support systems that parents who are raising a child with ASD need and access. My pilot study also pointed out a gap in the existing literature on knowledge about the support systems to South African parents of children with ASD.

The South African policy on Screening, Identification, Assessment and Support (SIAS) states that learning support also includes parent support (Department of Basic Education, 2014). Even so, inclusive schools, and specifically special schools for learners with ASD, seldom focus on parent support systems as part of their support to the learner with ASD. If schools are to become more effectively involved in supporting parents who are raising a child with ASD, they need to have a thorough understanding of the support systems that parents perceive as helpful so that they can develop better support strategies.

1.2 THE RESEARCH PROBLEM, AIMS, GOALS AND QUESTIONS

Policy regarding educational support requires educational institutions to become more involved in parent support (Department of Basic Education, 2014). Internationally, ASD is a well-researched field (American Psychiatric Association, 2013; Banach et al., 2010; Benevides, Caretta & Mandell, 2016; Cappe et al., 2011; Carrol, 2013; Clifford & Minnes, 2012; Cobb, 1976; Department of Basic Education, 2014; Fewster & Gurayah, 2016; Hall & Graff, 2012; Karst & Van Hecke, 2012; Siklos & Kerns, 2006), and so, too, are the emotional effects on parents and their coping strategies (Carrol, 2013; Banach et al., 2010). However, there appears to be a gap in the literature on the experiences of parents with regards to their personal support systems. This can be attributed to the limited liaising with and involvement of parents who are raising children with ASD, and the collection of information about their challenges and their need for support systems. This lack of collaboration with parents seems to have contributed to the paucity of literature on the phenomenon of parent support, especially as it pertains to the caregiver of a child with ASD.

The primary goal of the study was, therefore, to increase understanding of such parents' experiences when raising a child with ASD. The value of this research, thus, lies in its potential to advance an understanding of the challenges that such parents experience, as well as their individual experiences with different support systems. Such knowledge would be beneficial for services and professionals within a network of educational support and could spearhead the adoption of a systematic approach that considers the needs of both children with ASD and their parents.

The objectives of this study were to:

- Determine the support needs of parents raising a child with ASD
- Explore different support systems available to parents raising a child with ASD
- Understand why parents of children with ASD perceive certain support systems as valuable

The primary research question that the study aimed to answer was: What are the roles that support systems play in the lives of parents raising a child with ASD?

The three secondary questions that were formulated were:

- What are the support needs of parents raising a child with ASD?
- What are the experiences of parents with the support systems that they use?

- Why do parents raising a child with ASD endorse some support systems over others?

1.3 RESEARCH DESIGN

I conducted this study within the qualitative research paradigm, as the purpose of the study was to understand the support systems available to the parents as the primary caregivers of a child with ASD. Though they are all raising a child with ASD, each one's experience was unique. My understanding of their lives was that there are multiple realities with some shared similarities (McMillan & Schumacher, 2010). I made this assumption based on the understanding that context, personal factors and circumstances in the lives of individuals are unique; thus, it is hardly possible that there could be only one reality constructed around the shared life experience of the parenting of a child with ASD.

Because I studied these parents' subjective experiences of their worlds, I positioned myself in the interpretive paradigm. The methods that are associated with qualitative research allowed me to form subjective relationships with the research participants (Terre Blanche & Durrheim, 1999). It is never possible to entirely separate oneself and your own realities from theirs. Through a process of long, in-depth narrative interviews with each participant, relationships developed between myself and each of the participants, which influenced how I interpreted their life experiences. Through acknowledging this, and constantly reflecting on my research actions, I am demonstrating how subjectivity is an important aspect to qualitative research. As the researcher, I became part of my own research, but without sacrificing the validity of the data.

I chose a narrative approach to this study, because narrative inquiry as a method, makes use of the lived experiences of people as told in stories (Clandinin & Connelly, 2000; Creswell, 2007). The experiences that were the focus of this study were the parental experiences of support, delimited to parents who are raising a child with ASD.

1.4 METHODS

In narrative inquiry, data can be collected in a variety of ways including conversations, interviews, and the studying of artefacts such as photos and journals (Savin-Baden & Howell, 2013). However, oral interviews seem to be the most common method used for narrative research (Squire, 2008). Data for this study was collected by conducting individual interviews with four purposively selected participants. Four parents were carefully selected as participants for their potential to provide rich and useful information (Savin-Baden & Howell, 2013). Selection criteria

were that they had to be the biological parent and primary caregiver of a child who has been diagnosed with ASD.

I gained access to participants through various professional contacts and networks. I delimited my population to native South Africans who speak either Afrikaans or English, as these are the languages in which I am competent. I made use of an interview guide to conduct semi-structured interviews with each participant. Each interview was recorded, transcribed and then analysed inductively. Interviews were all conducted in a physical location that was chosen by the participant.

1.5 ETHICAL CONSIDERATIONS

When I considered the ethical aspects of this research project, I gave substantial attention to the possible risks and benefits of my research and I committed myself to conducting every aspect of the research with integrity. This means that I gave due credit to any sources I had consulted, and that I did not fabricate or falsify any data or findings (Mouton, 2001).

In my relationship with the study's participants, I was also committed to full disclosure about the study's aims, so anyone participating in the study was informed of the aims and goals of the research and how the data will be used. I negotiated that I would also only use data that I had collected from the research participants with their full and informed consent. As privacy and confidentiality are considerable concerns in narrative research (Clandinin & Connelly, 2000), I made every effort to protect the identities of the research participants throughout the research process.

Research studies have the potential to cause harm. Researchers must ensure that they do not cause any emotional or psychological harm to any of the participants through their research (Savin-Baden & Howell, 2013). The topic could potentially have been a sensitive issue to parents who are facing the challenge of raising a child with ASD and the questions asked during the interviews could possibly have elicited reactions from the participants that might have included various feelings of dissatisfaction with their existing support system. Though I endeavoured to prevent this from happening, participants were informed of the availability of a counsellor should they, at any time, have felt the need to attend a debriefing session following their interviews.

1.6 CLARIFICATION OF KEY TERMS

Autism Spectrum Disorder:

The term Autism Spectrum Disorder, or the acronym ASD, refers to the diagnosis of children who meet all four of the criteria set out in the new diagnostic criteria for the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V). In keeping with the DSM-V, the term Autism Spectrum Disorders includes disorders previously identified as Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) and Rett's Disorder (Kaufmann, 2012).

Parent:

For the purpose of this study, the term 'parent' will refer to any adult who acts as the primary caregiver of a dependent minor who is his or her biological offspring or legal adoptee.

Educational support:

The concept of 'educational support' in this study is wide and refers to any action undertaken by any person involved in any aspect of education with the intention of improving teaching and learning in some way. It, therefore, includes not only support in schools and classroom environments but it also involves support to teachers, other professionals and, of course, parents.

Support systems:

In this study, 'support systems' are defined as complex and interrelated social systems (such as family, friends, therapists, or social media, for example) that provide physical-, emotional-, social- or psychological support to someone who is struggling, and which leads to that person feeling valued, cared for and supported.

1.7 OUTLINE OF THE RESEARCH REPORT

The first chapter serves as an orientation to the study and provides the relevant background information in light of which the remainder of the study should be understood. In this chapter, a brief background and rationale for the study is provided as well as an introduction to the research problem, methodology used for the research and the specific aims of the study. Key terms are also briefly explained to clarify concepts for the purpose of the study.

Chapter Two will provide a thorough overview of existing literature related to ASD, parent support systems, and educational support. It will also illustrate the research gap that I have identified which served as the justification for my study and its potential contribution to the field.

The research design and methodology of this study will be carefully outlined in Chapter Three. The chapter will include details regarding the selection of participants and the interview guidelines used during the parent-interviews, as well as a detailed description of the methods used to analyse the data collected. All relevant ethical considerations will also be discussed in this chapter.

Chapter Four of this study will present the findings of the research. Data will be organised according to the themes that emerged through the careful processes of inductive analysis and presented in a structured and concise way.

In conclusion, the findings and themes presented in Chapter Four will be discussed in Chapter Five. This chapter will also include a description of the limitations of this study along with any implications for practice and my recommendations for further research.

CHAPTER 2

2.1 INTRODUCTION

In the previous chapter a brief introduction and overview of the study was set out. A further part of a researcher's process is to engage in an in-depth literature review of the topic. The purpose of a literature review is to give an overview of existing literature on the research phenomenon under investigation. The need for further research stems from gaps that are identified in the existing literature that warrant further inquiry into a specific field of research.

When reviewing studies that have been done in the field of ASD and parent support, there are generally two types of studies to consider: quantitative studies and qualitative studies. Quantitative studies are typically used to research the effect of interventions in pretest-posttest studies such as a study by Dardas and Ahmad (2015a) which compared the stress levels and quality of life of parents of children with ASD. These were measured before and after an intervention that sought to equip them with particular coping strategies. The study determined the value of those coping strategies. Other studies compare the psychological distress, parenting-stress and anxiety of parents of children with ASD as compared to those of the parents of typically developing children, as was done in a study by Keenan et al. (2016).

Qualitative studies, on the other hand, are studies that are aimed at understanding the experiences of group or individuals, such as parents who are raising a child with ASD. The research methods used in these studies differ greatly from those in quantitative studies. Woodgate, Ateah and Secco (2008), for example, conducted a study of the general experiences of parents who are raising a child with ASD, by using interviews to gather personal accounts of what it is like to live with and be responsible for a child with ASD. Alli, Abdoola and Mupawose (2015) explored parents' journey into the world of autism by means of interviews in an attempt to understand the challenges and coping strategies of parents raising a child with ASD.

When I embarked on this study, I found ASD to be a well-researched field and that much research has been done on the experiences of parents raising a child with ASD. However, I identified a gap in the literature on parent support amongst the parents of children diagnosed with ASD in South Africa. Thus, by researching the support systems of South African parents who are raising a child with ASD, I hope to add new information to what is already known about the support needs of these parents. Potentially, new information on how to provide support to these parents, can lead to improved educational support systems too.

2.2 THEORETICAL FRAMEWORK: ECOSYSTEMIC PERSPECTIVE

The primary theory that shaped my theoretical framing for this study, is Urie Bronfenbrenner's bioecological theory of human development. He argues that, by strengthening human relationships within supportive environments, it is possible to increase the extent to which a person's development has a positive outcome (Bronfenbrenner & Ceci, 1994). Bronfenbrenner (2005, p. 6) explains that "over the life course, human development takes place through processes of progressively more complex reciprocal interaction (proximal processes) between an active, evolving, bio-psychological human organism and the persons, objects, and symbols in its immediate external environment." I would argue that humans develop through the interaction they have with other humans and their external environment, which supports the need for an inquiry into the systems that provide support to the parent of a child with ASD in his/her process of development as a parent and a human being.

For Bronfenbrenner, there are four interrelated systems within which human development takes place, namely the microsystem, the mesosystem, the exosystem and the macrosystem, all of which interact with the chronosystem that represents chronological time (Donald, Lazarus & Moolla, 2014). Microsystems are the innermost systems where regular interaction takes place between the individual and the people and objects in his or her life. Bronfenbrenner refers to these interactions as proximal processes and they lie at the very core of his theory. This system is important in the study because it is where the daily interactions between the parent and his/her child with ASD happen, as well as other face-to-face interactions within the family unit (Algood, Harris & Hong, 2013). These various microsystems interact within a mesosystem where the other relationships within the family also impacts on the parent, such as the interactions between the children in the family or the interactions between parents and the individual children in the family. It encompasses all the proximal processes within the immediate family circle and also has a great effect on development (Algood et al., 2013).

The local community forms part of the exosystem. Within this system one finds the healthcare system, the educational system and the social circles in which the parent functions, such as the workplace, church or a friend-group. The exosystem also includes contexts in which the parent might not directly be involved, but which may influence the people who have proximal relationships in the microsystems. These are places such as a spouse's workplace or the schools of other children in the household (Donald, Lazarus & Moolla, 2014). The macrosystem is the context where broader issues such as poverty, social values within society, politics and the

provision of social services take place (Algood et al., 2013), and the chronosystem makes provision for the effects of prior life events on human development, because events that took place at a certain point in time, even far into the past, may still affect the contexts of one or more of the other systems (Bronfenbrenner, 2005).

2.3 INTRODUCING AUTISM SPECTRUM DISORDER (ASD)

In this section of the review, I start by unpacking the term, autism. The term ‘autism’ is derived from the Greek word *autos*, meaning ‘self’. This term was first used in 1912 in an American Journal of Insanity to describe schizophrenic tendencies of isolation, but it was in 1943, during the Second World War, that Leo Kanner first identified autism. Between one and four children in 10,000 were thought to have the disorder at the time of its discovery. It was also during the Second World War that Dr Hans Asperger observed children who appeared to have relatively normal intelligence but portrayed autistic tendencies. The research of both Kanner and Asperger has made substantial initial contributions to the knowledge base within this field (Glazzard & Overall, 2012).

Today, Autism Spectrum Disorder (ASD) is diagnosed in one in every 59 children worldwide (Centre for Disease Control, 2018), but incidences increase every year as more and more children are diagnosed with ASD. At present, South Africa also relies on this prevalence rate as no reliable local statistics are available on the number of ASD cases. ASD affects people of all cultures and socio-economic classes, though it has been found to be four times more common in males than in females (Association for Autism, 2012).

The new diagnostic criteria for autism, according to the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) which was published in May 2013, can be summarised as follows:

Children diagnosed with ASD must meet criteria A, B, C, and D.

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all three of the following:

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviours used for social interaction
3. Deficits in developing and maintaining relationships;

B. Restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change
3. Highly restricted, fixated interests that are abnormal in intensity or focus
4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities);

D. Symptoms together limit and impair everyday functioning. (American Psychiatric Association, 2013).

Though it is scientifically necessary to establish specific criteria for the diagnosis of ASD, it is important to remember that all cases of ASD are unique. ASD is a spectrum disorder and it manifests very differently in each individual. Just like fingerprints, no two cases are the same (Glazzard & Overall, 2012). What needs to be understood is that every case of ASD comes with a specific context with regards to the individual, the immediate family, the extended family and community, culture, background, education, socio-economic status and a host of other factors. It is, therefore, valuable to study individual cases and experiences as the realities for everyone involved will most likely be unique.

With these differences in mind, the DSM-V has specifiers where the level of severity of the ASD diagnosis is recorded as being on one of three levels of “support needed for each of the two psychopathological domains” (American Psychiatric Association, p. 52) which are social communication and restricted, repetitive behaviours. The three severity levels are described as “requiring support” (Level 1), “requiring substantial support” (Level 2), and “requiring very substantial support” (Level 3) (Kissel & Nelson, 2016).

Along with the symptoms defined in the DSM-V, there is a wide range of other social behaviours that are associated with ASD. Many of these are described in the literature as maladaptive behaviours and as having the potential to result in social isolation and exclusion from social activities (Hall & Graff, 2012). It is necessary to mention here that, from an inclusive education perspective, this classification of behaviours is still firmly based on the medical model where the problem is considered to lie within the child. This works against focusing on the specific needs of the diagnosed individual and on how barriers to development can be removed. However, for the

sake of this study, and because the focus of this study was on the parents of children with ASD rather than on the children themselves, it was deemed acceptable to refer to some of the behaviours associated with ASD as maladaptive.

