A Qualitative study exploring the psycho-social experiences and difficulties of parents who have a child with Autism Spectrum Disorder (ASD): Within a South African context.

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Submitted in partial fulfilment of the requirements for the degree of Psychology Masters of Social Sciences (Clinical Psychology) in the School of Applied Human Sciences - Psychology

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ABSTRACT

ASD is a neuro-developmental disorder that is associated with lifelong deficits in social and communicative abilities as well as ability to function independently. A diagnosis of ASD also has major consequences for the parents, with the potential to radically change and affect the entire family. It has been suggested that amongst childhood developmental disorders, ASD may be one of the most stressful for parents to manage. The evidence of increasing prevalence rates worldwide and of the burden of care associated with ASD emphasises the need for further exploration of parental experiences. This study investigated the experiences and challenges of parents who have a child with ASD within a South African context, specifically the Western Cape.

Methodology: The study examined parental difficulties qualitatively, through semi-structured interviews and analysed the results using thematic analysis. The results were discussed within the theoretical context of the Resiliency Model of Family Stress, Adjustment and Adaptation proposed by McCubbin and McCubbin (1993).

Findings: An analysis of the interviews revealed a number of significant themes which offer insights into the psychosocial experiences of parents of a child with ASD as well as the factors that impact family resilience and coping. Emerging themes highlighted two contending and yet interlinked trends (vulnerability and resilience) that permeated the experiences of parents of children with ASD, thus expanding the insights into parental experiences beyond that of a deficit-based understanding to a multi-faceted perspective. The findings suggest a multi-dimensional perspective on resilience in these parents may be beneficial in order to fully understand their experiences and in turn support them appropriately.

ASD research remains limited in South Africa despite growing interest in expanding the research base within this context. This research study provided the opportunity for in-depth exploration of parental experiences and challenges relating to raising a child with ASD in a South African setting. The findings highlight the value further research in this area could hold and therefore emphasises the need for further exploration.

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DECLARATION

This dissertation is submitted in partial fulfilment of the requirements of the degree of Masters of Social Science (Clinical Psychology), University of KwaZulu-Natal, Durban, South Africa.

I declare that this dissertation is my own work. All citations, references and borrowed texts have been duly acknowledged. This work has not been submitted before for any other degree or examination at any other university.

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ACKNOWLEDGEMENTS

To my research supervisor, Sachet Valjee, thank you for the support, patience and encouragement that you have provided through this process. Thank you for believing in me.

To my wonderful Mom, Thank you. Thank you for all the love and encouragement you have provided, especially in the final weeks. I could not have done this without you.

To my never-failing cheerleader, Dad, thank you. I am so grateful for the words of encouragement, your unrelenting support and love. Thank you for your invaluable guidance.

To my partner, words do not adequately capture my appreciation and gratitude for you. I whole-heartedly appreciate your support, your words of wisdom in the longest hours, your kindness and understanding.

I would like to thank the research participants for your honesty and willingness to participate, without you this dissertation would never have taken place.

DEFINITION OF TERMS

TERM	DEFINITION	ABBREVIATION
Autism Spectrum Disorder	Autism Spectrum Disorder (ASD) consists of a continuum of multifaceted neurological and developmental disorders presenting with deficits in reciprocal social interaction and communication, alongside repetitive and stereotyped interests and behaviours (Alli, Abdoola, & Mupawose, 2015; Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016; Karst & Van Hecke, 2012)	**ASD**
	The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published in 2013 includes Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorders not otherwise specified (PDD-NOS) as part of ASD, rather than as separate disorders.	

CHAPTER 1

INTRODUCTION AND BACKGROUND

1.1 INTRODUCTION & BACKGROUND

1.1.1 Study aims and objectives

This study aimed to qualitatively investigate the psycho-social challenges and experiences of parents of children with Autism Spectrum Disorder in the Western Cape.

The objectives of this study were as follows:

1. To compare intrinsic and extrinsic challenges for parents of children diagnosed with ASD
2. To understand the impact this diagnosis had on family coping
3. To determine 'meaning' ascribed to coping in the context of burden of care
4. To understand common and dissimilar experiences of participants caring for their ASD child

1.1.2 Chapter structure

The chapters are set out in the following manner. Chapter One includes an introduction and background on ASD while Chapter Two presents a review of current research on relevant topics relating to this research study and highlights important gaps in research. Chapter Three describes the methodology used in this study and the theoretical components of analysis. In Chapter Four, the resulting themes are presented and later analysed in Chapter Five. Chapter Six includes a discussion and conclusion as well as limitations of the study and future recommendations.

1.1.3 Background

Autism Spectrum Disorder (ASD) consists of a continuum of multifaceted neurological and developmental disorders presenting with deficits in reciprocal social interaction and communication, alongside repetitive and stereotyped interests and behaviours (Alli, Abdoola, & Mupawose, 2015; Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016; Karst & Van Hecke, 2012). Children with ASD present with a number of deficits in these areas which are often disruptive and impair daily functioning (American Psychiatric Association, 2013). The deficits and impairments present in ASD greatly impact the child diagnosed, however also impact the functioning and well-being of parents and the entire family unit (Alli et al., 2015; Karst & Van Hecke, 2012; Meadan, Halle, & Ebata, 2010).

The impact of ASD on parents appears to have been reported as early as 1975 by Holroyd, Brown, Winkler and Simmons. Research studies in the period between 1975 and 2018 have shown that an ASD diagnosis is intrinsically linked with a number of changes and challenges in family life, expectations for the future and parental well-being. Parents of children with ASD face a number of challenges within their daily life, social life, and occupational areas as well as within the community and health system (Estes et al., 2013; Huang, Yen, Tseng, Tung, Chen, & Chen, 2013).

Literature suggests that amongst childhood developmental disorders, ASD may be one of the most stressful for parents to manage, as parents of children with ASD consistently report greater levels of parenting stress than parents of both neuro-typical children and those with other developmental disorders, as ASD can be considered to bring with it a unique set of deficits and symptoms (e.g. Estes et al., 2013; Hastings & Johnson, 2001; Hayes & Watson, 2013; Huang et al., 2013; Meadan et al., 2010; Stewart, Knight, Mcgillivray, Forbes, & Austin, 2017). The daily challenges and stressors faced when parenting a child with ASD can be considered unique as the plethora of deficits and challenges are often significant and far reaching.

This study investigated the experiences and challenges of parents who have a child with ASD within a South African context and included their attempts to access health care and support, the impact on resources and more specifically, challenges in relation to familial dynamics. This study also explored the psychosocial effects on the parents themselves. This included their perception of themselves and their parenting ability, the parent-child bond and their relationships with others.

1.2 INCIDENCE AND PREVALENCE RATES
1.2.1 Global: Incidences/ prevalence rates

ASD prevalence rates have become a global concern as they have reportedly increased considerably over the last decade (Altiere & Von Kluge, 2009; Bakare & Munir, 2011; Fewster & Gurayah, 2015; Karst & Van Hecke, 2012; Malcom-Smith, Hoogenhout, Ing, Thomas, & De Vries, 2013; Meadan et al., 2010; Mitchell & Holdt, 2014). The current global prevalence rate of ASD is reportedly estimated to be 1- 2 % (Centers for Disease Control and Prevention, 2014; Franz et al., 2017).

With the growing prevalence rates, there has been an increase in awareness of the burden of care associated with this developmental disorder and the need for further research (World Health Organization, 2013).

1.2.2 Africa: Incidences/prevalence rates (estimates)

"Over the last decade, knowledge about ASD and its prevalence has been documented as being on the rise in different regions of the world, with most literature coming from the western world – the situation in Africa on aspects of ASD remain unclear" (Bakare & Munir, 2011, p. 208). According to Franz et al. (2017), "no population-based prevalence studies of ASD have been performed in Africa to date" (p. 2), however it is assumed that prevalence trends in Africa and other developing countries may mirror those in the USA (Fewster & Gurayah, 2015; Franz et al., 2017; Holdt, 2008; Springer, Van Toorn, Laughton, & Kidd, 2013).