2.4. CHARACTERISTICS AND MALADAPTIVE BEHAVIOURS IN ASD

My review of the literature shows that, unlike the child characteristics previously described as typical for an ASD diagnosis, maladaptive behaviours are not specifically part of the ASD diagnosis. Even so, it is tied to a wide range of socially unacceptable behaviours that have been found to consistently predict greater levels of general stress in parents caring for a child with ASD (McStay et al., 2014). The occurrence of these behaviours varies from child to child and presents on various levels of severity, as is the case with any criteria in an ASD diagnosis. However, they are all considered maladaptive, socially disruptive or disturbing and they impair successful social functioning of the child and, consequently, often the parent to some extent (Glazzard & Overall, 2012).

Violence, hostility, anger and self-destructive tendencies as well as disruptive or repetitive behaviours are only a few of the maladaptive behaviours associated with ASD (Costa et al., 2017). Along with these we can list anxious personalities, a total lack of empathy, mild to severe food aversions, intolerances and allergies, the absence of speech, as well as the inability to read and respond appropriately to social cues (Glazzard & Overall, 2012). Parents of children with ASD often also describe their children as being difficult, with frequent and long-lasting tantrums, easily frustrated, inattentive, and withdrawn or depressed (Costa, et al., 2017).

What these studies on ASD have found was that, if these behaviours are not carefully managed, they have the potential to result in negative consequences for those on the spectrum and their families. Hall and Graff's (2012) research found a positive relationship between these kinds of behaviours and parental stress levels. Part of the reason for this is that most parents desire for their children to behave in ways that are typical for children of a specific age and that are socially acceptable. From the very term 'maladaptive behaviour', it is clear that the child with ASD's behaviour is considered to be inadequately adjusted to social encounters. This often causes stress in parents because they feel that they are unable to control their child's unacceptable behaviour (Hall & Graff, 2012; McStay et al., 2014). It is, therefore, not surprising that many of the therapies and treatments that parents seek for their children are intended to improve the children's social integration and to teach them social skills. The hope is also that the treatments would

lessen the symptoms of allergies, sleeplessness, anxiety and depression (Vasilopoulou & Nisbet, 2016).

2.5. COMMON CHALLENGES FOR PARENTS OF CHILDREN WITH ASD

Parenting stress is a complex construct that involves behavioural, cognitive, and affective components and is a combination of child and parent characteristics, as well as family situational components as they relate to the person's appraisal of his or her role as a parent (Whiteside-Mansell, Ayoub, McKelvey, Faldowski, Hart, & Shears, 2007). It is a normal reaction for parents to become troubled or stressed when their child is short-tempered, introverted, irritable, non-compliant or unable to communicate (Hall & Graff, 2012). The conditions and actions that cause stress to the parents of children with ASD are, however, more complex than this.

What my literature review showed is that families who live with ASD experience problems that typical families do not have to deal with on a daily basis (Whiteside-Mansell et al., 2007; Hall & Graff, 2012; Cappe et al., 2011; Willis, Timmons, Pruitt, Ekas, Schneider & Alessandri, 2016; Alli et al., 2015; Weiss et al., 2014). Children diagnosed with ASD often experience disturbed sleep, agitation, cries, stereotyping and self-injury. As babies they are typically challenged with difficulties in feeding and toilet-training, and some suffer epileptic seizures. According to Cappe et al. (2011) such children struggle to engage with others, due to a lack of social or emotional reciprocity and their exhibition of other unusual behaviours. For example, children with ASD often struggle to comprehend basic concepts, and as a result might not be able to understand and adhere to instructions (Alli et al., 2015; Zaidman-Zait, Mirenda, Duku, Vaillancourt, Smith, Szatmari, et al., 2017). Such behaviours often lead to public scrutiny of the child (and the parent), especially since children with ASD have no physical traits by which their disorder can be identified and are consequently often falsely accused of simply being naughty or undisciplined (Willis et al., 2016). Families who live with ASD often also experience communicative problems in the family, as the child might not be able to answer questions, communicate with his siblings or take part in family discussions (Alli et al., 2015; Weiss et al., 2014).

Raising a child with ASD also puts financial and marital strain on a family because, in many cases, children with ASD never grow up to live and function independently from their parents. Unlike the parents of typically developing children, who can expect their parental responsibilities to lessen as their children reach maturity, caring for a child with ASD becomes a lifelong endeavour (Alli et al., 2015; Zaidman-Zait et al., 2017). The research shows that parents are often

exhausted by the physical demands of taking care of a child who needs constant supervision (Kissel & Nelson, 2016). This problem is commonly aggravated by constant sleep deprivation. Sleep is an important factor in a child's development and health. A symptom of ASD is that children might have disrupted or irregular sleep patterns and awaken considerably earlier than a typically developing child. This, in turn, means that parents unavoidably also suffer from a lack of sleep, which can increase parental stress and fatigue (Glazzard & Overall, 2012).

What some studies found is that the positive relationship between raising a child with ASD and increased levels of parental stress can be ascribed to the additional burden that a child with ASD's emotional and behavioral difficulties present to parents (Costa et al., 2017; McStay, et al., 2014). Furthermore, when children seem unhappy and have emotional or behavioral problems, parents could start questioning their parenting skills and start feeling responsible for or guilty over their child's behaviour (Costa et al., 2017). This idea is supported by a study done by McStay, et al. (2014) that found that it is especially the maladaptive behaviours associated with ASD that are significantly related to parental stress, because these parents experience their child's behaviour as reflecting poorly on their parenting skills. This kind of parenting stress is not directly caused by the child's behaviour, but rather by the parent's perceptions and feelings about themselves as parents and the role that they play in their child's behaviour. Studies have shown that more severe cases of ASD lead to higher stress levels in parents (Kissel & Nelson, 2016; Glazzard & Overall, 2012). This includes personal stress, stress caused by interaction with the child with ASD as well as stress caused by the maladaptive behaviour of the child with ASD (Kissel & Nelson, 2016). In the long run these high stress levels have a negative impact on both the parent and the child with ASD, because parenting stress leads to poor mental health and maladaptive parenting practices which makes it increasingly hard for the parent to implement behavioural interventions effectively (Zaidman-Zait et al., 2017).

It seems that for some parents the relationship between child behavioural difficulties and parental wellbeing may become a vicious cycle. More severe symptoms of their child's ASD only leads to more stress which in turn exacerbates the child's symptoms leading to more parental stress and, often, feelings of failure along with an increased need for the use of time-consuming coping strategies, which can limit the time available for respite through friendships even more (Glazzard & Overall, 2012; Vasilopoulou & Nisbet, 2016). When parents experience extreme stress and hopelessness along with depleted resources and a lack of social support, they often end up experiencing a crisis. This also leads to poor parenting, which in turn impacts negatively on the

child (Weiss et al., 2014). On the other hand, it seems that parents who adopt a positive mental attitude are less likely to encounter crisis (Glazzard & Overall, 2012). During or following such times of crisis parents require social support and more effective coping strategies (Weiss et al., 2014), because interventions which provide parental support may help disrupt this vicious cycle and improve psychological outcomes for the whole family. It may, therefore, be beneficial for services and professionals within a network of educational support to adopt a systemic approach in the presence of such issues and to assess the needs of both parents and children (Vasilopoulou & Nisbet, 2016).

In a study by Woodgate et al. (2008) parents describe the journey of raising a child with ASD as ‘living in our own world’. They explain that they feel isolated and talk about the many challenges of social interaction – both with the outside world and within the family. Many parents of children with ASD describe their lives as ‘an endless routine of treatments and therapy’ and they miss having what they describe as ‘a normal life’. This causes feelings of isolation from their friends and even from their family who is often their greatest source of support (Woodgate et al, 2008; Glazzard & Overall, 2012).

2.6. PARENTAL SUPPORT NEEDS AND STRATEGIES

The literature suggests that parental stress and wellbeing affects the wellbeing of a child. For example, the stress that the parents of children with ASD experience can compromise both their own and their children’s coping resources and affect their ability to problem-solve (Vasilopoulou & Nisbet, 2016). It is, therefore, imperative that the parents of children with ASD develop effective strategies to cope with the, often lifelong, challenges presented by their child’s disorder (Dardas & Ahmad, 2015a). However, as varied as the challenges that different parents face in raising a child with ASD are, so varied are their perceived needs for support and the coping strategies that they employ (Costa et al., 2017). Learning how parents cope is of great value when attempting to improve support structures and support provision for parents raising children with ASD.

Dardas and Ahmad (2015b, p. 622) defines coping as “the cognitive and behavioural efforts that are constantly changing to master, reduce, or tolerate a specific stressor appraised as exceeding one’s available resources and abilities”. Coping is considered to be of critical importance in determining whether a stressful event results in adaptive or maladaptive outcomes. Ineffective coping strategies can lead to negative and harmful long-term effects on emotional and physical

health. On the other hand, effective coping strategies promote an overall state of emotional and physical well-being, and, in parents of children with ASD, it can have a significantly positive effect on the outcomes of their parenting experiences and their general quality of life (Dykens et al., 2014).

Cappe et al., (2011) makes a distinction between avoidance coping strategies and approach coping strategies. Avoidance coping strategies, such as denial, self-blame and withdrawal, generally result in higher levels of stress and anxiety in parents while approach coping strategies, such as problem-solving and seeking social support, lowers stress levels and lead to increased well-being. These two categories are also referred to as adaptive coping strategies and maladaptive coping strategies respectively (Lai, Goh, Oei, & Sung, 2015). Optimism and positivity, as adaptive coping strategies in parents raising children with ASD, have also been explored in a number of studies. The results of these studies showed that family support led to greater positivity which, in turn, increased relationship satisfaction with the child and between spouses (Ekas, Timmons, Pruitt, Ghilain & Alessandri, 2015). Ekas et al. (2015) explains that there is a difference between optimism, which refers to the general expectations that a person has about the future, and benefit-finding, which refers to striving for positivity in the midst of challenging circumstances. Both of these are forms of approach- or adaptive coping strategies.

Holdt's (2008) research shows that families cope better when they have strong support systems. Support may come from a variety of sources, including grandparents, friends, extended family, support groups or social services, but accessing social support has been proven to be a very effective coping strategy for parents of children with ASD, because the level of social support greatly influences the outcomes for such parents (Holdt, 2008). Several studies have reported on how parents of children with ASD attempt to reduce the elevated stress levels they commonly experience (Kissel & Nelson, 2016; Zaidman-Zait et al., 2017; Vasilopoulou & Nisbet, 2016). Among parents raising children with ASD, specific coping strategies have been found to be associated with either reduced or elevated levels of parenting stress. For example, attempting to avoid or denying the existence of the stressor, or diverting the attention elsewhere, is associated with increased levels of stress. On the other hand, positive strategies such as attempting to view the stressor from a more positive perspective or facing daily problems pro-actively and, occasionally, even with humour, has been shown to lower the levels of parental stress (Zaidman-Zait et al., 2017; Glazzard & Overall, 2012; Vasilopoulou & Nisbet, 2016).

Two main sources of coping with stress are personal characteristics (resources) and social resources. Personal resources are aspects of the individual, such as their coping style and preferred strategies for solving problems (Zaidman-Zait et al., 2017). These personal characteristics can influence how the parent of a child with ASD approaches stressful day-to-day situations and potentially help them to cope with some of the effects of extreme stress. One factor that may be an important coping strategy is self-compassion, which involves being kind to oneself in difficult times, recognizing the shared nature of human suffering, and not dwelling on negative thoughts and emotions (Neff & Faso, 2015). Social resources that can help parents to manage the demands associated with raising a child with ASD include familial and extra-familial social support systems. This encompasses social support from family and friends, but also extends to the wider community to include, for example, the educational- and health sectors and the media (Zaidman-Zait et al., 2017).

When people experience stressful events that make a constant demand on their personal resources, it is important for them to maintain and replenish their personal resources because a loss of these resources can leave them vulnerable to stress. Proper support can help to strengthen the personal resources needed to face and overcome their daily stressors (Zaidman-Zait et al., 2017). Research indicates that good social support systems are positively associated with lower stress levels, less anxiety, and decreased marital and family burden in parents of children with ASD (Zaidman-Zait et al., 2017; Kissel & Nelson, 2016). The relationship between the severity of the child's ASD symptoms and parental depression can also be lessened by the provision of social support (Kissel & Nelson, 2016). Social support determines the degree to which a parent feels integrated into the community and views the community as a source of social, emotional, or networking support (Kissel & Nelson, 2016). Many parents report a reliance on informal support systems such as partners, family and friends (Kissel & Nelson, 2016), while others emphasise the importance of more formal support such as respite care for their children with ASD (Vasilopoulou & Nisbet, 2016; Harper, Dyches, Harper, Roper & South, 2013; Glazzard & Overall, 2012).

2.7. SUPPORT AVAILABLE TO PARENTS

One of the most important considerations in the provision of support to the parents of children with ASD, are their own beliefs concerning the specific support they need and their own perceptions of whether or not their support needs are being adequately met. (Siklos & Kerns, 2006). It is not a simple task to determine the typical needs of a parent who is raising a child with

ASD. Firstly, because every case of ASD is so unique, and, secondly, because the perceptions and beliefs regarding the support needs of every family will be different. Support needs might also change with time as parents encounter periods when they lean more heavily on formal support systems such as professional services and support groups, but then experience other times when they rely much more on the informal support provided by family and friends.

For some parents support groups seem to be a very helpful support structure. These groups are especially useful to help facilitate the acceptance of the ASD diagnosis, create a platform for parents to share their experiences and ideas and encourage parents to support one another (Banach et al., 2010). Participation in such groups are associated with lower levels of stress and a more positive demeanour. It also provides a relatively cost-effective way to provide support to parents raising children with ASD, especially with the help of technology and social media (Clifford & Minnes, 2012). Support programmes aimed at increasing parent's perceptions of their parenting skills are also linked, in the literature, to decreased experiences of parenting stress as it empowers parents in their roles as therapists and co-therapists to their child with ASD and assists them in making decisions surrounding their child's treatment and future (McStay et al., 2014).

Another form of support that my literature study uncovered was the provision of respite care for children with ASD. This special kind of service can be provided either at home or at a childcare facility and it gives parents the opportunity to take a break from the constant demands of caring for their child with ASD. Parents are then afforded some time to spend with their partners or the opportunity to participate in social events or health-promoting activities such as exercising, which leads to better physical health and consequently improves mental health (Vasilopoulou & Nisbet, 2016). This kind of support may be associated with increased emotional uplifts, reduced levels of parenting stress, improved marital relationships and a general improvement in parental quality of life (Harper et al., 2013; Vasilopoulou & Nisbet, 2016).

Employment opportunities for parents of children with ASD have also been linked to a greater quality of life in the parents of these children. Parents who work, either full-time or part-time, can contribute towards the family income which means greater access to medical- and therapeutic services and a more comfortable home-environment. This increase in family income also serves to relieve the burden of planning for future care and financial security for the child with ASD. Furthermore, job satisfaction in parents with ASD has been linked to more positive outcomes for these parents and contact with colleagues or clients might increase their possibilities for social

support and support-networking (Vasilopoulou & Nisbet, 2016). The challenge with employment for parents of children with ASD though, seems to be twofold: For one thing, the issue of respite care becomes very relevant because, unless there is proper care for the child, at least one of the parents is not in a position to seek employment. The other factor is the level of understanding of the employer. If there is a constant conflict between the demands of the family and those of the workplace, employment might add to parental stress and strain instead of relieving it. Should a workplace, however, prove to be understanding and provide more flexible working hours, employment can greatly benefit many parents of children with ASD (Vasilopoulou & Nisbet, 2016).

2.8. CONCLUSION

This literature study explored the diagnosis and other behavioural patterns commonly associated with ASD, and the challenges they pose to parents raising children with ASD. It also discussed different coping strategies used by parents and the support structures available to them. By gaining a greater understanding of the experiences of parents who are raising a child with ASD, this study aims to add to existing knowledge on parent support within the South African context.

CHAPTER 3

3.1 INTRODUCTION

In this chapter, I describe my research paradigm and design decisions. I motivate my choice of research design and methodology for this study and present the methods of data collection. I also describe how the data was analysed. To reach the objectives of this study, as set out in Chapter One, I was guided, throughout the study, by these three research questions:

- What are the support needs of parents raising a child with ASD?
- What are the experiences of parents with the support systems that they use?
- Why do parents raising a child with ASD endorse some support systems over others?

3.2 QUALITATIVE INQUIRY

Qualitative research is not about testing hypotheses; rather, it is an inductive process that moves from the collected data towards the discovery of emerging themes (Lichtman, 2011). Creswell (2007) explains that it begins with the posing of research problems that investigate the meaning that individuals or groups ascribe to a specific social or human problem. Unlike quantitative studies, the purpose of the qualitative study, and what it is exploring, often changes throughout the research process (Clandinin & Connelly, 2000). Qualitative research is always multi-layered and multi-dimensional, and the research field is constantly influenced by political, cultural and social norms. It is, therefore, a dynamic, ever-changing context which necessitates that research standards change with the field (Lichtman, 2011). Shank, (2006) describes two domains of qualitative research. The first is ‘qualitative science’, which aligns itself more to scientific methods, and the second is what he calls ‘qualitative inquiry’. He describes qualitative inquiry as a “systematic, empirical alternative to science” (Shank, 2006, p.7).

There are three basic characteristics that define a qualitative inquiry. In qualitative inquiry the role of the researcher is important. He/she is actively involved in the research and is an integral part of the research. It is, therefore, important that the researcher discusses his/her role in the research honestly and openly so that the reader can evaluate the position/role of the researcher and the validity of the findings in light thereof. The focus of a qualitative inquiry is on gaining a deeper understanding of the posed problem rather than building transferable theories. The hope is often that better understanding will lead to changes in policies and practices, and that those who are involved will benefit from the findings. A third characteristic of qualitative inquiry is that it embraces new ways of looking at the world. It makes use of new research methodologies that

make it possible for the researcher to discover different kinds of truths, such as the truths that individuals construct based on their personal life experiences (Shank, 2006). Because the purpose of this study was to understand the support systems of parents of children with ASD, I chose to conduct my research within this qualitative research paradigm.

3.3 THE INTERPRETIVE RESEARCH PARADIGM

When knowledge construction is done together with those whose realities the researcher is trying to understand, it can be considered a social activity (O'Donoghue, 2007). One's decisions about research is strongly influenced by how you understand the world, and knowledge construction. I define the research paradigm as a research practice and a way of thinking based on reflections along three different dimensions, namely ontology, epistemology and methodology (Terre Blanche & Durrheim, 1999). Ontology specifies the nature of these realities and what can be known about them. Epistemology is concerned with the relationship between the researcher and that which can be known, and the methodological dimension of a study describes how the researcher decides to go about the process of studying what she believes can be known (Terre Blanche & Durrheim, 1999).

Because this study elicits parents' views and opinions on their experiences of the support systems available to them as they raise a child with ASD, I positioned myself within the interpretive paradigm. This means that my primary goal was to understand the phenomenon from the participants' perspectives (Merriam, 1998; O'Donoghue, 2007). The interpretive research paradigm requires research methods that necessitate a lot of interaction between the researcher and the participants. In fact, it can be argued that the research leads to realities that have been socially constructed by the researcher and the participants together (Wills, et al., 2007; Terre Blanche & Durrheim, 1999). When we work with people's experiences, there are multiple truths and realities to consider (Lichtman, 2011). Because interpretive research seeks to understand, rather than explain, the realities and situations within the social world (Burnett & Lingham, 2012), an understanding of this paradigm is mainly to reflect on the participant's understanding of a certain reality within a certain context and how it informs his/her practice (Wills et al., 2007). Therefore, the aim was to understand the meaning of, and not the truth about, a reality (Bailey & Tilley, 2002).

The interpretive paradigm considers the nature of reality to be an internal reality formed by subjective experience. It argues that no one has access to an external reality that is separate from

the internal realities that they experience. Though the population of this study consisted of participants who share similar life experiences as the primary caregivers of children with ASD, I argue that they also have unique life experiences due to their unique contexts and personal responses to it. I argue that each of the participants is constructing his/her unique reality as he/she goes through the shared life experience of raising a child with ASD (McMillan & Schumacher, 2010; O'Donoghue, 2007). This required of me to acknowledge the internal validity of each participant's subjective experience of the support systems available to him/her (Terre Blanche & Durrheim, 1999).

3.4 RESEARCH DESIGN

3.4.1 The researcher as narrative inquirer

In qualitative research the role of the researcher is critical, especially in narrative inquiry, which always has a relational aspect to it (Lichtman, 2011). In fact, the researcher often tries to get as close as possible to the participants that are being studied and, on some levels, become a part of the research without sacrificing the validity of the data being gathered (Creswell, 2007).

As narrative inquiry is a relational form of research and requires a relationship between the researcher and the participants, the tension of moving between full involvement with the participant during the interview, on the one hand, and distancing oneself when analysing the narrative data collected during the interview, on the other, is part of the nature of a narrative inquiry (Clandinin & Connelly, 2000). It was, therefore, important for me, as the researcher, to keep in mind that there is a difference between a conversation and an interview. In an average conversation there is a symmetry of disclosure until the pair reach a place of mutual intimacy with which they are both comfortable (Shank, 2006). In an interview, however, the qualitative researcher aims to go past the superficial levels of a conversation to reach a place where there is a deeper understanding of the experiences of the interviewee. The challenge was to reach this place without disclosure on the part of the interviewer. Thus, it required the researcher to be empathetic when interviewing participants while, at the same time, maintaining the role of the researcher. The interview guide was a useful tool in this regard, along with the constant awareness that I was situated in the role of the researcher and that I had to maintain the balance between being emphatic and being professional.

Another challenge for the narrative researcher relates to composing research texts. Trying to maintain one's balance in expressing your own voice as a researcher, during an inquiry designed

to tell the participant's stories of their experiences, implies finding your voice while staying true to their narratives. The difficulty when presenting the findings is often that there is a close relationship between the researcher and the participants; the researcher needs to move away from the intensity of reliving the stories with the participants, to retelling the stories through research texts (Clandinin & Connelly, 2000). This balance was not always easy to maintain, because of the personal and emotional nature of the research question. However, being aware of the dangers of using my voice in the research text over that of the participants, helped me to navigate the potential pitfalls and focus on using the narratives of the participants, rather than my own voice, to construct the research text.

3.4.2 Narrative inquiry

According to Clandinin and Huber (2010), the aim of a qualitative study's research design is always to gain a better understanding of particular human experiences, as they are told or lived. As I wanted to understand the individual lived experiences of parents raising a child with ASD with regards to their support needs and -systems, I chose the narrative inquiry as my approach. Narrative inquiry can simply be defined as "the scholarship of stories" (Journal of interior design, 2000, p. 4). Clandinin and Huber (2010, p. 3) describe it as "the study of experience as story" and expand on this idea by explaining how stories shape the everyday lives of people and create a way for them to make sense of their past experiences. Narrative inquirers identify stories as the key elements of their approach. According to them, people use narrative, or storytelling, to organise personal and social knowledge, because the stories that they live become the stories that they tell, and, by using narrative methodologies, it is possible to use these stories in scientific research (Clandinin & Huber, 2010; Lichtman, 2011). In this study, the parental experiences of support, for parents who are raising a child with ASD, will be explored through the stories that they tell.

There are three dimensions to a narrative inquiry that need to be considered. The first dimension, temporality, is concerned with time and events that are in constant motion and, therefore, are changing as they are being studied. Sociality, the second dimension, refers to the personal and social interactions that need to be considered, because the participants are within a particular context. The third dimension considers the place, which ties experiences to specific locations (Clandinin & Huber, 2010; Clandinin & Connelly, 2000). The starting point for a narrative inquiry could either be the telling of stories or the living of stories. Participants could tell their stories individually or in groups, after which texts are created and analysed using one or more of

a variety of approaches (Clandinin & Huber, 2010). The design requires close collaboration between the researcher and the participants, because the researcher enters the lives of the participants and shares in their experiences (Clandinin & Huber, 2010).

3.5 RESEARCH METHODS

3.5.1 Participants

In a narrative study, one needs to find individuals to study – individuals who are accessible, willing to provide information, and who have had experience with the phenomenon that is being studied which, in this case, is a parent raising a child with ASD. Participants were purposively selected based on their ability to inform an understanding of the research problem of the study (Creswell, 2007). The researcher carefully selected parents who had a story to tell about their lived experience as the parents of a child with ASD.

Any South-African parent who is the primary caregiver of a child who has been diagnosed with ASD, could potentially have provided rich and useful information in this study, because they are all living the experience of raising a child with ASD. Any such person who was willing to share this experience with the researcher could, therefore, have been considered as a suitable participant in this study. However, in qualitative studies one seeks to understand human experience, which requires a more detailed investigation of each individual's experience. It thus made sense to have a small sample group (O'Donoghue, 2007). I delimited the population for accessibility by geographic location, for the interviews. The number of participants in a qualitative study is usually small, and participants are selected in a non-random manner (Lichtman, 2011). Qualitative researchers use the concept of saturation. This means that data collection continues until the researcher finds that no new information about the research questions can be obtained from additional cases. The sample eventually consisted of four parents who participated in the study.

The purpose of a narrative inquiry, as a form of qualitative research, is not to generate generalisable findings but rather to understand individual experiences. Therefore, the study does not claim to be representative of all South African parents raising children with ASD. Rather, it represents an understanding of the unique personal experiences of the four parents who participated in the study, with raising children with ASD.

3.5.2 Data collection methods

Creswell (2007, p. 18) describes data collection as a “series of interrelated activities aimed at gathering good information to answer emerging research questions”. According to Lichtman (2011), there are no specific prescriptions when it comes to gathering data for a narrative inquiry. Though data can be collected in a variety of ways, the oral interview seems to be the most commonly used method in narrative research. In the tradition of narrative inquiry, I chose the semi-structured interview as the instrument for data collection for this study. Most qualitative interviewers, favour semi-structured interviews for data collection, because it allows them a level of freedom in the manner and order in which the questions are asked. Importantly, though, it still assures that all interviewees are asked about the same basic issues, because the researcher makes use of an interview guide. This helps the interviewer to maintain some level of comparability between the different interviews (Castillo-Montoya, 2016; Shank, 2006).

When a study, such as this, is conducted with a small number of participants, it is encouraged that the interviewee be the one to set the pace of the interview and slight departures from the guideline is not considered problematic (Silverman, 2013). However, Castillo-Montoya (2016) explains that the purpose of an interview guide, or interview protocol, is to assure that the same topics are covered in each interview and that all relevant questions are discussed with every interviewee. This means making sure that the information covered in the interview guide will lead to rich narrative data, that will help to answer the research questions in the study. It also helps the researcher to make optimal use of the time available for each interview (Patton, 2015). To give some structure to the interviews, I developed such an interview guide (see Addendum C) and I interviewed each participant individually. Each interview was recorded and afterwards transcribed verbatim and analysed inductively.

The process required for this design involved the gathering of field texts which included field notes and transcriptions of interviews. Permission was sought of each participant for the interview to be recorded. The transcriptions, along with any relevant observational notes that the researcher made during the interview, became the data of these interview sessions (Savin-Baden & Howell, 2013; Squire, 2008; Lichtman, 2011). These field texts were then assembled into interim research texts (or drafts) and finally, the research texts.

Creswell (2007) suggests that data has to be collected in a natural setting which is sensitive to the people and places that are being studied. The only requirement from the side of the researcher

was that the location be conducive to the quality of the interview, that is: quiet enough that recordings are clear and that the interview is not interrupted. Each of the interviews were, therefore, conducted in a physical location of the participant's choosing. All data and findings were stored on a password protected computer to which only I had access. The data will be stored for five years, as required by the university, and destroyed once this period ends. However, all audio recordings of the interviews were destroyed as soon as they had been transcribed and the study had been completed.

3.5.3 Data Analysis

The move from field texts to research text is a complex process. Field texts have great research potential and requires lots of reading and re-reading, as the researcher looks for patterns and themes that shape field texts into research text. According to Clandinin and Connelly (2000) there is no clear path one can follow that will work for every inquiry. This could lead to the inquirer being frequently filled with doubt. However, as a researcher who had selected to work within the qualitative tradition, I was aware that data analysis in qualitative research is inductive and attempts to establish themes or patterns. Thus, my process entailed preparing and organising the data for analysis and then reducing the data into themes through a process of coding and condensing the codes and, finally, representing the data in the form of a discussion (Creswell, 2007).

Elo, Kääriäinen, Kanste, Pölkki, Utriainen and Kyngäs (2014) explains that qualitative data analysis involves organising the data by creating coded categories that emerge from the collected data. Coding essentially involves making a note if you are picking up the same sort of things as you go through the field notes, in this case the data in the form of transcribed interviews, and coding them according to recurring themes (Shank, 2006). The method of coding that I used is based on steps of data analysis suggested by Creswell (2007), but it is also supported in the writings of McMillan and Schumacher, (2010) and Wertz (2011). Creswell (2007) describes a procedure called 'intentional analysis' which is a procedure by which to analyse how experiential processes take place and what is experienced through them. He also explains how qualitative research makes use of inductive data analysis, which is a process by which generalisations are generated from the ground up.

I started my analysis developing basic codes that I expanded as I went along, and I gave recurring words or ideas that emerged from the data similar codes. Moving beyond coding to look for and

organise the coded data into categories or themes, is called classification. These themes emerged from the coded data and were not predetermined (see an example in Addendum D). Next, I took to interpreting the classified data in an attempt to make sense of what there was to be learned from the data gathered during the narrative interviews. In my presentation of the final report, I included the voices of participants, my own reflections, and a description and interpretation of the research problem in the form of a narrative text (Creswell, 2007).

When it comes to putting our narrative understandings into practice, Shank (2006) suggests that there are three metaphors that we can use: The ‘mirror’ is a metaphor for reflection that explains how narratives are reflective in nature and never cease to reveal to us something about ourselves and our cultures. It argues that all stories help us see ourselves and the world in a new and different way. The ‘window’ is concerned with the use of narratives as tools to study stories as a science and create a greater awareness of the truth as experienced and told by individuals. Finally, the ‘lantern’ can be used as a metaphor for shedding light where, before, it had been dark. This is the process of wrestling with the narrative to illuminate its deeper, more subtle meaning and it assumes that there is always a legitimate meaning, though it is often hidden.

3.5.4 Trustworthiness in qualitative research

In empirical research, we always need to be certain that what the researcher has reported is trustworthy (Lincoln & Guba, 2007; O’Donoghue, 2007). The validity or trustworthiness of an interpretivist study, such as this one, is determined by the following four criteria, as described by Guba (2007): credibility, transferability, dependability and confirmability.