1.2.3 South Africa: Incidences/prevalence rates (estimates)

Official statistics on ASD in South Africa are almost non-existent despite an increase in ASD research in recent years. One study that explored the prevalence of ASD between 1996 and 2005 in South Africa found a rise of 8.2% in the number of children with features of ASD at a clinic in the Western Cape during this time (Springer et al., 2013). As mentioned above, it is proposed that statistics in South Africa will most likely parallel those reported in developing countries (Fewster & Gurayah, 2015; Franz et al., 2017; Holdt, 2008; Springer et al., 2013). In their study, Franz et al., (2017) found "no epidemiological, early intervention, school-based or adult studies" that met requirements in Sub-Saharan Africa since 1970 (p.1).

Research findings globally suggesting that ASD is under-identified, underdiagnosed and left untreated for long periods of time in low-socioeconomic communities is particularly concerning for South Africa (Grinker et al., 2012; Kim et al., 2011; Mitchell & Holdt, 2014).

In recent years South Africa has seen an increase in ASD research within a South African context alongside a growing awareness surrounding the need for this with initiatives such as Centre for Autism Research in Africa (CARA) in the Western Cape. There remains however a dearth of ASD knowledge in South Africa. Most children with ASD in South Africa are not appropriately diagnosed due to a lack of services and resources such as appropriate and accessible primary, secondary and tertiary assessment and intervention facilitates in South Africa (Bakare & Munir, 2011; Franz et al., 2017; Mubaiwa, 2008).

This is significantly more prominent in communities where socio-economic inequalities result in discrepancies in access to services (Leonard et al., 2010). This is supported by Mitchell and Holdt (2014) who report that "diagnostic and intervention services, particularly at state level, are scarce. Hence, those that are in place are heavily overburdened. Standardised assessment tools, available in multiple languages, are not available" (p. 50).

1.3 ASD: RESEARCH AREAS

1.3.1 ASD: global research areas

A comprehensive meta analytic review by Franz and colleagues (2017) identified a total of 24, 467 publications about ASD between 1970 and 2015 (see Figure 1). Of this, the majority were from North America (11,569) and Europe (7,577) with fewer publications emerging from Asia (3,540) and Australia (1,192). A substantial difference in ASD research output was seen between the aforementioned continents and those from South America (348), North Africa (121) and Sub-Saharan Africa (120) (p. 5).
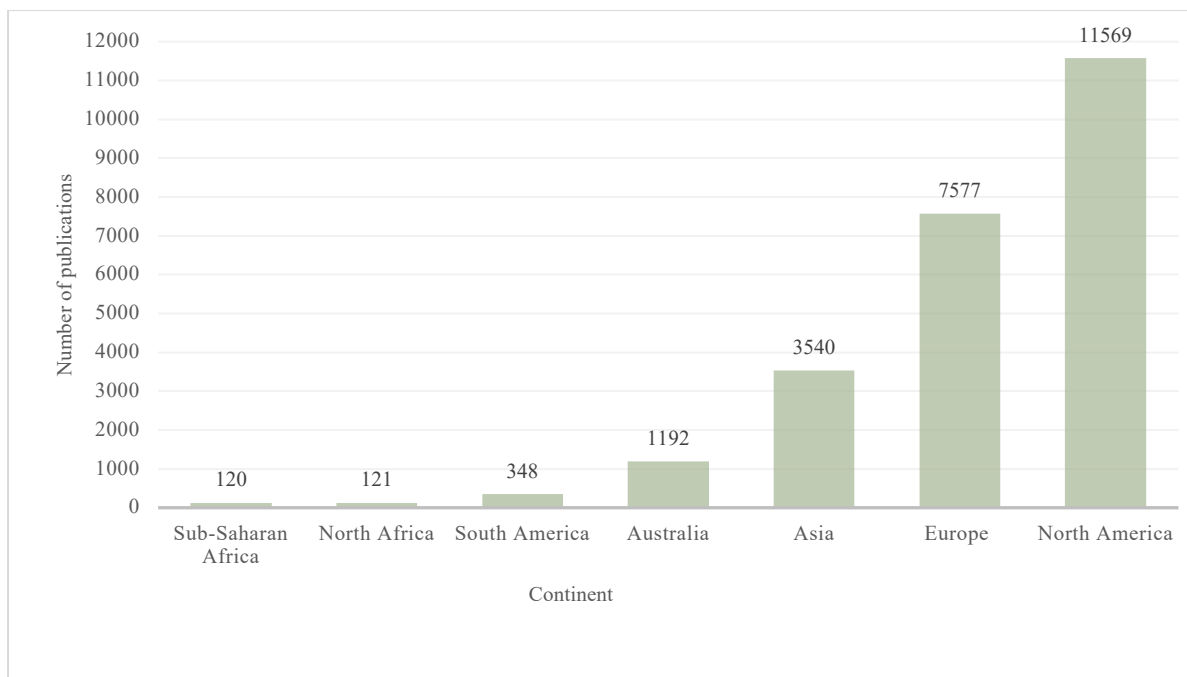
Figure 1.1 Number of publications about ASD by continent (1970-2015). Adapted from Franz et al. (2017)

The main research domains emerging globally include:
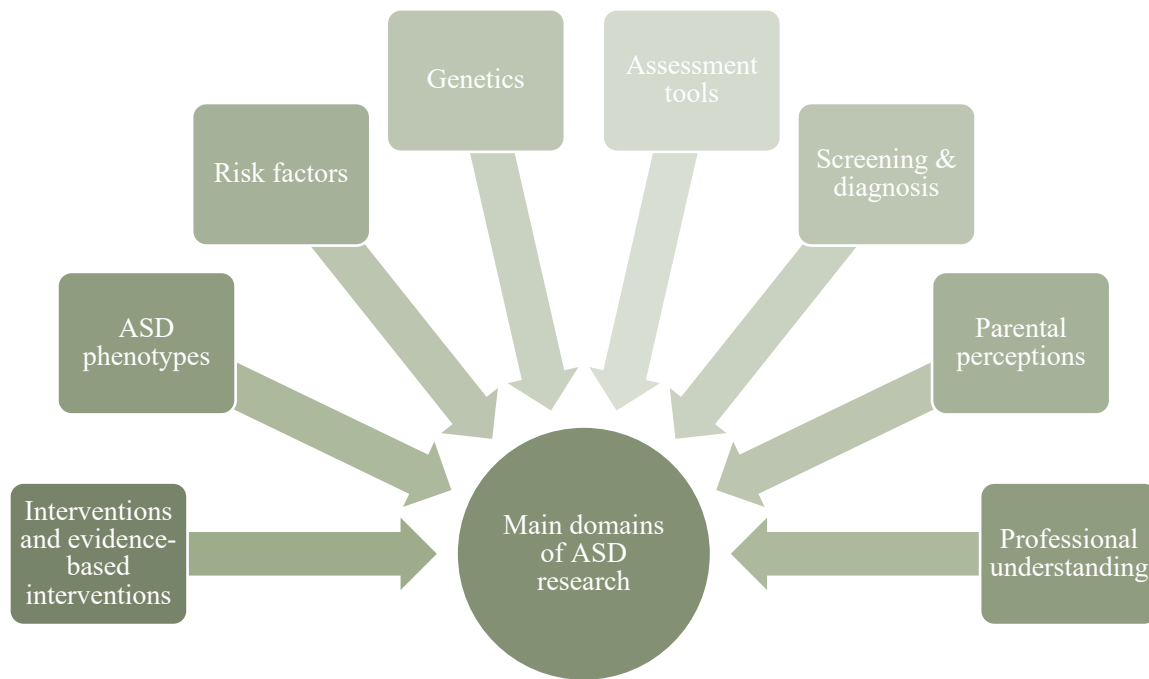
Figure 1.2 Main domains of ASD research emerging globally

According to Pellicano and colleagues (2018) current trends in ASD research have had a strong focus on "underlying biology and causes of autism" (Pellicano et al., 2013, 2014). Notwithstanding the benefit of this, there has been a call for a shift towards research agendas "that will have more immediate and direct impact on the daily lives of autistic people and their families, especially related to services and supports, and with underserved populations" (p. 82). This shift has been supported by the Interagency Autism Coordinating Committee (IACC) and emerges from greater interaction and engagement with those allied with the ASD community but more importantly autistic individuals themselves (Pellicano et al., 2013, 2014, 2018).