Credibility is the naturalistic term for the truth value aspect or internal validity of empirical research (Guba, 2007). Credibility, in this study, was achieved by adopting well-established methods of data collection, engaging in frequent debriefing sessions with my supervisor and providing thick descriptions of the data gathered through carefully conducted narrative interviews. This was done to provide readers the opportunity to make their own judgements about the credibility of emerging themes and the conclusions reported in the findings (Creswell, 2007). Though the aim of narrative research is not to seek certainty or a type of truth which will be generalisable or transferable to other contexts (Lichtman, 2011), when we make the reader see the major themes that run through the study, it allows readers to make their own generalisations and transfer the theories to their own contexts (Uhrmacher, 1993, in O’Donoghue, 2007). The contribution of a narrative inquiry involves creating a new sense of meaning and significance

with respect to the research topic, more than it does the addition of new knowledge to the field. The narrative inquirer also prefers to offer readers the opportunity to imagine their own applications of the findings rather than suggesting specific uses for the findings of a narrative study (Clandinin & Connelly, 2000).

When we say that interpretivist theories are usually not meant to be generalised, it does not mean that they have no transferability. Instead, Stake (1978), as referred to in O'Donoghue (2007) explains that readers who can relate to a study, can gain a better understanding of their own situations and experiences as well as to those of others. When this happens, we can say that a study has "reader or user generalisability" (O'Donoghue, 2007, p. 66). The development of an audit trail is a generally acceptable method of establishing consistency throughout a study. This means that the researcher guides the reader through the project from start to finish so that they can understand the process and, consequently, the reliability of the research findings (O'Donoghue, 2007; Guba, 1985). This chapter of my research thesis effectively serves as an audit trail of the study, because it provides a detailed description of the research process and the methods that were employed throughout the study. Confirmability as a criterion deals with the researcher's ability to remain neutral or objective throughout the study (Guba, 2007). The researcher is an active participant in the study and, therefore, the narrative inquiry can lead to personal reflection and discovery. The narrative researcher is, thus, always struggling with personal tensions through the course of the narrative inquiry. Narrative inquirers need to reconstruct their own narrative histories and be alert to possible tensions (Clandinin & Connelly, 2000). Because I am not a parent, and by implication also not a parent to a child with ASD, I do not have personal narratives that are related to the research topic. However, during the research process, I was always cognisant of my personal involvement and empathy, and how it could potentially interfere with my objectivity in the study.

3.6 ETHICAL CONSIDERATIONS

Research studies have the potential to cause harm, and it is necessary for researchers to ensure that their research does not cause any form of emotional or psychological harm to any of the participants (Savin-Baden & Howell, 2013). It, therefore, was necessary for me to provide proof that the research was conducted with integrity and that the data were not falsified, as this could have compromised the findings.

3.6.1 Vulnerability and non-maleficence

When considering the ethical aspects of this research project, I gave considerable attention to the possible risks and benefits of my research (Mouton, 2001). The research topic of this study is a sensitive issue to parents who are facing challenges with raising a child with ASD. The questions asked during the interviews could potentially have elicited reactions from the participants, that might have included various feelings of dissatisfaction with their existing support systems. I, therefore, acknowledged that any emotional discomfort that a participant might have experienced during an interview was a risk and that participants should be made aware of this risk. Participants were informed of the availability of a counsellor should they, at any time, have felt the need for a debriefing session, following their interviews.

3.6.2 Anonymity and confidentiality

A qualitative researcher conveys to the participants that they are participating in a study, explains the purpose of the study and does not engage in deception about the nature of the study. In my relationship with the study's participants, I was committed to full disclosure and confidentiality. All the participants in the study were informed of the aims and goals of the research and how the data would be used. Each participant was also required to sign a consent form that confirms that their participation in the study is voluntary (see Addendum B).

As anonymity is a considerable concern in narrative research (Clandinin & Connelly, 2000), I made every effort to protect the privacy of the research participants throughout the research process. This was done by using pseudonyms to protect the identity of every participant. All the data was also stored on a password-protected computer that only the researcher had access to.

3.7 CONCLUSION

The research design and methodology of this study was outlined in this chapter. By following the research process as explained, I endeavoured to conduct the research project in a systematic and ethical manner. The following chapter will present the data gathered through the narrative interviews and the findings of the research.

CHAPTER 4

4.1 INTRODUCTION

This chapter tells the stories of four mothers who are each raising a child with ASD. Because this is a narrative inquiry, I believe it is necessary to respect the authenticity of each parent's story, as each individual situation and experience is unique. Humans use narratives as a means of making sense of their life experiences (Squire, 2008), therefore, each narrative will inevitably be different from the next. It was, however, necessary to also analyse the narratives together and find the emerging themes, to finally present the grand narrative of the study, from which one could come to a more general conclusion. This type of analysis is acceptable in the practice of narrative research, according to Squire (2008), who states that, in narrative research, stories are often reconstructed across the boundaries of time and space.

4.2 INTRODUCING THE PARTICIPANTS

I begin this chapter by introducing the reader to the four parents who were the participants in this study. They are all the mothers of sons who have been diagnosed with ASD, are married and have one or two other children. These four South African families live in different geographical areas of South Africa and can be classified as middle- to upper middle-income families.

The table below provides an overview of the four family units and lists the members of the individual families, as well as the participants' professions. The table is supported by a brief introduction to each of these mothers and their families. Please note that, throughout this chapter, as well as chapter five, I will be using pseudonyms for each of the participants and for their children and other family members. This is done to protect the privacy of the participants and their families.

Table 4.1: The participants and their family members				
Participant	Esther	Hannah	Rachel	Mary
Spouse	Mark	William	Richard	John
Profession of participant	Social worker	Public relations officer	Lecturer in tertiary education	Music, dance and drama teacher
Child with ASD	David (5yrs)	Sam (15yrs)	Ben (16yrs)	Jamie (24yrs) Daniel (19yrs)
Age of diagnosis	3 years	2 years	3 years	3 years
Other children	Miriam (5yrs)	Annie (13yrs)	Peter (20yrs)	Amelia (26yrs)
Extended family in home	None	Hannah's mother	Richard's mother	None

Esther is the mother of five-year-old twins, David and Miriam. Although Esther is a qualified and experienced social worker, as parents, Esther and Mark decided, soon after David's diagnosis, that she would not go back to work. Since then she has been a full-time parent devoting her time and energy to the task of taking care of their children, while Mark works as a quantity surveyor in the city. Her parents live nearby and have a close relationship with the children. Despite her hearing difficulties, Miriam attends a mainstream nursery-school, while David is enrolled in preschool at a special school for children with ASD.

Hannah is the mother of Sam and Annie, and is married to William, who is an accountant. Hannah holds a full-time job as the public relations officer of a law firm. Since Sam's diagnosis at the age of two, Hannah's mother has been living with the family to help take care of the children, while Hannah is at work. Annie attends a mainstream school and Sam attends a special school for children with intellectual disabilities.

Rachel is the mother of 16-year-old Ben, and Peter, a 20-year-old university student. Rachel is a lecturer at a university and is married to Richard, who is an engineer. Peter lives in a university

residence and Ben lives with Rachel and Richard. Ben, who was diagnosed at three years of age, has attended various special schools and was also home-schooled for the last three years, mostly by his grandmother and older brother.

Mary is the mother of Amelia, a qualified veterinarian, Jamie, and Daniel. She is a dance, drama and music teacher who manages her own art school. She also puts a lot of her time and energy into running a yearly craft market where people with disabilities can display their talents and sell handmade products. Mary's husband, John, works as a project engineer, but is also very involved with their craft-market venture. Both Jamie and Daniel have attended various schools over the years, but Mary eventually resorted to home-schooling both of them, in order to best meet their individual needs.

4.3 THE DIAGNOSIS

The process of reaching an ASD diagnosis can be challenging and exhausting for many parents. Because ASD is a spectrum disorder, and no two children present with exactly the same symptoms, parents often experience frustration over the time it takes to reach a final diagnosis.

4.3.1 Hearing our son has ASD

As an introduction, each of the participants in this study were asked to narrate how they came to know about their children's condition. What follows is a description of events that led up to their children's diagnosis with ASD.

Esther's twins were about three years old when David was diagnosed with ASD and Miriam with a hearing disability. Esther stated that, as his mother, she had just known early on, that something about David was different. With him being one of twins, it had been relatively easy for her to notice that he was not developing at the same pace as his sister. The doctors had thought, at first, that he had a hearing problem, because he had not reacted when spoken to. However, it later turned out that it was Miriam who had hearing problems and that David's problems were not with his hearing.

Esther had had previous encounters with children with ASD when she had worked as a social worker in the UK. However, because all the children on her caseload had been older, she had been unsure of how ASD manifested in such a young child. She, nevertheless, suspected some of David's behaviour to be typical for a child on the spectrum. She had mentioned her concerns to

his teacher, but the teacher had remained positive and had not necessarily shared Esther's concerns, even when David's behaviour at school was troubling. Out of desperation, Esther contacted Autism Western Cape and was referred to a therapist who confirmed Esther's suspicions, when she diagnosed David with ASD.

Hannah remembers that when Sam had been about 18 months old, he had gotten very sick and had had to be hospitalised. It had been around this time that his language development practically came to a standstill. Hannah recalls that she had noticed he was developing differently from other children of his age in other ways too. Especially his social- and emotional development had not been normal for a child his age. William eventually reached out to a friend who referred them to an institution in Durbanville, in the Western Cape. She elaborated further:

We flew down with him for two weeks of intensive intervention and afterwards one of their therapists came to our home in Pretoria to assist and train us in behavioural therapies, and how to communicate with (Sam) at home.

Rachel said she had known from the first moment she had held Ben in her arms, that there was something very different about him. After a difficult birth, with many complications, she remembers her first words to him as he grabbed onto her chest, digging his nails into her flesh, having been "it's okay, we will fight. You are going to be fine".

Twelve years ago, getting a diagnosis for ASD was not an easy process. As is often the case with parents of children with ASD, Richard and Rachel's first concern had been that their child might be deaf, because he had not reacted to sounds or turned to them when he heard the sounds of their voices. Still, all the tests had come back normal for Ben, so it had been clear that his hearing was not affected. Also, what made Ben's ASD especially hard to diagnose, was the fact that he is very partial to hugs and physical affection and, at that stage, it had been generally believed that children with ASD would always shy away from physical touch. What was established after the diagnosis, however, was that he is hypo-sensitive (touch-seeking) and not hyper-sensitive, like so many other children on the spectrum. So, it was only when Ben was three and a half years old, that a team of professionals finally looked at all the tests that had been done by the paediatricians, psychologists and occupational therapists and diagnosed him with PDD-NOS ¹.

¹ Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) was one of several previously separate subtypes of autism (as was set out in the DSM-IV) that were folded into the single diagnosis of autism spectrum disorder (ASD) with the publication of the DSM-V in 2013. According to the DSM-V (2013) individuals previously diagnosed with either autistic disorder, Asperger's, Rett's syndrome or PDD-NOS, should now be given the diagnosis of ASD.

Mary's son, Jamie, was diagnosed with ASD 21 years ago, when he was three years old. His younger brother, Daniel, was also diagnosed with ASD when he was five, although his diagnosis is not nearly as severe as that of his brother. Like Rachel and Esther, Mary knew that Jamie was different right from the beginning. She recalls how he even cried differently. Mary stated that she had noticed a significant deterioration in his development after his MMR vaccination at nine months:

You could see it on his card which measures his weight and such, you could see how he was regressing. He lost weight, his head-circumference came to a standstill and his facial expression changed.

At first, it had appeared as though Jamie was deaf. He did not respond to sounds or people around him and his language was not developing at all. The otolaryngologist who was treating Jamie at the time was very concerned and suggested that, if Jamie's speech and vocabulary did not improve dramatically within a few months, they should have him tested. At that stage, all he could do was jump on his toes, flap his arms and hands and give a constant high-pitched scream. He couldn't talk and struggled to keep any food down. He also had very severe meltdowns that seemed like extreme anxiety attacks. Eventually, when he was three years old, he was diagnosed with primary autism. Daniel's diagnosed with ASD happened only when he was five. He also had specific food aversions and he struggled with language and communication. However, because his problems were so much less severe than Jamie's, it took Mary much longer to notice them. It was the staff at the preschool that he attended who first voiced their concerns about Daniel's developmental delays. When his parents had him tested, he was diagnosed with PDD-NOS.

What all four of these stories have in common, is that the parents had known before the diagnoses that their boys were different from their peers and that their development was slower than that of other children at their developmental stages. Initially, each parent attributed her child's lack of response to hearing challenges. However, there were other developmental delays that eventually led to a diagnosis on the autism spectrum. Three of the mothers were grappling with these challenges longer than 12 years ago, when an ASD diagnosis was not as common as it is today and when information was not as readily available.

4.3.2 Devastation and shocking relief

One of the themes that came through strongly in the mother's narratives, was the devastation and, in one case, the relief felt when they had received confirmation of their children's condition. In response to what their reactions and feelings had been when they had received the ASD diagnosis, the participants all spoke about how they had, in no way, anticipated what they would have to go through, being confronted with the various challenges associated with raising a child with ASD.

Esther describes how devastated she was when her son was diagnosed, and how she completely fell apart. She feared for what the future would hold for her family, as she had had some experience of ASD, having worked with older children who presented with ASD, in the UK. She said "I saw what these children look like when they are older... I knew what lay ahead for us!" However, two years later, when the interview took place, she was in a better space, and could talk about her experiences. She said, "if you had asked me two years ago, I would probably have said no. I wouldn't have had the courage to talk about it then."

Hannah remembers that when Sam was finally diagnosed at the age of two, she and William were devastated. As this was quite a number of years ago, she recalls that support, or even information available for parents who had just received an ASD diagnosis, had been very limited and not easily accessible. This lack of information and support had made her feel completely lost and helpless:

It was devastating, because there was very little information and help available at that time and we had no idea who to turn to for help. Even the doctor who had diagnosed him didn't offer any help beyond the diagnosis.

Rachel recalls the night, more than twelve years ago, when the group of specialists all came to their house to explain the diagnosis to them:

They told us that, according to the tests - he was about three and a half then - he was about on the level of a nine-month-old. They said that he would never talk, because by that time he hadn't started, that he was untrainable and that we had to decide when we wanted to have him institutionalised.

She remembers that, although her husband had been shocked and had shown the team of specialists the door, she had been less shocked and rather relieved, because she had already

known that there was something wrong. She said, “for me it was a matter of ‘now I can do something about this’”.

At the time of Jamie’s diagnosis, his behaviour and developmental delays had been so significant and challenging that getting the diagnosis had not really been a big shock to Mary. She also remembers having been thankful that they finally had a diagnosis as a basis when considering treatment and therapy. It had, however, brought about a very significant change in her life, because she gave up her art-school to be able to give her full attention to Jamie’s therapy.

At that stage my husband had told me “it’s only the mother who is going to be able to make the difference”. I had a school of 150 students at that stage, and he told me to leave everything and give my full attention to the child.

4.4 THE CHALLENGES OF ASD

Raising a child with ASD presents many challenges to parents. The following themes that emerged from my analysis of the interview data can be divided into three main categories, namely, personal challenges, family challenges and social challenges.

4.4.1 Personal challenge: Communication

Every-day communication and social interaction is an essential part of any typical parent-child relationship and it is taken for granted, by most parents, that they would have this kind of relationship with their child. For parents raising children with ASD, however, even basic communication can be very challenging to establish. In many cases it requires hours of therapy and very hard work, just to establish a basic vocabulary, and for others, communication only ever happens through signs and pictures, if at all. This appears to be a great cause of frustration for some parents because it requires immense effort, often with limited results. Both Rachel and Mary mentioned this struggle during their interviews. According to Rachel, Ben’s vocabulary had consisted of only three words namely ‘mommy’, ‘yes’, and ‘no’, and Mary commented on Jamie, saying, “He didn’t talk. At one stage he could say up to ten words, but he doesn’t communicate”.

The narratives speak of the tireless hours that these mothers put into establishing alternative methods of communication, and the frustration they experience when even these fail them. Hannah recalled that Sam had once been anxiously looking for his ‘rectangle-one-two-three-four-five’, and it had taken her days to figure out that he was looking for his ruler. Her

experience is validated by Esther's frustration when David sometimes refuses to use the picture cards to communicate at home, as he had learned in therapy. She said, "...some days I can do whatever, it doesn't matter – even if I stand on my head!" Along with this frustration and disappointment, communication-deficits also cause these parents to be concerned over how their child is coping physically and emotionally. Parents worry about their children not being able to assert or defend themselves in difficult situations. Mary said that there had been a time when she thought it might do Jamie good to live in the school hostel for a while, but she had taken him home again, because she had been concerned about his vulnerability, due to his communication difficulties. It also bothers her that Jamie can't tell her, verbally, how he feels. She relies only on signs to communicate with him and says

(Jamie) really can't talk. That is why I took him out of the hostels and those places, because you don't know... children like that are targets. People could molest them, and you wouldn't know. Because he can't talk, I don't know if he is happy. I mean, he still has a right as a person to say what he does and doesn't want... Then you just have to keep asking questions until you ask the right question that he can answer with a show of his thumb.

Rachel, on the other hand, was concerned that her child would not receive the necessary attention in school, because he does not speak. As a teacher, she knows that children who are quieter are more easily neglected or ignored, because they do not demand the teacher's attention, and because it is an effort for the teacher to communicate with such a child. Her view had been that "the children who don't talk suffer the most, because they get unintentionally pushed aside".

Esther spoke of her feeling of helplessness and loss, as a parent, being denied one of the basic tools for successful parenting- effective communication, as well as the joy of a typical parent-child conversation. Esther shared, for example, an experience she had had when her twins had both been sick with a stomach-flu at the same time, and how it had been so much more challenging to care for Daniel than for Miriam, because he hadn't been able to use language to communicate his needs. She explained:

it's so difficult with him... (Miriam) can tell me "mommy I feel like I'm going to throw up" and then I run to the toilet with her... but he can't say anything... later I could tell by the sounds he made that he was going to throw up. And he just lay there on the floor curled up in pain... one feels so helpless!

Her feeling of loss concerning David's lack of speech, however, is not only related to communication for practical reasons, but also to the pleasure of building a relationship through conversation. She misses, for example, having a simple conversation with her children while driving in the car:

Before we knew (Miriam) had hearing problems we would be driving in the car and I would be talking to my children... and neither of them would respond! Then I would cry, because my one child can't talk to me and the other one won't talk to me. I literally cried on my way everywhere... I cried going to school... I cried going home... I cried on my way to my parents'...

4.4.2 Personal challenge: Maladaptive behaviour

Each of the stories I was told, was laced with numerous examples of maladaptive behaviour exhibited by the children with ASD. It would, however, not serve any real purpose to repeat too many of them here, because they differ greatly from one child to the next. Still, this behaviour contributes largely to parenting stress for these mothers, and it seems that the one universal factor that underlies this kind of behaviour, is that it is especially triggered when the child is introduced to a situation that is out of the ordinary or unfamiliar. Mary explained it as follows:

Now, most of the time it's when something happens that he didn't expect... or a shock like the otolaryngologist that stuck a sharp object into my child's ear in the consultation room and he took off into the parking lot! Or if one day you take... let's say you walk to the bank and there are stairs down and the next day you go down where the trolleys go down, then he would collapse on the floor there and then and start hitting his head on the floor.

Esther also explained how a situation that might be traumatic, even for a typically developing child, such as being hospitalised, is so much more traumatic for a child who can't even handle a plaster on his skin. Furthermore, maladaptive behaviours necessitate certain adjustments to the daily lives of these parents that are often inconvenient. David and Jamie, for example, must follow strict diets that are sugar-, wheat-, gluten- and dairy-free, to make their behaviour more manageable for their parents. Esther monitors David's sugar intake very carefully, because "otherwise he is like a little ball", while Rachel had put Ben on a gluten-free diet for a very long time. Though both these parents found it difficult to manage their children's diets at times, these special diets kept their children calmer. Hannah said she especially struggles to get Sam to eat anything nutritious. Because there are so few things that he eats, she must feed him a shake with

a syringe every morning just to make sure that he gets something nutritious into his body. “It’s usually a drama, because he doesn’t like it, but I just push ahead with it.”

Like other parents, the parents of children with ASD also take their children along on outings and holidays, but these seemingly enjoyable happenings have the potential to turn into nightmares if the environment and situation does not cater well to the child’s specific needs. For David “it’s hard with sounds, for example. In the mall he goes crazy from the sound of the driers in the bathrooms. He has a phobia, so it’s only in the baby-changing room where he knows there isn’t one. Then he is fine.” So, Esther keeps a special pair of earphones handy for times when David feels overwhelmed by his environment.

Furthermore, these mothers are constantly worried over their children’s safety and whether they are happy or well looked after, especially in social environments where people are unfamiliar with the needs and behaviour of the child. Esther specifically voiced this challenge when she said that

one of the things that drive me crazy with worry is his tendency to wander off, because the child has no concept of danger! He just wanders off. Even at church I constantly worry about him there with all the other children. Then I just sit and cry in church. Not because I’m angry with the Lord, but just because I’m so emotional and I worry about my child.

Rachel had also had to deal with Ben’s nigh-time wandering, even when they went on holiday:

He slept in the caravan with us. Big brother slept in the tent, but we can lock the door of the caravan to make sure he doesn’t wander off in the night time. You never knew when he would get the idea that he wants to leave.

4.4.3 Personal challenge: The lifelong commitment

And you can’t stop. I can’t say that I’m going to retire one day, do you understand? Because I have... I have this child.

This quote by Mary represents the views of the participants on how they see their role in their child’s life. What these parents’ narratives show, is that raising a child with ASD is a lifelong responsibility. People with ASD often don’t grow up to be completely independent adults and, from the stories gathered for this study, it became clear that this is a matter of great concern for their parents, especially as these children grow older. Though parents like Mary, whose children are the oldest in the study, are trying to make their children more self-sufficient, they have their

doubts over whether their children will ever be able to live on their own. Mary explained how hard she is working to help Jamie run his own craft business, where he makes and sells bead jewellery online and how much money she spends on art classes for Daniel, because he enjoys drawing and colouring so much. However, she is acutely aware of how much responsibility still rests on her and John to make sure that their sons will be taken care of for the rest of their lives:

We want him to be self-sufficient and we have a big house, so we have a (Jamie)-trust where the smallholding is in and of which he will inherit the biggest portion, but one will have to appoint someone in your will or an institution that will appoint someone to live with them or keep an eye on them.

Rachel seemed to be struggling with the same dilemma in finding a suitable niche for her 17-year old son as he grows into adulthood. Given that he is neither completely dependent or completely independent, she is struggling to find a place of employment or residence that will cater well to his specific needs:

He is really rather independent. He does everything for himself, but there's just that certain psychological level where he can't... if something goes wrong, he won't be able to handle it.

Apart from the obvious financial implications of raising a child with ASD, who will probably be a financial dependant for the rest of his life, these parents also seem to be concerned about the kinds of jobs that their children might do one day and whether or not they will be able to hold a job at all. Mary tries hard to create job opportunities for her sons, but Rachel is still searching for viable options:

We really still don't know what we'll do from this point on, because... I won't say he is low-functioning, as in they can't do anything, but he's not that high-functioning that one could easily place him in a work-situation. When things go exactly right... let's say you give him something where he has to stack papers... then he can do that, but if one paper is not in the right place, he will stop there and won't know what to do next. He doesn't have that understanding of problem-solving.

4.4.4 Family challenge: Financial and opportunity costs

For the parents of children with ASD in this study, financial challenges ranged from paying for therapy and medication to making financial provision for the child's future. The narratives showed how these parents invest in their children in an attempt to secure a better future for them.

One of the challenges linked to raising a disabled child, is that such a child will most likely live with you for the rest of your life. When parents pass away, provision needs to be made for that child. Rachel and Richard, for example, bought a flat for Ben and their hope is that he might stay there one day, but otherwise it can be rented out as an income for him if they are not around to take care of him any longer. She explained that “it’s provision for the future, because you always need to think ahead, because you’re not always going to be here. I think that is one of the hardest things to try and do”. The parents also spoke about how time-consuming, and expensive, it can be to drive vast distances, daily to schools, doctor’s appointments and therapy sessions, and about how much valuable time home-therapy can consume. For Hannah, this is an especially great challenge, because Sam needs a lot of medication and therapy:

And all of this medication and therapy is not cheap, you know! It’s very, very expensive... and not because we’re trying to be fancy... it’s just to keep him functional!

According to Esther, Mark worries constantly about the financial challenges tied to raising their son, and that “...the school isn’t cheap, either, but for now it’s the best”. Mary, in turn, spoke of how, for the first two years after his diagnosis, she had spent countless hours doing exercises with Jamie. The therapists had recommended that she do exercises with him for three to four, and sometimes five hours per day, seven days a week, for two full years. Rachel also explained the challenges of driving between her and Richard’s workplaces and the children’s different schools:

Then in that time we realised that somehow, we had to make a plan, so we moved to be halfway between that school and our jobs. But it was still this terrible driving. All of it has financial implications! Everything you do, and I think often people don’t understand that...

4.4.5 Family challenge: Marriage

A strong theme that runs through all the narratives, is the toll that raising a child with ASD takes on the parent’s relationships, together with the daily challenges to the whole family. The general stress on both the parents as individuals, and the disruptions in the home and family life in general, caused by the behaviour of the child with ASD, contribute to this. Esther mentioned that, when David was diagnosed, the woman who diagnosed him “told us to look after our marriage, because it’s tough on a marriage... I understand what she meant.”

Partners also go through their processes of acceptance and mourning at different paces and through all of this they still need to support one another, support their child with ASD and support their other children. All this stress and strain can sometimes cause marital problems—something that Rachel and her husband experienced when Ben was diagnosed:

We were in totally different places. For a long while after that (the diagnosis) my husband was angry with me because he had cried that night and I was happy, and he couldn't understand where this thing had come from.

This is validated by Esther, who explained how differently she and Mark deal with their stress and disappointment. She thinks that Mark also needs to open up and talk about his experiences:

I've told (Mark) that I think we should go and see someone, because I talk, talk, talk, and cry, cry, cry, but he doesn't really talk. And I know he is also going through his own mourning process. He also had dreams for him and (David) for the future.

Marital strain can also occur when the parent who is the main caregiver of the child with ASD, starts resenting their marriage partner because he does not take equal responsibility, or does not put in equal amounts of effort. This is what Hannah shared in her narrative regarding marital challenges in raising a child with ASD:

I really sometimes feel as if I am attempting everything to see progress and breakthrough in (Sam), but my husband is not willing to put in the same amount of effort. He would rather take the route of the least resistance, because it's an effort.

4.4.6 Family challenge: Immediate family

The data shows that raising a child with ASD affects all members of the family. Grandparents, just like parents and siblings, go through their own process of coming to terms with their grandchild's ASD, and it can result in relationship challenges between the different generations within the family. Hannah, for example explained that “at first, my mother really struggled to connect with (Sam). And, because she had distanced herself from him, he also didn't allow her to come close to him”. Rachel attributed this challenge to grandparents' lack of understanding of ASD. Before Jamie had been diagnosed, they had had very little support from either grandmother. Even when he was first diagnosed, both grandmothers had been very anxious and terrified of looking after him for an evening, because they had not known what to do and they had not built up a good relationship with him. About her own mother she says

I don't think my mother knows what autism means. She doesn't know how to explain to someone what it is. She won't tell someone that there is something the matter with her grandchild, so she rather says nothing.

My analysis of the narratives also show that worry and guilt, pertaining to the other children in a family, seemed to be experienced by all these parents. They worry about the emotional well-being of the siblings as a result of the daily challenges they face, and they feel guilty for the loss that these siblings inevitably suffer and the sacrifices they have to make, due to their brothers' ASD. For Esther, this guilt and loss lies on an emotional level; she told me about her concerns for Miriam. She said that they have other friends with twins and that Miriam sees how they are around each other. She said, "I think she feels that bond with (David), but it's so difficult and she's still so small to try and understand". Due to Esther's concerns, Miriam was sent to a play therapist to help her deal with the challenges related to her brother's ASD. Hannah's feelings of guilt towards Annie are mostly related to financial matters. She told me "sometimes I feel guilty, because, if we had rather put all that money into (Annie), she would have been a champion by now". Mary also had to make financial sacrifices when her husband had told her to "drop everything and only give attention to the child", but she said that it had affected her daughter in other ways, because Amelia received less attention from her mother as a result of Jamie's rigorous exercise programme.

4.4.7 Social challenge: Lack of understanding and insensitivity

When it comes to the understanding and empathy of the general public, with regards to children with ASD, and the social challenges that parents face in raising these children, there was a consensus amongst the participants that people, even friends, are generally uninformed and, as a result, often very insensitive.

Esther spoke of how she gets tired of always having to explain and make excuses for David's behaviour, and how it bothers her that she is so often forced to do it in front of him:

Sometimes I can feel him cringe. It's almost as if I can hear him thinking: 'here we go again...' but I don't know how else, because I also want people to understand why he acts differently. It's so hard.

Hannah echoed this sentiment when she told me that people do not understand how to be with Sam. It also bothers her that they don't specifically encourage their children to reach out to him. She said, "I mean, he also has a need for friends, even though he behaves differently from other

children”. Even well-meaning friends, like the friends who had invited them to Disneyland once, found it impossible to understand why, with all the colours and sounds and the noise in the airplane, it was such a distressing experience for Sam. “People just don’t understand all the challenges!”

Both Rachel and Mary spoke about the challenges they had faced with hospital staff being uneducated in the field of ASD and how, even though they had been kind to the child, they had had no idea how to handle the patient’s ASD. These parents stated that they are placed in a role of always having to educate people, even medical professionals, about the ‘do’s and don’ts’ of how to work with their child. Furthermore, it seems that these challenges are not limited to social encounters outside the home but can also present themselves when friends and family are in the home of the child with ASD. Hannah spoke about how difficult it can be when people come into your home and do not know how things work.

(Sam)’s needs always have to be considered, otherwise it is chaos. Like if someone just switches off the television with no warning he will be in a state, because he is used to being warned if the television is going to be shut off in ten minute’s time.

As a result of people’s lack of understanding, they sometimes say things that are insensitive and even hurtful. Esther, for example, talked about how her husband had dared to tell one of his friends that his child has ASD

and the first thing that man said to him was: ‘at least you have the money to help him’. It hurt him so unbelievably! He just closed himself up. So, he doesn’t talk easily. I think it took him almost a year at his new job before any of his colleagues knew.

She has also had other experiences where people have remarked that “he doesn’t look as if something is wrong with him”, or “the Lord knows to whom he can give such children”. She said that comments like that come not only from strangers, but also from friends, and that she longs for people to just be open so that she can be truthful about the challenges she faces, because “ASD sucks so bad and I just want for us to be able to say that to one another”.

Rachel related an experience where she had gone shopping with Ben and the day had just been too long for him, so he was screaming in the checkout line “and then further back in the line someone commented out loud that my child only needs a good hiding”. She said that she had become quite upset and had told the person that her child has ASD and is having a meltdown.