This new phase of recognising the importance of studying the "daily realities" of autistic individuals and their families, also highlights how critical it is that the voices of autistic children, young people, adults and their families are included in research findings (Pellicano et al., 2014, 2018).

1.3.2 ASD: Africa research areas

According to current literature there is a lack of research on ASD within an African context (Franz et al., 2017). The methodological approaches of those that have been published remain concerning as many were often below the standards required for generalisable and valid

findings (Abubakar, Ssewanyana & Newton, 2016; Franz et al., 2017). The majority of the studies emerging from Africa (North Africa and Sub-Saharan Africa) involved small samples that may not be representative of the greater population (demographically or otherwise) (Abubakar et al., 2016; Bakare & Munir, 2011; Franz et al., 2017; Malcom-Smith et al., 2013).

A review by Bakare and Munir (2011) aimed to explore ASD research in Africa during the period from 2000- 2009, while two other studies focused on reviewing ASD research in Sub-Saharan Africa (Abubakar et al., 2016; Franz et al., 2017).

According to Franz and colleagues (2017), findings from their comprehensive scoping review indicated that between North Africa (121) and Sub-Saharan Africa (120) there have been a total of 241 published articles that are peer-reviewed, and data driven since the 1970's in Africa. Abubakar and colleagues suggest that the majority of the articles published have been in the last decade or so. Findings from Bakare and Munir (2011) support this as they indicate that only 12 articles were published in a nine-year period (2000-2009), with the majority of published articles emerging after this (Abubakar et al., 2016; Franz et al., 2017).

Bakare and Munir (2011) reviewed literature from Pubmed and reported findings related to ASD and Africa, and found articles relating to aspects of epidemiology, diagnosis, aetiology and knowledge about ASD. In total their study highlighted 12 published articles on ASD and Africa, emerging from Nigeria (4), Egypt (3), Tunisia (1) and Tanzania (1). Two articles were based in Sweden and covered ASD prevalence in African children in Sweden.

Franz et al. (2017) found a total of 53 peer-reviewed, data-driven publications about ASD in Sub-Saharan Africa ever published. The majority of the studies emerged from South Africa (28) and Nigeria (15) while the remainder was made up of publications from Kenya (3), Tanzania (2), Zimbabwe (1), Uganda (1), Seychelles (1) and Ghana (1).

Table 1.1 Showing the number of "peer-reviewed, data-containing publications ever published by country" (Adapted from Franz et al., 2017)

Sub-Saharan Country	Number of publications
Multiple countries	1
Ghana	1
Seychelles	1
Uganda	1
Zimbabwe	1

Tanzania	2
Kenya	3
Nigeria	15
South Africa	28
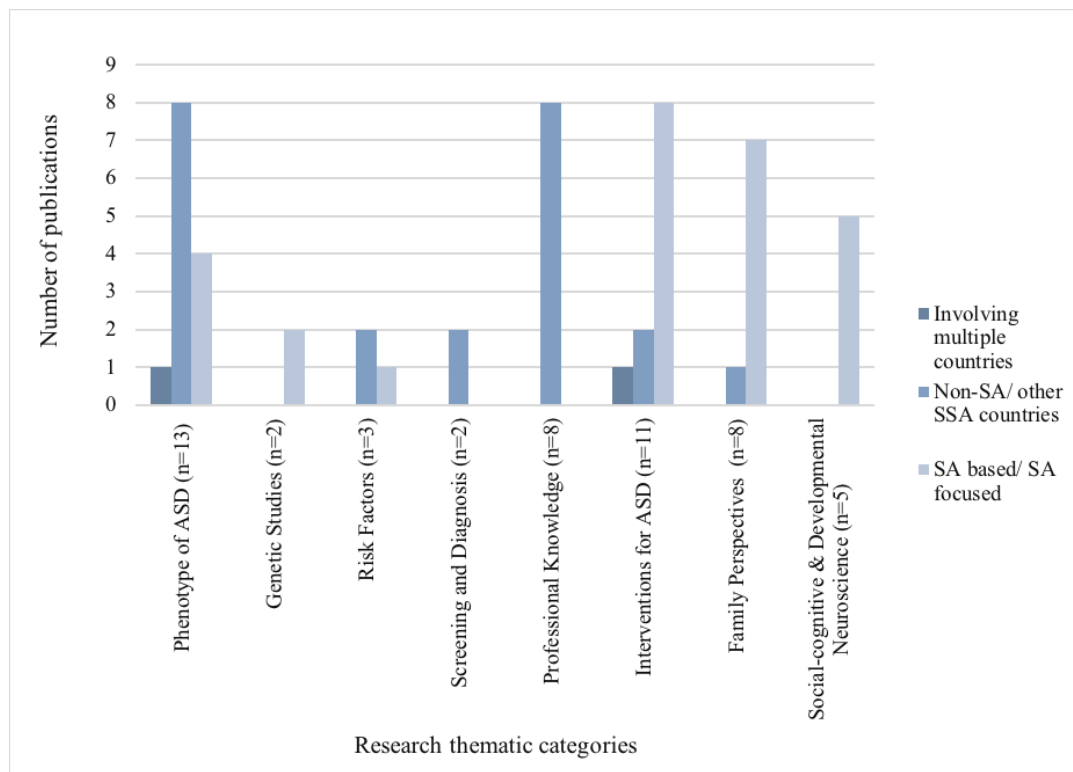
Figure 1.3 Number of publications per research theme category per African country

Thematic categories covered in the above-mentioned studies included phenotype of ASD (13), genetic studies (2), studies of risk factors (3), screening and diagnosis (2), professional knowledge (8), interventions for ASD (11), family perspectives (8) and social-cognitive and developmental neuroscience (5) (figure 1.3).

1.3.3 ASD: South Africa research areas

Limited research and understanding of ASD in a South African context may have various consequences including delays in diagnosis and in turn the loss of the benefits that early intervention may have for a child with ASD (Grinker et al., 2012; Kim et al., 2011; Malcom-Smith et al., 2013; Mitchell & Holdt, 2014).

An Ebscohost search resulted in a total of 33 articles related to ASD and South Africa. In their review Franz et al. (2017) found 28 articles that met their inclusion criteria, suggesting only 28 articles on ASD in the period from 1970 to 2015 were peer-reviewed and data- based.

This search yielded 12 studies relating to psychosocial experiences of parents and 21 articles that involved ASD research in South Africa that were not focused directly on the topic of parental experiences.

Franz et al. (2017) reported only eight publications relating to family perspectives that were peer-reviewed and data based (e.g. Alli et al., 2015; Du Toit & Kok, 1999; Fewster & Gurayah, 2015; Greeff & Van der Walt, 2010; Kapp & Brown, 2011; Mitchell & Holdt, 2014; Olivier & Ah Hing, 2009).

Three studies were aimed at exploring challenges and strategies of parents of a child with ASD in South Africa (Alli et al., 2015; Fewster & Gurayah, 2015; Oliver & Ah Hing, 2009); Mitchell and Holdt (2014) examined parent experience of the diagnosis process while Greeff and Van der Walt (2010) explored family resilience. Another study examined family routines and quality of life (Schlebusch, Samuels, & Dada, 2016). Two studies explored informal support sources, specifically social media (Cole, 2017; Gerber, 2014). One study explored the adolescent transition through the perspectives of parents and professionals (Meiring, Seabi, Amod, Vorster, & Kern, 2016). A study by Pottas and Pedro (2016) explored the experiences of father carers and finally two studies involved parent perceptions of different aspects of treatment (Louw, Bentley, Sorsdahl, & Adnams, 2013; Wetherston et al., 2017).

1. 4 ASD RESEARCH IN SOUTH AFRICA
1.4.1 Research on family experiences and ASD in South Africa
1.4.1.1 Challenges and strategies of parents of a child with ASD in South Africa

Alli et al. (2015) found that parents experience challenges in both communication and interaction, supporting previous research findings indicating that ASD impacts daily family functioning. This study highlighted challenges in communication and interaction as key factors that parents find most difficult however of importance to note is that the studies originates within a speech and therapy degree context thus this may result in some bias when exploring difficulties.

Olivier and Ah Hing (2009), aimed to study challenges facing parents and found that many parents reported difficult diagnostic processes and their difficulty accepting their child's ASD diagnosis. The study also highlighted the important role of the practitioner as parents reported a lack of guidance from health care practitioners on the specific needs of their child and a need for professional and social support and the personal challenges and changes parents face (Olivier & Ah Hing, 2009). This study aimed to provide insight into the experiences of parents in order to make recommendations for health care professionals.

Table 1.2: Research on ASD in South Africa, directly related to family experiences.

	Total	Label	No. per topic	Topic	Authors (date)	Sample size	Method
Psychosocial experiences (focused on parent experiences)	12	A	2	Parent challenges and strategies	Alli et al., 2015	10	Semi-structured interviews
					Oliver & Ah Hing, 2009	8	Semi-structured interviews
		B	2	Parent experience of diagnosis process	Fewster & Gurayah, 2015	11	Semi-structured interviews
					Mitchell & Holdt, 2014	7	Semi-structured interviews
		C	1	Family resilience	Greeff, 2010	34	Self-report questionnaires and an open-ended question
		D	1	Family routines and quality of life	Schlebusch et al., 2016	180	self-administered survey
		E	2	Support sources (informal): social media	Cole et al., 2017	6	Qualitative, phenomenological design
					Gerber, 2014	10	Open ended questionnaire (electronic)
		F	1	Transition to adolescent-parent perspective of child	Meiring et al., 2016	14	Semi-structured interviews
		G	1	Regarding father carers	Pottas & Pedro, 2016	8	Semi-structured interviews
		H	1	Regarding treatment knowledge	Wetherston et al., 2017	46	Quantitative, Electronic questionnaire survey
		I	1	Use of medication for their child	Louw et al., 2013	65	Descriptive, quantitative, analytic study using survey questionnaire and the Nisonger Child Behaviour Rating Form (NCBRF).

1.4.1.2 Parent experience of diagnosis process

In their study, Fewster and Gurayah (2015) highlighted the difficulties parents face on the journey to a diagnosis with a notable feature emerging regarding the role of the practitioner. This study emphasised the need for parents to feel heard and acknowledged during this stressful and vulnerable period (Fewster & Gurayah, 2015). Another study focused on describing the experiences of a sample of South African parents who had a child that had received a diagnosis of ASD also found that parents encountered significant challenges in obtaining a diagnosis and often perceived practitioners as lacking ASD knowledge and as reluctant to provide a diagnosis (Mitchell & Holdt, 2014).

The importance of the role of practitioners in the diagnosis process was emphasised in both of these studies, echoing insights from research conducted in other South African studies (e.g. Olivier & Ah Hing, 2009) as well as global findings.

Findings also emphasised the lack of formal and informal support, limited access to suitable facilities and notable delays in diagnosis (Fewster & Gurayah, 2015; Mitchell & Holdt, 2014). These findings also mirror those mentioned above as well as globally and appear to concur with the argument that these factors are accentuated in lower socioeconomic settings.

These studies highlight the common challenges parents of children with ASD may face including:
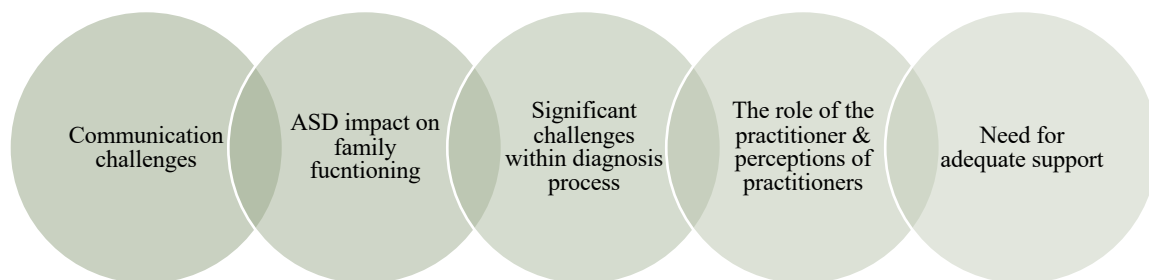
Figure 1.4 Common findings amongst 4 articles on parental experiences in South Africa

1.4.1.3 Family resilience

One study was particularly relevant to the current research. Greeff and Van der Walt (2010) used self-report questionnaires and an open-ended question to explore the characteristics and resources families employ in order to assist them in adapting successfully to having a child with ASD. Results suggest that resilience factors included social support, family socio-economic status, family patterns of behaviour including communication level of support and

hardiness. Internal and external coping strategies, positive outlook and family belief systems were also found to be significant (Greeff & Van der Walt, 2010).

1.4.1.4 Family routines and quality of life

A study by Schlebusch et al. (2016) aimed to explore the relationship between "family routines, cognitive appraisal of ASD impact and family quality of life" in families raising a child with ASD in South Africa. Findings suggest that a greater amount of regularity of family routines was significantly associated with greater satisfaction in relation to family quality of life. It was also found that cognitive appraisal of the impact of ASD emerged as a mediator between the two.

1.4.1.5 Support sources (informal): social media

Two studies investigated the relationship between social media and support for parents of children with ASD (Cole, 2017; Gerber, 2014). Findings were mixed as they suggested a possible source of support however the ability to derive benefit from this depended on unique parent characteristics such as needs and experiences, and their individual perceptions of the interactions within the group. The studies suggest that social media groups may provide a platform for discussing management of behavioural difficulties and providing emotional support for caregivers. This may be relevant as an avenue for providing parental support in low resource contexts where support group attendance and availability may be limited.

1.4.1.6 Transition to adolescence- parent perspective of child

The study by Meiring and colleagues (2016) examined the challenges experienced by adolescents with ASD transitioning into adulthood. Findings highlighted several challenges including inadequate planning and a lack of service facilities for adolescents with ASD after school. Interpersonal challenges participants faced involved feelings of fear and uncertainty. Parents and professionals alike reported that this period was distressing for all.

1.4.1.7 Regarding father carers

In a study of father carers of children with ASD, Pottas and Pedro (2016) found that fathers reported less optimism regarding the future of their child, however, this seemed to be associated with their child's level of functioning. Significant time demands, and a lack of support were reported however positive benefits to caring for a child with ASD were also reported. It was also found that participants felt they were able to adapt to their child's needs.

1.4.1.8 Regarding treatment knowledge

Wetherston et al. (2017) was one of the newest studies published and aimed to explore parental knowledge of treatments available. The results suggest that the majority of the parents were unfamiliar with treatment options and, those that were, had limited understanding of them. Other findings also included parent perception of treatments as expensive and not easily accessible as well a lack of guidance from health care professionals regarding their child. In contrast to previous research, this study found that participants had good relationship with health professionals (Wetherston et al., 2017).