Unfortunately, even after being told that, many people still know too little about ASD to really understand:

For example, you can be sitting in the (name of a restaurant) and he's a bit upset but when you tell the waitress that he's autistic she says: 'Oh that's nice!' That we've also had.

Eventually, these social challenges lead to some parents avoiding certain social engagements because they dread the response that they or their children will receive. One example of this came from Rachel's narrative: she remembered a social gathering at Peter's school, where Ben needed to be calmed down and the only way to do that had been to turn him upside down with his feet over her shoulders and his head hanging down

and I had my hands around him and I stood rocking. Then I could carry on any conversation because he is quiet. But the people stood and looked at me and wondered 'what is this woman doing?'

Esther, on the other hand, was quite honest about the fact that she would rather avoid parties and such "because one gets so tired of always having to explain and make excuses for your child's behaviour that it's easier to crawl into your shell". She said that "some friends try to understand, but there are also others for whom David is almost like a swear-word. They don't talk about it. They try to avoid it".

4.4.8 Social challenge: Lack of respite care

Most parents occasionally enjoy some time away from their children. They might need time to relax, spend quality time with a friend or spouse, or to keep an appointment with, for example, a teacher. For the parents of typically developing children this can sometimes pose a logistical problem if a babysitter is unavailable, but for some parents of children with ASD, finding someone who is willing and able to look after their child, is a much greater challenge. For Hannah, there is no one, besides her mother, with whom she can just leave Sam for a bit, or even a friend where she can go visit with him. She said, "it's only my sister who is up to it." Esther also agreed that she won't just leave David with anyone, because they would not know how to handle his ASD and Rachel, in turn, admitted that for a long time, when Ben was younger, it had always been a challenge to arrange for someone to look after him, if she and Richard had had go out together.

4.4.9 Social challenge: Lack of social support

From my analysis of the data, there seemed to be a general feeling that whatever social support was available to the parents in this study, it was not adequate in terms of their need for support. It appears that even within the wider community of parents with children with ASD, there is little contact and even less support for one other. Esther said the following about trying to rally support from other parents of children with ASD:

I know of more people in our estate that has children with autism and I've suggested that we do something together for awareness in our estate, handing out letters or something, but they don't really sound eager. Even at school, one actually has very little contact with the other parents. It's a lonely road. Very, very lonely. I looked everywhere for a support group or something, but I couldn't find anything.

It appears the parents of children with ASD don't feel that they can support one another, partly because their circumstances are so different. Another reason could be that they might not have the emotional capacity to support anyone, because they are barely coping with their own challenges. It has been Rachel's experience that it is a lonely struggle because your child is just so different from other people's children. So, even though you meet other parents of children with ASD, their journey is usually so different from yours that it makes it very hard to support one another. This was confirmed by Hannah who said, "I was in a support group for a while, but it was really only a lot of mothers venting about their children and I just realised I have my own package to deal with. We each received our own package and I really can't help other people with their packages too".

4.5 VALUABLE SUPPORT SYSTEMS

My analysis of the data shows that each of the participants in this study have valuable support systems on which they depend. I present these as three sub categories, namely, personal-, formal social- and informal social support systems. Figure 4.2 below provides the reader with the characteristics of each of these categories:

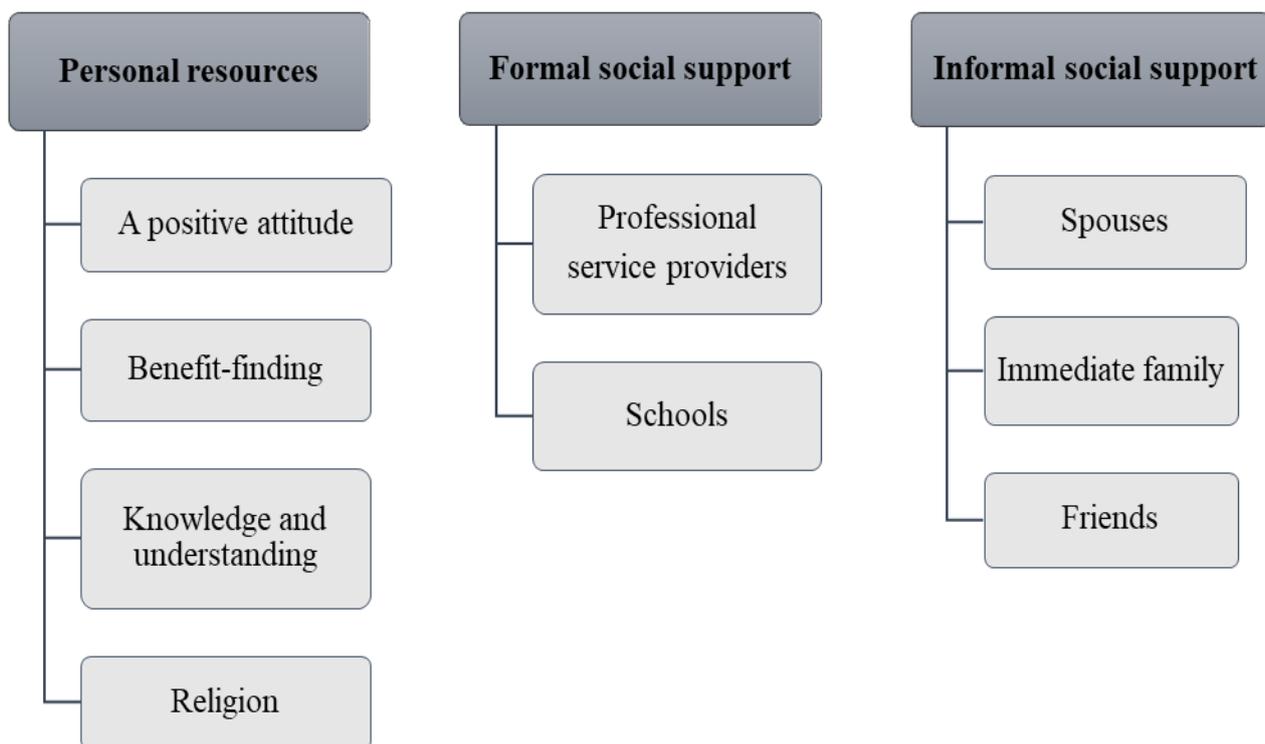


Figure 4.2 Support systems

4.5.1 Personal resource: A positive attitude

From the data analysis, it seemed that Esther and Rachel were the two participants who clearly showed a very positive, but realistic attitude towards coping with their children's ASD. They try to maintain the perspective that, although ASD is a part of their family life, it has not become their identity. Nor have they allowed it to become their child's entire identity. In this regard, Esther explained the following:

He is a happy, lovely boy who likes to wrestle and run and jump on his trampoline and climb... yes, he also has autism, but that's not all there is to him! Yes, he has autism, but he is also a boy, so I can't compare him only to his sister either.

Rachel echoed this frame of mind when she talked about the impact that Ben's ASD has had on their family through the years. She said that, though Ben's ASD has had a big impact on their quality of life, they never allowed it to become who they are. She admitted that their family life is different from families with two normal children, but that they "didn't stop living just because

Ben is autistic”. Rachel described herself as a realist. She explained that it helps her not to have unrealistic expectations of Ben, because, if she does, she sets herself up for disappointment:

I won't say I'm a pessimist, but I'm a realist in the sense of 'if it happens it happens and if it doesn't then that's that'. So, we put in everything we could, but I walked around knowing that every time he does something new then it's 'yeah', but if there's something he can't do then it's not the end of the world because I don't expect him to be able to do it.

Despite her determination to do everything in her power to help Ben develop his abilities, she has not been too hard on him or on herself, because she is realistic about the challenges that ASD presents to them both. As seen previously, she is concerned about what the future holds for Ben, and yet she said that they have learnt to “take it one day at a time and to only worry if you get there...”

The use of humour was also a coping mechanism that emerged as a theme from the data analysis, but I linked it to this theme because it is a sign of a positive attitude. It is natural for people to turn to humour as a coping mechanism when they encounter difficult life events and it appears to also be the case for the parents of children with ASD, as Hannah and Esther demonstrate with the following two quotes:

We sometimes make the joke that we are probably the only people in the estate who put burglar bars in front of our windows, not to keep people out, but to keep our child in (laughs). (Esther)

We have laughed a lot at the names that he would give things. For example, he calls the kitchen the food-room (laughs). And, of course, that is exactly what it is! (Hannah)

4.5.2 Personal resource: Benefit-finding

What stood out during my interviews with the four mothers was how proud they are of their children's good qualities and how they celebrate their talents and achievements. Esther prefers to view a potentially negative quality in her son as something positive when she talked about how stubborn he can be at times. This, she described as one of his best qualities - that he is so determined.

So too, Mary and Hannah talked about how talented their boys are and list their artistic abilities. Hannah, for example, is in awe of Sam's artistic talents and thinks that he could be amazing, with the right guidance. Mary is still home-schooling her son. Even though he is 19 years old, she is carrying on, because she believes that he has amazing abilities and talents. She has also hired a private teacher to teach Jamie, at home, how to work with clay. He now has his own collection of bead-work, which they sell online and at their yearly craft market.

What the data shows, is how these participants have become adept at the skill of benefit-finding. Esther, for example, seems to be thankful for the smallest things and counts herself blessed, despite the daily challenges of raising David. One of the things she values, for example, is the fact that David is not averse to physical touch, as children with ASD often are. "He is touch-seeking, so thankfully I can hug and kiss him. That is such a blessing!" She is also thankful for their financial situation, because she is aware of how hard it can be for parents who can't afford proper treatment and education for their children with ASD. She said, "and the school isn't cheap either, but for now it's the best. We are just thankful that we are in a position to be able to do it...". Another way in which Esther practices benefit-finding, is by comparing herself to people who are, from her perspective, facing even bigger challenges than she is. She has found it helpful to think that "no matter what your situation is, there is always someone who is worse off than you:

I have a friend, for example, who had to bury her child at 16 months. Then I just say "thank you Lord for my children! I am SO blessed". Then I really don't want to complain! I have learnt so much from that woman.

Rachel, just like Esther celebrates the fact that she can show physical affection to Ben, because he is not touch-sensitive either and "up until this day he is extremely fond of hugs". She also enjoys his sense of humour and is proud of how well his abilities in reading have developed:

He reads English, but he reads very well, and he had a very good sense of humour. So, if he reads something funny, he will laugh out loud.

Rachel explains a possible reason she is able to cope with Ben's ASD so well, as follows:

Maybe because I'm a teacher and in those situations, I have always viewed all children as different and I understand that each child needs something different, and it has always been part of how I understand it works.

In other words, she does not believe Ben is all that different just because of his ASD, but that he is simply a unique person, like any other person. To her "'normal' is just a setting on the washing

machine”, because she believes that “if you think about it, all people fall somewhere on a spectrum of some kind”.

4.5.3 Personal resource: Knowledge and understanding

When asked about the time of the diagnosis, 13 years ago, Hannah spoke about how challenging it had been for her not to have information available and not knowing who to turn to for help and advice. Since then, information on ASD has become much more accessible and, as a young mother who is still learning to navigate the waters of a life with ASD, Esther spoke about how important it is for her to equip herself with information, especially since it helps her to cope better with some of David’s maladaptive behaviour. She said she reads a lot because when she understands his behaviour, she is able to cope much better with it.

For example, I used to get very disturbed if he hit his head...you know, sometimes he lies on the ground and hits his head rhythmically on the floor. But then I went and read up about it. And, you know, it’s truly amazing. They say that children with autism’s bodies are so smart. They can feel that something doesn’t feel right and then they do something that makes them feel better.

So, she said that she can remain calmer now and think to herself, “okay, my child, it does something for you”.

Rachel also put much effort into researching various aspects of ASD in order to understand Ben’s needs, and so that she and Richard could make beneficial decisions and take action in terms of his educational needs. She described herself as the “researcher” and Richard as the “fighter”. This made her feel empowered because she felt like they were “doing something” about Ben’s ASD.

4.5.4 Personal resource: Religion

Faith plays an important role as a support system for Mary and Esther, and they both experience their Christian faith as their strongest and most valuable support system. Mary said that, at times, she had had no support. “I had only my faith. That’s all that has carried us through this whole thing.” She said that she would not have been able to cope, had it not been for her belief in God. Her experience is that even her children’s accomplishments can be largely attributed to faithful prayer. Esther, too, lists her faith as what she experiences as her most valuable support system, and states that it is what gives her hope for David’s future. She believes that her God has a

wonderful future planned for her son and that gives her peace of mind and carries her through the difficult times:

I honestly don't know how people do it who don't have Him to hold on to! Most of the time that is all that carries me. To know that He is in charge and that He has a plan. I believe that he has an unbelievable plan with (David).

She referred to the story in the Bible book of Exodus, of Moses who was called by God to lead the Israelites out of Egypt into the promised land, and how he had been a powerful and influential leader despite the fact that he had struggled with a significant speech problem, saying, "and Moses also had a speech problem and yet the Lord used him very powerfully! I hold on to that, because I know that the Lord has an amazing plan with (David)'s life".

4.5.5 Formal social support: Professional service providers

Experts within the field of ASD, such as psychologists and therapists, form part of a valuable support system for many parents of children with ASD. They are often instrumental in the ASD diagnosis, and they also provide therapy and support to children and parents after the diagnosis. Shortly after Jamie had been diagnosed, Mary took him to an institution where he was assessed, and a special exercise programme was developed for him. This had been a very positive experience for her because the professionals at this institution were experts in their field at that time and Mary returned home with the knowledge and tools to support her child and help him develop. She described the experience as "amazing and life-changing". Esther had a similar experience at the institution where David had been diagnosed and received his first therapy. She remembered having felt fortunate, because they had accommodated David immediately, even though they hadn't really had space for him. Esther quickly saw an improvement, especially in David's communication skills. Mary was the only mother who made any mention of support from a psychologist at one of the schools that Jamie had attended. She said that, though the psychologist had had only one initial session with each of them, they had been assured that she would have been available should they have needed to talk to her again.

Another source of formal social support mentioned by the participants, is medical professionals. Rachel spoke of the support that she had experienced from two doctors when Ben had been hospitalised to be operated on, because of a broken arm. One could see, from her story of this incident, that she had a sincere appreciation for their understanding of Ben's needs during that time and for the exceptions they had been willing to make for their family, in order to accommodate their needs:

The doctor was amazing! He allowed my husband, the one who is best at keeping my son calm, to go into the operating theatre with him. My son had his ‘Finding Nemo’ pillow that went in with him. The anaesthetist allowed my husband to hold my son’s hand until he was asleep and only then we took Nemo out and dad went out... and they allowed him back in when he woke up and he sat with him, so he never even knew that Nemo and daddy had not really been with him all the time.

4.5.6 Formal social support: Schools

Rachel’s story was filled with accounts of the struggle that she and her husband has had through the years, to find suitable schooling options for Ben. However, with no small effort, they had gotten him into different schools at different stages in his development and she has the highest praise and appreciation for many of the teachers who have taught Ben throughout his school years. During his pre-school years, they had a private tutor work with him at home and Rachel was certain that her support to Ben had been invaluable in those years. She also values the love and care with which this woman taught Ben from seven to seven, six days a week:

And she managed it. Without ever raising her hands to him. Without ever yelling at him... without ever doing anything she did it. She is amazing.

Rachel believes that their greatest support when Ben was in primary school, came from the teachers that Ben had had at specific times. She said, “Maybe every time when he was there, we were just lucky to encounter these unbelievable teachers there”. Her high regard for Ben’s teachers is further illustrated by the following two quotes, and leads me to believe that when the child with ASD’s needs are properly met at school and the teacher makes a genuine effort to support the child, the parents also indirectly experience this as support to themselves:

And the teacher’s there were also unbelievable. He had an unbelievable teacher. Absolutely... that there was amazing that she managed with him. He knew very little of number sense, but she got him through Grade three Mathematics.