1.4.1.9 Use of medication for their child

Louw et al. (2013) investigated the "prevalence and patterns of medication use amongst a sample of school going children and adolescents with autism spectrum disorders (ASD) in the Western Cape, South Africa" (p. 69). The study found that children with ASD are a highly medicated group, which is supported by international studies of the same sample (Louw et al., 2013). Medications utilized were mostly psychotropics, with antipsychotics being the most common, followed by stimulants, antidepressants and mood stabilisers. Alternative complementary medications such as over the counter medicines and special diets were also used. According to the study, children of white or Asian ethnicity were more likely to use over the counter medications than those of black African or coloured ethnicity.

In summary, the figure below summarises the main findings from the articles discussed above as they relate to familial experiences in SA.
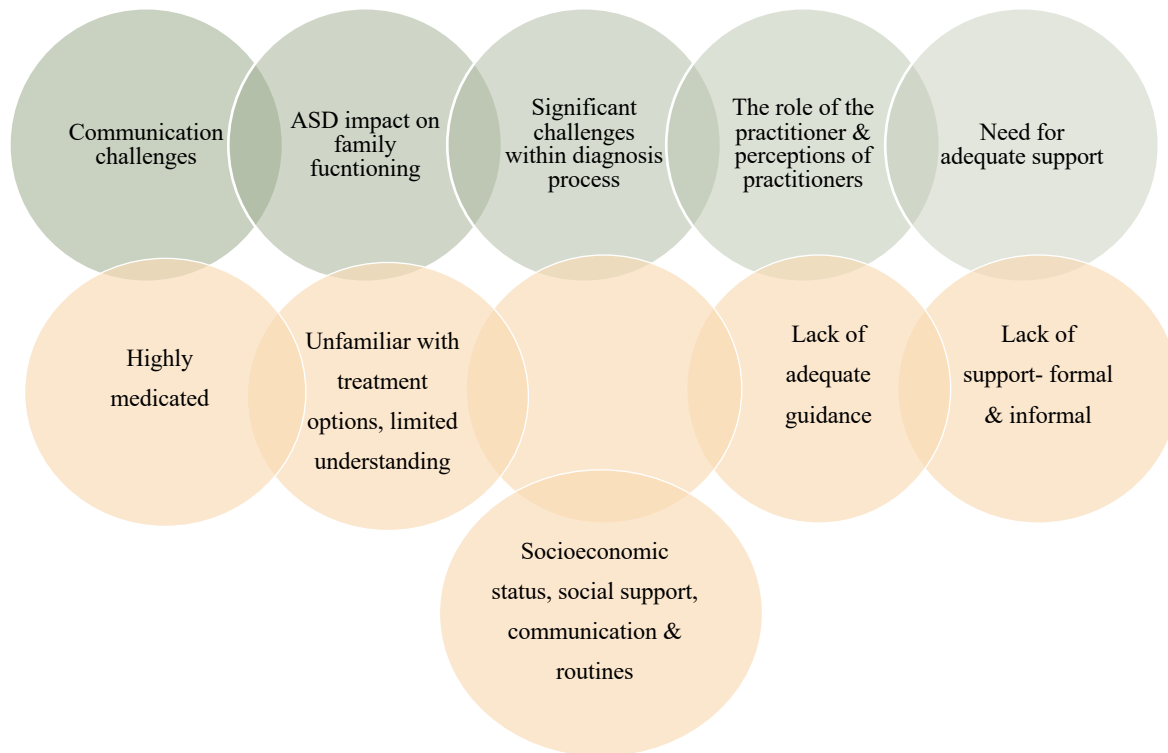
Figure 1.5 Main findings amongst articles on familial experiences in South Africa

1.4.2 Research related to ASD research in Africa and South Africa

Malcom-Smith et al. (2013), presented an article on the challenges being faced globally and within a South African context in relation to ASD. The authors discuss the lack of epidemiological research on ASD in South Africa and the scarcity of resources available. The authors also report that available resources are overburdened and lacking the necessary means to cope with the workload. The study describes the development of the new Centre for Autism Research in Africa and its aim to fully participate in developing the research on ASD within South Africa.

Springer et al. 2013, presented a study done in the Western Cape, South Africa which described the demographics, history, clinical features, co-morbidity and diagnostic yield of investigations in a group of children diagnosed with a Pervasive Developmental Disorder (know referred to as under the umbrella term ASD) at a tertiary developmental paediatric clinic. The study findings indicated that a high percentage of children with PDD attending this clinic had severe language impairment, behavioural problems and complex autism (Springer et al., 2013). The black African ethnic group presented with the highest number of non-verbal children. The

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majority of the children had difficulties requiring ongoing medical, social and educational support services (Springer et al., 2013).

Table 1.3 Research on ASD in South Africa, not directly related to parental experiences

	Total	Topic	Authors (date)
Psychosocial experiences (<u>not</u> focused on parent experiences)	3	Teachers attitudes on inclusion	Donohue, D., & Bornman, J. (2015)
		Assessing baseline knowledge of ASD in teachers	Hutton, N. K., Mitchell, C., & van der Riet M (2016).
		Sibling attitude	van der Merwe, C., Bornman, J., Donohue, D., & Harty, M. (2017)
Medical	3	Genetic studies	Sharma, J. R., Gameeldien, H., Davids, M., Kaur, M., & van Der Merwe, L. (2013); Arieff, Z., Kaur, M., Gameeldien, H., Van Der Merwe, L., & Bajic, V. B. (2010).
		Maternal stress as a risk factor for ASD	M. Claassen, H. Naudé, E. Pretorius, and M. C. Bosman
ASD research in South Africa/ Africa	4	Regarding current research available/ future goals.	Abubakar, A., Ssewanyana, D., & Newton, C. R. (2016); Franz et al., (2017); Catherine, E. R., & Li-Ching, L. (2017); Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G. F., & de Vries, P. (2013).
ASD in South Africa	3	Characteristics and demographics	de Vries, P. J., Venter, A., Jacklin, L., & Oliver, C. (2013); Springer, P. E., van Toorn, R., Laughton, B., & Kidd, M. (2013); Van Biljon, S., Kritzinger, A., & Geertsema, S. (2015).
ASD in Africa	1	Commentary	Newton, C. R. (2013).
Multi-country outside Africa	1	SA and South Korea	Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., Wetherby, A. M. (2012).
ASD & other Developmental disabilities	3	Stigma, resilience	Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015); Greeff, A. P., & Nolting, C. (2013)
Focus on other conditions	1	Screening for trauma	Collings, S. J., Valjee, S. R., & Penning, S. L. (2013)
Adaptation and validation of screening and diagnostic tools (SA)	3	2 translating scales; 1 assessing effectiveness	Chambers, N. J., Wetherby, A. M.; Stronach, S. T., Njongwe, N., Kauchali, S., Grinker, R. R. (2017); Smith, L. (2017); Travis, J., & Geiger, M. (2010).

1.5 SUMMARY

ASD is a neuro-developmental disorder that is associated with lifelong deficits in social and communicative abilities as well as ability to function independently. A diagnosis of ASD has

major consequences for the parents, with the potential to radically change and affect the entire family.

The burden of care associated with ASD and the evidence of increasing prevalence emphasises the need for further exploration of parental experiences. The literature providing insights into the contextual factors in South Africa that further complicate caregiver experiences support the importance of understanding ASD within this context.

1.6 RATIONALE

This study investigated the psychosocial experiences and challenges that impact parental functioning with the aim of highlighting these challenges so as to inform future intervention in the area of psychosocial adjustment for parents of children with ASD.

It is essential that factors be identified that can provide insights and understanding of parents' experiences with ASD and in turn provide plausible targets for intervention and efforts to support parents (Davis & Carter, 2008). Children do not exist in isolation and parents play a key role in facilitating a child's interaction with and optimal functioning within their environment.

By gaining knowledge around their experiences, specifically in a South African context, clinicians can begin to incorporate psychosocial interventions as a protective mechanism to prevent the onset of mental health issues that could compromise parent's abilities to manage their autistic children and cope with the multitude of obstacles they face.

Keen et al. (2010) states that it is a requirement to maintain and care for a parent's health and well-being in order to provide the optimal care for the child. However, it is vital that parental experiences are heard and understood in order to create interventions that are effective and supportive (Cited in Falk, 2014). This study aimed to generate an understanding of contextually relevant circumstances that contribute towards parents' experiences and difficulties in relation to managing a child with ASD within a South African context.

CHAPTER 2

LITERATURE REVIEW

2.1 ASD: SYMPTOMOLOGY

The term "spectrum" refers to the wide variance in symptomology, skill, and levels of impairment in functioning that can occur in people with ASD. This variation can be seen in the amount of independent functioning, as some individuals with ASD manage daily living requirements independently while others require significant amounts of support in basic daily living. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published in 2013 includes Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorders not otherwise specified (PDD-NOS) as part of ASD, rather than as separate disorders (American Psychological Association, 2013).

As mentioned above, core ASD criteria can be said to fall into two categories: a) Social impairment and communication difficulties and b) Repetitive and characteristic behaviours, see table 2.1.

2.1.1 Social impairment and communication difficulties

Social deficits and communication difficulties were previously presented as separate categories in the DSM-V however have been combined as they are inherently inter-related (DSM-5, American Psychological Association, 2013).

Commonly discussed deficits of ASD are those in the domain of social interaction and understanding. Deficits present in ASD impact the individual's manner of developing, understanding and maintaining social relationships with others (Van der Merwe, Bornman, Donohue, & Harty, 2017), often impeding appropriate social interaction (Van der Merwe et al., 2017). Social interactions can be considered very difficult for individuals with ASD due to deficits in social comprehension <u>and</u> communicative ability.

Communication abilities vary greatly amongst individuals with ASD, ranging from complete lack of expressive language ability to fluent but possibly inappropriate speech.

Impairments in theory of mind and hypothetical thinking present in children with ASD may impair the individuals' ability to understand and in turn use, non-verbal language cues and gestures, as well as in their ability to conceptualise the other individuals internal experiences.

Table 2.1 Showing criteria of Autism Spectrum Disorder and examples (adapted from DSM-5, APA, 2013)

Main category	Sub-category	Aspects within this	Examples
Social communication & social interaction deficits	Social-emotional reciprocity	Abnormal social approach	Language often one-sided, lacks reciprocity, used to label or request instead of commenting sharing feeling or converse.
		Failure of normal back-and-forth conversation	
		Reduced sharing of interests, emotions or affect	
		Failure to initiate or respond to social interactions	Difficulty processing and responding to social cues: when and how to join a conversation, appropriate things to say
	Non-verbal communication behaviours	Poorly integrated verbal & nonverbal communication	Difficulty co-ordinating non-verbal with speech: present as odd, wooden or exaggerated.
		Abnormalities in eye contact & body language	Absent, reduced, or atypical
		Deficits in understanding/ using gestures	Impaired joint-attention: a lack of pointing/showing/ bringing objects to share with others, failure to follow others pointing/ eye gaze.
		Total lack of facial expressions & nonverbal communication	May learn a few functional gestures, lack of spontaneous use of gestures.
	Developing, maintaining & understanding relationships	Difficulties adjusting behaviour to suit social contexts	Difficulties understanding deeper complexities of social behaviour (and language)
		Difficulties in sharing imaginative play or in making friends	Preference for solitary play, desire for friendships but a lack of realistic understanding of what friendship entails.
		Absent/reduced/ atypical interest in peers	Rejection of others, passivity or inappropriate approaches- seeming aggressive or disruptive.

Main category	Sub-category	Aspects within this	Examples
Restricted, repetitive patterns of behaviour, interests or activities	Stereotyped or repetitive motor movements, use of objects or speech	Simple motor stereotypies	Hand flapping, finger licking
		Lining up toys or flipping objects	Spinning items, lining up toys
		Echolalia or repetitive speech	Echolalia: delayed or immediate parroting of heard words, use of "you" when referring to self.
		Idiosyncratic phrases	Stereotyped use of words, phrases or prosodic patterns.
	Insistence on sameness, inflexible adherence to routines or ritualised patterns of verbal/ non-verbal behaviour	Resistance to change	Extreme distress at small changes: changes in packaging of a favourite food, insistence on adherence to rules, rigid thinking patterns; Need to take same route or eat same food every day, greeting rituals
		Difficulties with transitions	
		Ritualised patterns of verbal/ non-verbal behaviour	Repetitive questioning, pacing a perimeter
Restricted, repetitive patterns of behaviour, interests or activities	Highly restricted, fixated interests that are abnormal in intensity or focus	Strong attachment to or preoccupation with unusual objects	Attachment to a pan, or preoccupation with vacuum cleaners, spending hours writing out timetables.
		Excessively circumscribed or perseverative interests	
	Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment	Apparent indifference to pain/ temperature	
		Adverse response to specific sounds or textures	Extreme responses to specifics; extreme reaction to or rituals involving taste, smell, texture or appearance of food or excessive food reactions.
		Excessive smelling or touching of objects	
		Visual fascination with lights or movement	

The concept of ASD occurring on a spectrum is highly evident in these variances of communicative abilities as well as variations in social understanding and functioning, as a child with ASD may have any number of combinations of the above-mentioned deficits.

2.1.2 Repetitive and characteristic behaviours

Children with ASD may present with repetitive movements and unusual behaviour that can be disruptive. These include "flapping" (flapping their arms), rocking from side to side, or spinning. Some children engage in behaviours that may be self-injurious or difficult to stop. They may become preoccupied with parts of objects like the wheels on a toy truck. Individuals with ASD may become preoccupied or obsessed with unusual topics or parts of objects.

This rigidity of thought or 'repetitiveness' is also seen in the ASD individuals need for routine and familiarity. Many individuals with ASD have great difficulty coping with change or spontaneous activities as they tend to thrive with clear, set routines and daily patterns. Changes to this daily pattern or unexpected deviations can be extremely challenging and may result in emotional outbursts in response.

These are considered the "core" characteristics of ASD however there are a number of other behavioural and emotional difficulties that may present themselves as well as deficits in cognitive ability.

2.2 ASD: A UNIQUE DISORDER

The "unusual behaviours" discussed above (see Table 2.1) which manifest in ASD, result in children with ASD appearing to be very different from other children and often present alongside difficulties in child development and learning ability (Lecavalier et al., 2006; Windle & Windle 1996, cited in Huang et al., 2014; Van der Merwe et al., 2017). Alongside ASD behaviours, children with ASD may present with emotional and behavioural challenges such as difficulty with emotional regulation, hyperactivity, and impaired peer relations (Dumas et al., 1991; Hastings & Brown, 2002; Huang et al., 2014). Deficits in sensory processing and theory of mind are also common (Alli, Abdoola, & Mupawose, 2015; Van der Merwe et al., 2017).

ASD has been described as a 'unique' disorder for a number of reasons:

ASD occurs on a spectrum

ASD is considered to be highly heterogeneous (Hayes & Watson, 2013; Lenroot & Yeung, 2013).

ASD characteristics conceptualised as significant deviations from typical development (Beauchesne & Kelley, 2004).

Co-morbidities and secondary diagnoses are often present.

Medical complications/ physical or health issues are common.

ASD is associated with pervasive and lifelong impairments with no cure.