They have a special class group that are all in different grades and things and it’s an unbelievable teacher. She is just amazing!

Mary’s experience with schooling for Jamie has also been one riddled with challenges, but she echoed Rachel’s appreciation for the effort that some schools and teachers make to accommodate and support learners with ASD. What she most appreciated of one school, for example, was that they had made an effort to support parents in their quest to find a suitable place of care for their

adult child by taking them on field-trips to different institutions and ensuring that the child's name gets put on a waiting list.

4.5.7 Informal social support: Spouses

When Esther talked about the time that had surrounded David's diagnosis, she remembered clearly how supportive Mark had been. She said, "he was strong all the time. Maybe that's what a husband is like if he sees his wife is falling apart. Then he feels he must be the strong one, you know?". Both Esther and Rachel felt that their spouses partnered with them in raising their child with ASD. Esther recalled how she and Mark focused on different aspects of caring for David's needs, and said it enhanced their effectiveness in supporting David:

He, for example focuses on putting away money in case (David) can't work one day, you know. I can't think like that. I only focus here. Every day is a new day and I take it as it comes. So, it's probably a good thing... then I suppose we are a good team (laughs).

Rachel, too, stated that the journey of finding the best educational options for Ben throughout his school years was a great challenge that she could not have taken on without Richard. The following extract from my interview with her illustrates how she experienced this partnership:

We made a great team, my husband and me. We... I did the research and stuff and then I forwarded it to him- all the summaries of the things- and then he would read it and say "okay, look up this or this" and then for the rest he fought the battles. We provided good support for each other in the sense that, because I have a background in teaching and he is an engineer. It's that thing of... I can... I understand the child's soul and how learning takes place and he is this engineer that made plans and fought battles. If I was able to convince him that something had to be done, then he would fight for it and put the blocks right. So, there we made a good team.

4.5.8 Informal social support: Immediate family

Support from the participant's parents and parents-in-law, was significant in this study. For Esther, both her parents and her in-laws are valued support systems because they also care deeply for her children. This care and support are also part of what she experiences as care and support to herself:

My parents and (husband)'s parents are amazing! Especially my parents because they are close. They also live here so they help me a lot. And they have a very beautiful

relationship with (David). They love him so much and they laugh at his quirks. But not laugh at him, you know, but just because sometimes that is all that one can do.

She values the effort that they make to understand what ASD is and how they, especially her own parents, provide emotional support to her when she feels overwhelmed:

They don't always really understand, but they try. Shame, my mom also tries to use all the right terminology, but often the word is not right. Or sometimes she makes her own words, but one sees the effort. And especially with my parents I can just be myself. I can scream, or cry and my mom will just hold me tight and I know she will still be there tomorrow.

The grandparents' support also came in the form of respite care. For three of these mothers, the children's grandparents are the ones who most often provide this much needed support. Esther said that her parents sometimes look after the children and that she is extremely thankful for the respite care that her parents are willing to provide, because "it is so crucial. Sometimes one just needs to get away otherwise you will go crazy!". Rachel's mother-in-law has not only provided respite care when needed throughout the years, but was also, in later years, very involved in Ben's home-schooling:

When my mother-in-law agreed to teach him when he... that grade six year, those two learnt a lot from each other, so I think they understand each other pretty well by now and, uhm... she really does a lot for him. I can't complain about that.

Her mother-in-law had even lived with the family for a year to help with home-schooling and to care for the children during the week, while Rachel and Richard were at work. She has a close relationship with Ben and taught him many valuable life skills, such as how to smile for the camera when his picture is being taken. Rachel said that now that Ben is older, he stays at home during the day and does not need constant supervision. However, his grandmother still chooses to spend one day a week with him so that they can visit together and read books.

Out of all four participants, Hannah's mother is the only grandmother who lives with the family, permanently. She moved in shortly after Sam had been diagnosed which helps Hannah a lot, because she has a full-time job and doesn't really have other places where she can leave Sam when he is not in school. Her mother takes care of the children in the afternoons and helps with the cooking and other household chores.

It seems that these participants place a high value the support that siblings provide to their brothers with ASD, because, as parents, they also experience this as support to themselves. Esther

described her five-year old daughter's support to her brother and her attitude as "amazing". She explained how Miriam would often take David's hand and say to people: "this is my brother (David). He has Autism and that's why he can't talk". Rachel also appreciates the support that Peter has provided to Ben. Having a mature, responsible older child benefited the parents and the sibling in various ways. According to Rachel, Ben's older brother spent his gap-year helping his grandmother with Ben's home-schooling. He has since become a valuable provider of respite care. So, for example, the parents could leave Ben in his care, as the brothers got along well. It also freed them to engage in social activities such as going to the movies or to a restaurant. Rachel shared a very special event in her life; the day when Peter turned 18 and offered to be named his brother's guardian, should anything happen to her and Richard. She explained that Peter knew, from the beginning, that his parents had no expectations that he should take responsibility for Ben. They had always told him "You have your own life, so you go where you must go, and you do what you want to do".

And then, on the day that he turned 18, he came to us and said: "Daddy, you can change the will now to make me brother's guardian if something should happen to you". Completely out of his own will.

Hannah's sibling support does not come in the form of her other children, but rather it is her own sister who provides her with one more place where Sam is welcome and where she can just be herself.:

My sister is really the one who supports me the most. She is the only person where I can sometimes drop (Sam) and where he can even sleep over, when it's necessary.

4.5.9 Informal social support: Friends

Though it appears that the saying 'when times are tough, friends are few', might apply in the case of parents raising a child with ASD, these participants did list a close circle of friends as valuable support systems. For Hannah, the most valuable support system comes in the form of financial support from friends. These friends have made significant contributions towards Sam's medical expenses throughout the years, for treatments and therapies that are not covered by the medical aid, or when their medical aid funds were depleted.

Esther's narrative also mentioned establishing friendships with parents of children with special needs as a valued support system. One such support comes from a friendship with a parent whom she had met at the institution where David had been diagnosed and first treated:

That woman means so much to me. We try to get together once a month and then we go out to a restaurant and we vent about our children. Or we laugh about their quirks. Or we talk about our marriages, because we know... We can send each other messages and say things like “today was not a good day... my child smeared his room with hmmm again” and know the other one will understand.

Rachel described friendship as a valuable form of support, because she feels that the friends who came with them through the years accept Ben just as he is, and she feels comfortable knowing that she doesn't have to pretend when she is around them:

I can really say that friends that we have left are the ones who came with us through this thing and they take him as he comes. If he's like this today, he's like this and if he's like that the next day, then he's like that...

During the interviews, I tried to establish whether these parents also seek support through social media sites. However, it was only Esther who had experienced it as a valued form of social support. She had also been using it as a platform to spread awareness about ASD, and to lobby support for ASD. It has been her experience that, when her friends know what ASD is, they become more accepting and understanding of her child's behaviour and, consequently, more supportive to her. She went on to explain that each year during April, which is Autism awareness month, she makes an extra effort to post information. She described it as an unbelievable tool to share information and to educate others about ASD. She experienced that, as people learn more about ASD from her contributions to social media, they don't only support her there in the virtual world, but also in the physical world, when she encounters them socially. She told the story of how, on occasion, when she had gone to pick up Miriam from school, one of the other mothers had called her over and shown her that she had painted her toenails blue in support of ASD. Another time, some of her friends had posted a video online of themselves running a race in blue outfits with the heading ‘for you, David!’. Esther said that, when things like that happen, she feels supported and understood.

4.6 CONCLUSION

In this chapter, I presented the data that I collected for this study. I shared the four participants' unique stories and these mother's experiences, both in terms of their support needs and in terms of their available and valued support systems. In the following chapter I will discuss the findings

at which I have arrived, as well as the limitations of the study. I will also share possible implications for the practice of educational support, as well as suggestions for further research.

CHAPTER 5

5.1 INTRODUCTION

The primary research question that this study wanted to answer was: What are the roles that support systems play in the lives of parents raising a child with ASD? The process of data gathering through narrative interviewing of four purposively selected parents, sought information to respond to the following secondary research questions:

- What are the support needs of parents raising a child with ASD?
- What are the experiences of parents with the support systems that they use?
- Why do parents raising a child with ASD endorse some support systems over others?

In Chapter Four, I presented the themes that emerged from the analysis of the data. In this chapter I engage in discussion of these themes, using the research questions that were posed as a guide for the discussion of the findings. I then reflect on the implications of these findings for educational support, consider the limitations of the study, and make suggestions for possible further research.

5.2 DISCUSSION OF THE FINDINGS

5.2.1 What are the support needs of parents raising a child with ASD?

The data showed that the parents of children with ASD face many challenges. From my analysis of the data, three broad categories of challenges emerged, namely: personal challenges, family challenges, and social challenges.

The personal challenges that the four participants particularly raised, were difficulties they experienced in communication with their child with ASD, their child's maladaptive behaviour and the lifelong commitment they had made to raise a child with ASD. All children with ASD experience some level of difficulty with communication, and it seems that parents find this both a frustration and a cause for serious concern. They experience frustration, because they struggle with everyday parent-child communication and it saddens them that their relationship with their child suffers because it lacks a certain level of connection. Furthermore, it concerns them that their children must cope in a world where their poor or limited communication skills contribute to their invisibility, as well as make them vulnerable to exploitation by others.

The challenges arising from their children's maladaptive behaviours affected these parents on a personal level and required them to adjust their own routines and ways of doing things. This

requires them to stick to strict routines, eating habits, and social arrangements that do not trigger unwanted reactions from their children. Anything out of the child's daily routine or familiar surroundings could cause a meltdown at any time - a situation that these parents find stressful and constantly have to manage. These parents are also continually concerned for their children's safety, given that many children with ASD have the tendency to wander or run off, and lack comprehension of the danger it might hold for them. The third personal challenge that emerged from the data concerns the never-ending responsibility and lifelong commitment towards the child with ASD. These parents' narratives reflect the level of commitment that is needed to raise a child with ASD. Unlike typically-developing children, these children will always require some form of adult care and supervision, for the rest of their lives. This kind of care and supervision is often taken on by the parents. It also involves financial provision for their child to be taken care of, should they not be around anymore. This seemed to be a great concern for the older parents whose children are already adolescents and adults.

The family challenges that emerged as themes included financial and opportunity costs, marital struggles, and difficulties within the immediate family-circle. Taking care of the needs of a child with ASD is costly and time-consuming. All the parents shared stories about the financial strain that doctor's appointments, therapy, medication, and special schools place on a family. Along with this, there are also opportunity costs, because of the amount of time that these parents have to spend driving their children to and from appointments, and also the time that is spent on therapy at home and the money that families invest in providing for the future needs of their child with ASD.

It would seem from the narratives that personal- and financial challenges often place strain on the marriages of parents of children with ASD. The participants spoke of the challenge posed when both partners were dealing with their own challenges surrounding their child's ASD, whilst also working on maintaining a well-functioning family unit. It is also difficult that spouses go through their individual processes of mourning and acceptance at different paces, or in different ways

Family challenges, however are not limited to the child's parents, but extend to the other family members such as siblings and grandparents. These members of the immediate family also face personal challenges in dealing with their brother or grandson's ASD and also contribute to strained relationships within the family-circle. What appeared to be the main challenge in this regard, is when parents perceive their own parents as unsupportive and uninvolved, especially in

the early years after the diagnosis. Along with this, the participants all shared experiences of concern and guilt towards their other children, because of the sacrifices that they feel these children are required to make, as a result of their parent's over-involvement with their sibling with ASD.

From the data, there also emerged a number of social challenges that the participants attribute to society's lack of understanding, a lack of respite care and a general lack of social support. All the narratives contained numerous examples of how an uninformed and insensitive society can be towards children with ASD and their parents. These parents all said that they get exhausted from always having to explain their children's behavior and, as a result, some of them have stopped attending certain social gatherings. The data also showed that the parents of children with ASD find the general public judgmental and critical. This includes most of their friends, whom they say do not even try to understand the challenges that they face. On numerous occasions the insensitive comments from strangers and friends alike have been experienced by all the participants as hurtful.

The lack of respite care for children with ASD is a significant social challenge that the parents in this study identified. Because these children have such specific needs, it is not possible to leave them with just anyone. Furthermore, not everyone is willing to take up the task of looking after a child with such very specific needs. The data showed that all these parents have only one or two family-members, at the most, in whose care they can safely leave their child and that most of the time, parents must care for the child themselves.

A surprising finding was that the parents in this study have all had experiences of a lack of social support from other parents of children with ASD. It seems that, while they had expected to find support from parents who are experiencing similar challenges, they soon realised that there are a number of reasons why other parents of children with ASD are not always the most reliable support system. The first is that these parent's time is very limited, and they struggle to find opportunities to get together. Furthermore, these parents pointed out that it is assumed that the parents of children with ASD experience similar challenges, but that it is often not the case. The spectrum that these children fall on is so broad that there are not always many similarities between the challenges that different parents face. Thus, support also has to be adapted to each unique case.

5.2.2 What are the experiences of parents with the support systems that they use?

In the narratives of the four parents, they talked about a wide variety of support systems that they tap into. These, I categorized as personal resources, formal social support and informal social support. Personal resources are mostly internal coping mechanisms that can be inherent personality traits or learned behavior that supports the parent in facing her challenges. The personal resources that emerged as themes from the data were positive attitudes, the art of benefit-finding, religion and developing an informed understanding of ASD.

The value of personal resources as support systems should not be underestimated. Though these resources might not always be equally obvious to the parents themselves, my analysis shows that these resources serve as powerful coping mechanisms by which these parents support themselves. Benefit-finding, I link to having a positive attitude. Parents who possess a positive attitude are more easily able to practice the art of benefit-finding through which they can focus on their children's strengths rather than on their weaknesses and view them as differently-abled rather than disabled. Along with this goes the theme of knowledge and understanding, because these parents have experienced that, when they are armed with knowledge about their child's ASD, they can cope better with their children's behaviour, and be more pro-active in managing it. When their religion is central to their personal resources, the participants would attribute their ability to cope with their child's ASD almost entirely to their Christian faith, as I found with Mary and Esther.

In my analysis of formal social support, I distinguished between schools and professional service providers such as psychologists, doctors and therapists. This study was conducted within the field of educational support, so, from there, my focus on how schools and educators can benefit from this knowledge. What I found particularly significant in this regard was that, although there was little said about direct support from schools to the parents of the children with ASD, there was an intrinsic understanding that the teachers and schools that the children have engaged with, care. There was a consensus view that teachers were involved and made an effort to support the needs of the child with ASD within the school- and classroom environment. As such, the parents consider the teachers' involvement with their child with ASD as indirect support to them, as parents.

Finally, data from this study showed that informal social support can be provided by spouses, immediate family and friends. The parents in this study have all, except for one, experienced

strong social support from their spouses through the years. They welcomed their partners as their team-members and valued their partners' commitment to overcoming the challenges of securing proper schooling and making financial provision for their child's future. Their children's siblings and grandparents were also very reliable sources of support, both for the child with ASD and for themselves. For some, friends have stepped in financially when medical aid funds were depleted and when expensive medication, treatments and therapies were required for the child. The participants acknowledged the commitment and sacrifices that their immediate and extended family members and friends have made, because it ultimately contributes to the well-being of the family.