Treatments and interventions aim to improve rather than 'cure'.

Figure 2.1 Showing factors making ASD a unique disorder

2.2.1 ASD: Spectrum heterogeneity

ASD presents on a spectrum with variations in behavioural phenotypes within each domain and the type and severity of the deviations that manifest. Clinically, ASD is considered to be highly heterogeneous (Hayes & Watson, 2013; Lenroot & Yeung, 2013). This means that each individual case presents with different characteristics and clinically varied presentations. Therefore, one individual may not necessarily meet the diagnostic criteria or be impaired in the exact same way as another individual with ASD.

2.2.2 ASD: Deviation from typical development

In comparison to other developmental disorders such as developmental intellectual impairment, ASD manifests itself in prominent divergences in development rather than developmental delays alone (Beauchesne & Kelley, 2004). Therefore, the understandings gained from the study of non-ASD developmental disorders may have limited generalisability to ASD. In turn, presenting a unique plethora of deficits and characteristics for clinicians and families to navigate. In comparison, children with ASD tend to on average, present with greater levels of behavioural problems than those with other developmental delays (Estes et al., 2009; Xu, Neece, & Parker, 2014).

2.2.3 ASD: Common co-morbidities and secondary diagnoses

The combination of various co-morbidities commonly present in individuals with ASD further expands this variability, making providing care challenging and rendering experiences across families highly variable (DePape & Lindsay, 2015). As discussed above, ASD often presents

with co-morbid diagnoses which impact presentation. According to Simonoff et al. (2008), a population-based study found that seventy percent of participants diagnosed with ASD also met the criteria for at least one other co-morbid disorder.

Many children with ASD also present with co-morbid intellectual disabilities (Baker, Neece, Fenning, Crnic, & Blacher, 2010; Borthwick-Duffy & Eyman, 1990; Neece, Baker, Blacher, & Crnic, 2011; Neece, Green, & Baker, 2012). Other than intellectual disability, the most commonly reported co-morbid diagnoses include 'anxiety, attention-deficit/ hyperactivity disorder (ADHD), depression, obsessive compulsive disorder (OCD) and oppositional defiance disorder (ODD)' (Kim et al., 2000; Mayes et al., 2011; Simonoff et al., 2008). Each of which are associated with their own behavioural and functional impairments.

2.2.4 ASD: Secondary medical complications/physical and health states

Many individuals with ASD present with medical issues as secondary diagnoses or at times consequences of behavioural problems (e.g. banging head or ears). A number of health issues such as epilepsy, tuberous sclerosis, and seizures may co-occur with ASD (Boisjoli & Matson, 2009; Gillberg & Billstedt, 2000; Xu, Neece, & Parker, 2014). Gastrointestinal complications and poor sleep are also common.

2.2.5 ASD: Pervasive and long-term impairment/s

Many individuals with ASD present with cognitive and/or adaptive impairments that hinder their ability to live self-reliantly thus resulting in a need for continued care from caregivers for the duration of their lives (Volkmar & Pauls, 2003, cited in Karst & Van Hecke, 2012). Regardless of level of intellectual impairment, ASD is pervasive and persists across the individual's lifespan (DePape & Lindsay, 2015). According to Abbott, Bernard and Forge (2012), a diagnosis of ASD is associated with a lifetime impact on the family as well as the child. This lifelong burden placed on parents and siblings of children with ASD may exacerbate the difficulties faced by the family, alter their perception of parenting, and likely impact positivity about their future- as individuals and as a family (Karst & Van Hecke, 2012).

2.2.6 ASD: Treatments aim to improve rather than 'cure'

As there is no known cure for ASD, treatments and intervention objectives focus on the improvement of the child's functioning (Woodgate, Ateah, & Secco, 2008).

Targets of interventions include developing social, communication, adaptive, behavioural, and academic skills as well as decreasing maladaptive and repetitive behaviours (Committee on Children with Disabilities, 2001, cited in Woodgate et al., 2008). A combination of strategies is required in order to attempt to address the diverse range of deficits that may be present (Woodgate et al., 2008).

The intra-variability and inter-variability of effectiveness of treatment means that therapies that are highly effective in one instance may not work in others. Furthermore, interventions that work initially may begin to decrease in effectiveness over time or at a later stage in development. Due to this, and the heterogeneity of ASD, interventions and treatments tend to be highly individualised and expensive.

With improvement in functioning as the goal of interventions alongside the high variance in presentation amongst individuals with ASD, there is a vast array of intervention and treatment possibilities (Karst & Van Hecke, 2012). The numerous debates surrounding ASD further complicate this picture- leaving parents with a massive amount of possibilities to comb through and decipher- often without sufficient guidance from health care professionals (Karst & Van Hecke, 2012; Woodgate et al., 2008). Individuals with ASD and their families encounter numerous professionals beginning prior to diagnosis and throughout their lifespan, ranging from general practitioners and paediatricians to clinical psychologists, occupational therapists, speech therapists and educators. Some studies suggest that prior to receiving a formal diagnosis, an average of four and a half practitioners are seen however in South Africa, Mitchell and Holdt (2014) found that the number of practitioners seen ranged from six to eleven.

There are a multitude of interventions available for children with ASD, with new ones emerging daily however, very few meet the requirements of 'evidence based standards'- especially within lower income countries.

Interventions are demanding on parents as they attempt to attend a multitude of therapies while trying to cope with the daily demands of caring for their child with ASD. Interventions that rely on parents- often as key therapist- have gradually gained momentum. The focus of clinical attention is the child whereas not much attention may be given to the parent/s regarding their need for psychosocial support.

This clinical heterogeneity results in variations in diagnostic processes, treatment protocols and requirements however it also inherently results in dissimilarities in the experiences of each

family. This is essential to consider when attempting to provide support and intervention for the family of a child with ASD.

2.3 ASD: DIAGNOSIS AND EARLY INTERVENTION

Studies suggest that early identification and accurate diagnosis of ASD are fundamental to ensure appropriate and effective intervention (Mitchell & Holdt, 2014). There is a compelling evidence base supporting the role of early intervention in better prognosis for the child and the family (Carlsson, Miniscalo, Kadesjö, & Laakso, 2016; Mitchell & Holdt, 2014). Literature suggests that parents noticed and recognised something atypical in their child's behaviour and development early on (Altiere & Von Kluge, 2009; Carlsson et al., 2016; DePape & Lindsay, 2015; Estes et al., 2013; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014) and began to seek professional guidance. A number of studies (Goin-Kochel et al., 2006, Jónsdóttir et al., 2011; Mitchell & Holdt, 2014) suggest that it is possible to accurately diagnose ASD before the age of two years.

Despite the early concerns of many parents and the research suggesting early, accurate diagnosis is possible, there was often a long delay between the recognition of these concerns and actually obtaining a diagnosis (Estes et al., 2013; Mitchell & Holdt, 2014). Crane et al. (2016) found an average of three and a half years of delay between first contact with a healthcare provider and receiving a formal diagnosis. Studies suggest that the diagnostic process was a frustrating and confusing one and that delays in diagnosis contributed considerably to parents' levels of distress (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014). Delays in diagnosis ultimately delayed earlier intervention for ASD children impacting their prognosis (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014).

Throughout the literature it is clear that having a child with ASD is intrinsically linked to a number of changes and consequences that are unique to this state, for both the child and the family. The factors discussed above support the concept of ASD as unique and in turn highlight the consideration that parents of a child with ASD face a number of unique obstacles given the nature of ASD and the distinctive challenges it brings with it (Chong & Kua, 2017; DePape & Lindsay, 2015). This, and the pervasive nature of the deficits in ASD, require parents to devote a substantial amount of time and energy to care-giving (DePape & Lindsay, 2015).