Though online support on social media was not widely tapped into by the participants, it was a valued support system for Esther. It became a resource as well as a platform for lobbying support for ASD. The fact that the other parents did not make use of social media support could potentially be attributed to a generational difference between this parent and the others in the study. She is much younger than the other three participants and social media might be a platform with which she is much more familiar.

5.2.3 Why do parents raising a child with ASD endorse some support systems over others?

It appears that the parents of children with ASD do not necessarily consciously choose or prefer certain support systems over others, but rather, it appears that they rely on and appreciate whatever support is available for them, from whichever source it comes. When professional support and care of teachers to their children is assured, they perceive this as indirect support to themselves. These parents pointed out the complexity of ASD and how each case is unique. This makes support from other parents with children with ASD challenging. There was also acknowledgement that the support needs of parents change with time and circumstances, thus, the support systems they endorse will also change with time and circumstance.

5.3 REFLECTIONS ON THE IMPLICATION FOR EDUCATIONAL SUPPORT

When it comes to putting our narrative understandings into practice, Shank (2006) suggests three metaphors to explain the process. He uses the 'lantern' as a metaphor for the process by which the researcher wrestles with the narrative to shed light on its deeper meaning. For me, the research process involved a lot of wrestling with the narrative in my efforts to uncover the meaning of each parent's experiences with raising a child with ASD. I experienced the process of

inductive analysis as multi-layered and complex and reaching the truth of someone else's experiences was, at times, a challenging task.

The 'window', as a metaphor, is concerned with the use of stories to create a greater awareness of the truth as experienced and told by individuals. The truth that was revealed by this study is that there is no one story of ASD, and that these parents face many challenges and have unique support needs. However, the findings show that parents felt their needs were met when their children with ASD were given access to support and were properly supported by schools and teachers. Within the framework of educational support, this should encourage schools to go to even greater lengths to include and support learners with ASD.

The 'mirror' is the third metaphor that is useful for reflecting on how research has influenced the researcher's thinking on the subject, because stories are helpful in seeing ourselves and our communities from different angles. What I learnt about myself and my profession as a teacher in educational support, is that it is of great importance to make every attempt to understand the challenges that a particular parent or child faces in order to try and support them as well as possible. It would be naïve to think that, because I know something about ASD, that I am fully capable of supporting each parent and learner with ASD who might cross my path. I have learnt that each parent and child's story is truly unique and extremely relevant when planning support to that child or parent.

The stories confirm the relational aspects of educational support and the value it holds for children with ASD and for their parents. This finding is validated by Bronfenbrenner's motivation for person-to-person and individual-context relationships in the practice of educational support, and the importance of understanding each individual's context as unique

5.4 LIMITATIONS OF THE STUDY

This research was done as part of a structured master's degree programme and is a 50% requirement for the degree. Because this was a study of limited scope, there were some limitations that need to be pointed out. The study had to be delimited to the experiences of four parents of children with ASD, who were a purposively selected sample of middle- and upper middle-income families. The stories that families from other socio-economic backgrounds might tell about support, are thus not presented here. The time available to conduct the study and the

geographical locations of the participants also placed constraints on decisions about data methods and methodology.

5.5 SUGGESTIONS FOR FURTHER RESEARCH

One could argue that the possibilities for further research are endless, but I would still like to make the following suggestions for further research:

This study's participants were all parents of relative financial means who were able to secure support for their children. Further research that explores the support systems of parents from low-income families, needs to be done to inform us about the challenges and needs of such families. Comparative studies could present possibilities to inform about the needs for support for children with ASD across diverse family structures.

The study's participants were female and could be representative of a particular parent-lens. Future South African research involving the fathers of children with ASD as participants could make valuable contributions to knowledge about parent support in the field of ASD and educational support.

5.6 CONCLUSION

In this chapter, I have discussed and drawn conclusions from the narrative data presented in Chapter Four. I have also reflected on the possible implications for the practice of educational support and made suggestions for further research. In conclusion, though the purpose of this study was to understand parent support systems, the findings also show how support needs and valued support systems of each parent of a child with ASD are just as much on a spectrum as the children with ASD themselves. It is, therefore, imperative that the learning-support teacher cultivate the ability to listen to the narratives of parents with children with ASD and make every attempt to understand their needs and to support them and their children accordingly.

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ADDENDUM A: ETHICAL APPROVAL



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC Humanities New Application Form

26 March 2018

Project number: 0566

Project Title: Raising a child with Autism Spectrum Disorder (ASD): The role of parent support systems

Dear Mrs Nana Eksteen

Your response to stipulations submitted on 14 March 2018 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
28 September 2017	27 September 2018

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (0566) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	20416016 Research Proposal (NE)	31/07/2017	1
Informed Consent Form	20416016 Revised Consent form (NE)	01/01/2018	
Data collection tool	20416016 Revised Interview guide (NE)	01/01/2018	
Default	Response to REC stipulations	01/01/2018	

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032. The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research:

Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

ADDENDUM B: PARTICIPANT CONSENT FORM



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STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Raising a child with Autism Spectrum Disorder (ASD): The role of parent support systems.

You are asked to participate in a research study conducted by Mrs. Nana Eksteen, a MEd Educational Support student in the Department of Educational Psychology at Stellenbosch University. The results of this study will contribute to a master's thesis. You were selected as a possible participant in this study because you are the primary caregiver of a child who is diagnosed with Autism Spectrum Disorder (ASD).

1. PURPOSE OF THE STUDY

The primary goal of this study will be to increase understanding of how parents who are raising a child with ASD experience the support systems available to them. The study will aim to advance a greater understanding of the support systems available to parents who are raising a child with ASD within the framework of educational support.

2. PROCEDURES

If you agree to participate in this study, we would ask you to do the following things:

- Participate in a semi-structured interview with the researcher in which you will be asked to share your experiences of support in your journey as a parent of a child with ASD.
- Negotiate, at your discretion, the possibility of allowing the researcher access to your own contributions to online support groups, blogs or other kinds of social media that form a part of your support system.

3. POTENTIAL RISKS AND DISCOMFORTS

I foresee very little risk to participants in this study. However, in participating, you might have to revisit painful or difficult experiences as you share them with the researcher. This could potentially lead to some level of emotional discomfort. Should this occur, debriefing sessions would be scheduled for you with facilitators within the Department of Educational Psychology. Contact the researcher (contact details below) or Prof. Doria Daniels at the Department of Educational Psychology (doria@sun.ac.za) to make the necessary arrangements.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

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By participating in this study, you could help advance a greater public understanding of the support needs and -systems of parents raising a child with ASD. The potential benefit for you could be capacity-building and personal empowerment.

5. PAYMENT FOR PARTICIPATION

You will not receive any payment for participating in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of code names to protect your identity as well as that of your child and other persons you might mention. All data will be stored on a password-protected computer and only the researcher and her supervisor will have access to it.

Interview recordings will be stored only as long as the researcher needs them as data for the study and then destroyed. You maintain the right to review the recordings at any time in the study and edit information that you shared with the researcher.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you voluntarily participate in this study, you have the right to withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may also withdraw you from this research if circumstances arise which warrant doing so.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Nana Eksteen. Telephone: 044 934 1009, cellphone: 0723637656; email: nana.eksteen@gmail.com.

8. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was explained to me by Nana Eksteen in Afrikaans. The information on the form was satisfactorily translated for me.

I am in command of this language (English) and was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the participant*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in Afrikaans and no translator was used.

Signature of Investigator

Date

ADDENDUM C: INTERVIEW GUIDE

SEMI-STRUCTURED INTERVIEW GUIDE

Raising a child with Autism Spectrum Disorder (ASD): The role of parent support systems

Demographic information.

I would like to start by getting to know you, and the context within which you, as a parent raising a child with ASD, function.

1. Could you introduce yourself? [name/who you are; profession (if any)]
2. I would also like to know more about (insert name of child). [date of birth, age, gender, etc]
3. Tell me about the members in your household: [spouse, other children, extended family living together in your house]

Information about diagnosis

1. At what age was your child diagnosed with ASD?
2. How did the diagnosis come about?
3. Describe your emotional responses or feelings when your child was diagnosed.
4. How did the ASD diagnosis lead to changes in the way you did things (if any)?

Challenges

Next, I would like to talk about the challenges of living with your child's diagnosis for your family.

1. Could you speak about personal challenges for you? (Sacrifices?)
2. And for your family members? (Probe!)
3. Social challenges?
4. Financial implications?
5. Other challenges?

Support systems

Now I would like to focus on the support systems that you have available to you. Let us start with your family. How are they involved in the raising of (insert name of the child)? [Probe and ask for examples. Also ask how they are helpful/supportive (emotionally, physically, financially or other)]

In what ways do your friends form part of your support system and what is the nature of their support? [Probe and ask for examples, also ask about online support from friends.]

Do you receive support from any medical or educational professionals? [Doctors, psychologists, therapists, teachers, school staff] If so, tell me about your experience with the following: (also ask for examples)

- Support from professionals
- Support from school
- Community support
- Support groups
- Online support groups
- Social media
- Other support (explain)

6. In what ways are these support systems helpful? Elaborate.
7. Explain which of your support systems you value more than others.
8. Why you value these specific support systems above others? Elaborate
9. What would you say is your most valuable support system?

ADDENDUM D: EXAMPLE OF CODED TRANSCRIPTION

COLOUR-CODING KEY FOR INTERVIEW TRANSCRIPTS:	
Information about diagnosis:	
Challenges:	
Support systems:	

249 P: En ag, om 'n lang storie kort te maak, het die spinale blok toe alles laat
 250 doodgaan tot bo die hartlyn. So, toe is ek eers in ICU terwyl hulle dit uitsorteer
 251 want hulle kan my nie laat gaan voordat dit weer lewendig is nie, want hulle was
 252 bekommerd netnou gaan staan my hart. En hy is toe in 'n broeikas gesit eers
 253 en...ja. Maar dit was die weirdste ding... kyk, ek is glad nie ... ek is self half
 254 outisties... Ek is nie goed met mense se body language lees en sulke tipe van
 255 goed of whatever nie. En toe hulle hom vir my bring en ek hou hom vas toe gaan
 256 sit hy soos 'n paddatjie hier teen my en hy trek sy beentjies en sy alles so op en
 257 hy druk sy naeltjies... jy kan sien die kind is totaal verskrik en die eerste ding wat
 258 ek net gedink het was... en ek het dit vir hom kliphard gese al was daar
 259 niemand om my nie "dis okay, ons sal fight, jy sal fine wees"
 260 En ek weet nie hoekom ek dit gese het nie, want daar was niks om te se dit was
 261 iets anders as net bang nie...

262 N: Ja...

263 P: Maar van daar af: Ek het geweet iets is nie reg met hierdie kind nie... en my
 264 man het dit ook redelik vroeg opgetel. Hy... ag dis daai hele doodgewone ding
 265 van die outisme van almal dink hy's doof omdat hy nie draai na klanke toe nie en
 266 sulke tipe goeters nie maar al die toetse kom normaal terug maar hy leer nie
 267 praat nie. Hy is op sy eie... hy wil niks... die eingste ding.... Die groot ding
 268 hoekom hy lank gevat het om te diagnoseer was hy's tot vandag toe ongelooflik
 269 lief vir drukkie (glimlag).

270 N: Ja, okay.

271 P: Want hy is hipo-sensitief en nie hiper-sensitief nie en dis mos net 'n klein
 272 deeltjie van hulle wat so is. En almal het gese omdat hy van drukkie hou kan hy
 273 nie outisties wees nie...

274 N: O ja, (lag)

275 P: (lag)... En as die radio aan is dan gaan staan hy met sy hande so teen die
 276 speakers wat vibreer en dan lag hy. , aan die een kant laat dit jou dink hy is
 277 doof , maar dit kan nie outisme wees nie, so niemand kan hom op iets sit
 278 nie...

279 En toe op, drie en 'n half, het hulle toe na AL die toeste wat die sielkundiges en
 280 die arbeidsterapeute en almal gedoen het gekyk en toe besluit hulle 'okay, hy is
 281 PDD-NOS. On sweet nie presies waar om jou te sit nie, maar jy is duidelik
 282 outisties'.

283 N: (lag) Okay. En praat hy nou?

284 P: Ja. Die, die... Hulle het vir ons gesê met die toetse, hy was so drie en n
 285 half, dat hy op nege maande vlak omtrent is. Hulle het vir ons gese hy gaan
 286 nooit praat nie – as hy nog nie toe al iets begin doen het nie- hulle het vir ons

Information about
diagnosis: difficult
 birth

Information about
diagnosis: first
 awareness leading
 to diagnosis

Information about
diagnosis: struggle
 to reach a
 diagnosis

Support system:
 personal resource-
 benefit-finding

Information about
diagnosis: struggle
 to reach a
 diagnosis

Information about
diagnosis: eventual
 diagnosis

287 gese hy is nie opleibaar nie en ons moet besluit wanneer ons hom wil laat
 288 institutionalise.

289 Nou daai aand, dit was die sielkundige, die pediater, die arbeidsterapeut, die
 290 hele lot was by ons aan huis. My man het daai tyd... sy werk het hom verskriklik
 291 baie rondgestuur en dit was vreeslik moeilik vir hom om by 'n dokter se
 292 spreekkamer uit te kom.

293 N: Ja jaja

294 P: En as gevolg daarvan het hulle toe almal een aand na ons huis toe gekom
 295 en toe hulle toe nou daai goeters sê... my man is Afrikaans... hy is goed
 296 Afrikaans... hy het rooi hare... en hy het net vir hulle gese "daar is die
 297 voordeur" (lag)

298 N: (lag) En dit nie aanvaar nie?

299 P: Nee, dis nie aanvaarbaar nie. 'Daar gaan julle'. Maar ten minste het ons toe 'n
 300 diagnose waarmee ons kan werk en ons het 'n baie goeie span saam gemaak ek
 301 en my man. Ons het... ek het die navorsing-goeters gedoen en dan stuur ek vir
 302 hom aan – die opsommings van die goeters – en dan lees hy dit en sê, "okay,
 303 soek dit of dit" en dan... verder het hy die baklei gedoen.

304 N: Okay.

305 P: Waaaant, ons het net gese daar's geen manier nie want hy klank... daar's
 306 klank – dis nie dat hy nie iets maak nie- en hy't drie woorde gehad. Hy't
 307 'mamma', 'ja' en 'nee' gehad. Wat hy baie goed kon gebruik, maar niks anders
 308 nie.

309 N: Okay...

310 P: So... toe het uhm... ons het toe gekyk... want ons het toe gesê: 'nee
 311 institutionalise gaan nou nie gebeur nie... dan is die volgende ene, ons moet
 312 hom by (XXX) skool probeer inkry'. Nou op daai stadium was hy eers hier in
 313 (XXX) by 'n plek vir ernstig gestremde kinders wat net basies 'n dagsorg
 314 was... my man noem dit 'n bum-wipe... 'ons gooi vir jou kos bo in en ons vee
 315 onder wat onder uitkom'. Dis al wat gebeur daar.

316 N: So nie eintlik stimulasie nie?

317 P: Nee, maar ons het net nie 'n keuse gehad... ons het nie op daai stadium
 318 geweet wat om anders te doen nie... totdat hy toe nou amper oud genoeg is.. of
 319 nie oud genoeg nie, maar hy moes ek dink vyf wees voor hy kon (XXX) toe of so
 320 iets...

Information about diagnosis: feelings around time of diagnosis

Support system: spousal support-being team members

Challenge: personal challenge-communication

Support system: personal resource-positive attitude

Challenge: finding an educational niche