ASD deficits, the emotional and behavioural problems seen in individuals with ASD, and the multitude of stressors parents face as a consequence of their child's diagnosis have been

explored in relation to parenting stress and well-being (Davis & Carter, 2008; Falk, Norris, & Quinn, 2014; Hastings, 2003; Huang et al., 2014; Lecavalier et al., 2005; Tomanik, Harris, & Hawkins, 2004; Xu, Neece, & Parker, 2014).

2.4 PARENTING A CHILD WITH A DISABILITY

Parenting is an extremely complicated and multidimensional undertaking to navigate (Chong & Kua, 2017). Raising a child with a disability has a complex and dynamic relationship with psychological distress (Estes et al., 2013) and the experience of having a child with a disability can be one that is fraught with difficulties at multiple levels of a family's life (Watson et al., 2011). Each developmental stage brings with it new challenges and obstacles to overcome. Parents experience psychosocial difficulties in relation to being a parent, however parenting a child with a disability brings with it many diverse challenges over and above these (Beresford, 1994).

2.4.1 The importance of context and the child's diagnosis when exploring parental experiences

It is essential that parenting a child with a disability be understood in the context of the entire family unit. Literature has suggested that the diagnosis of the child (and in turn the behavioural phenotypes that manifest) may directly relate to variations in experiences of parenting stress (Dykens & Hodapp, 2001; Hayes & Watson, 2013; Seltzer et al., 2004). The parenting stress associated with caring for a child with a disability has been shown to be strongly associated with the nature of the disorder, associated behavioural problems, and the demands of attention due to daily care needs (Faust & Scior, 2008; Gupta, 2007, cited in Greeff et al., 2013).

Using insights from parents of typically developing children to understand those of parents of atypically developing children is misguided. Even more so, insights regarding parenting a child with a specific disability cannot be generalised across the board to those with any disability. This is especially true for ASD as it presents with a plethora of unique challenges and experiences. Thus, it is insufficient to assume that insights that emerge in the context of parenting neuro-typical children or children with non-ASD disabilities, can adequately encapsulate the experiences and difficulties of parents who have children with ASD.

As seen in research, parents of children with ASD consistently report higher levels of stress, decreased well-being and mental health issues. The unique presentation of ASD and unique challenges experienced by parents of children with ASD have been reported.

Findings below emphasise the points discussed above, highlighting the importance of studying parenting experiences in the context of the child's specific diagnosis.

2.5 PARENT AND CARE-GIVER WELL-BEING IN RELATION TO ASD

Substantial empirical evidence suggests links between psychological stress and poor well-being of parents and parenting a child with ASD (e.g. Chong & Kua, 2017; Davis & Carter, 2008; Estes et al., 2009; Hayes & Watson, 2013; Pottie & Ingram, 2008). Research findings have studied parenting stress in parents of children with ASD in comparison with parents of typically developing children and those with non-ASD disorders such as intellectual disabilities and other developmental disorders.

2.5.1 The impact of ASD children compared to typically developing children on stress in parents

Hayes and Watson, (2013) identified several studies that have investigated stress and poor well-being of parents of children with ASD in comparison to parents of typically developing children (e.g. Brobst et al., 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Lee, 2009; Rao & Beidel, 2009), the findings are discussed in categories below.

2.5.2 The impact of ASD children compared to typically developing children and children with other developmental disorders on stress in parents

The pervasive and severe deficits present in children with ASD are related to a number of strains in parents that differ from those experienced by parents of typically developing children and children with other developmental disorders (Karst & Van Hecke, 2012).

A meta-analysis by Hayes and Watson (2013) analysed previous research conducted that compared stress in parents of children with ASD, children with other developmental disabilities (non-ASD) and typically developing children. They found that the overall effect size calculated was large, suggesting that stress in families with a child with ASD was significant and thus warranted intervention and support.

2.5.3 The impact of ASD children compared to children with other developmental disorders on stress in parents

Hayes and Watson (2013) reported that several studies compared stress in parents of children with ASD in comparison with stress in parents of children diagnosed with other developmental disorders. These included those children diagnosed with Down syndrome (DS), intellectual

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disability (with no known aetiology; ID), cerebral palsy, fragile X syndrome, cystic fibrosis, fetal alcohol spectrum disorder (FASD), or externalizing behaviours (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Dabrowska & Pisula, 2010; Donenberg & Baker, 1993; Eisenhower et al., 2005; Estes et al., 2009; Griffith et al., 2010; Hamlyn-Wright et al., 2007; Konstantareas & Homatidis, 1992; Pisula, 2007; Stewart et al., 2017; Watson et al., 2012; Wolf et al., 1989).

2.5.4 The impact of ASD children compared to typically developing children and children with non-ASD disabilities on stress and well-being in parents

According to a number of studies (Davis & Carter, 2008; Falk, 2014; Huang et al., 2013; Lee, Lopata, Volker, Thomeer, Nida, Toomey, Chow, & Smerbeck, 2009; Jones, Totsika, Hastings & Petalas, 2013; Mount & Dillion, 2014; Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012), being a caregiver of a child with ASD was found to involve encountering problems and demands daily that caused substantial amounts of stress and impacted mental health and well-being negatively, more than that of parents of typically developing children or non-ASD disabilities.

In their review of literature, Meadan, Halle and Ebata (2010) found that parents of children with ASD reported greater stress than parents of children with down syndrome and parents of typically developing children (e.g. Hastings & Johnson, 2001; Perry et al., 2004; Poston et al., 2003).

2.5.5 The impact of ASD children compared to typically developing children, children with non-ASD disabilities and other psychiatric disorders on stress and well-being in parents

According to Estes et al. (2013) the risk for increased levels of stress and mental health problems is much greater in parents of children with ASD when compared to parents of typically developing children and children with psychiatric and non-ASD developmental disorders (Estes et al., 2009; Griffith et al., 2010; Naseef, 2001; Schieve et al., 2007).

Findings emerging from their study, were found to be consistent with this as mothers of toddlers with ASD reported higher parenting-related stress than mothers of toddlers with non-ASD developmental delays (DD) and typical development. However, when measuring psychological distress- characterised by anxiety and depressive symptomology- their findings contrasted this assumption as, psychological distress was not significantly dissimilar amongst

the sample of mothers of ASD and non-ASD toddlers. This suggests that mental health concerns relating to psychological distress may be present among mothers of toddlers regardless of diagnosis.

Falk, Norris and Quinn (2014) report that existing literature has recognised that parents of children with ASD present with greater mental health concerns than the parents of children in other clinical and/or non-clinical groups (e.g. Benjak, 2009; Bitsika & Sharpley, 2004; Kuusikko-Gauffun et al., 2013; Micali et al., 2004; Singer, 2006).

The abovementioned study by Hayes and Watson (2013) supported this suggestion, reporting that a number of researchers have identified greater incidences of depression and anxiety (e.g. Dumas et al., 1991; Eisenhower et al., 2005; Hamlyn-Wright et al., 2007; Koegel et al., 1992) and lower overall well-being (Blacher & McIntyre, 2006) in parents of children with ASD.

2.5.6 The impact of ASD children compared to children with non-ASD disabilities and non-ASD intellectual disability on stress and well-being in parents

Research findings have indicated that parents of children with ASD consistently report more psychological stress and poorer well-being than parents of non-ASD children or parents of children with other intellectual disabilities (e.g. Estes et al., 2013; Hastings & Johnson, 2001; Hayes & Watson, 2013; Meadan, Halle, & Ebata, 2010; Stewart et al., 2017).

These findings collectively suggest that having a child with ASD is linked to higher levels of stress and poorer mental health than those seen in parents of non-ASD children, highlighting the need for parental support and intervention.

As ASD presents a unique series of challenges, it is not sufficient enough to base our understanding of parental experiences on the experiences of parents of typically developing children or those with disabilities other than ASD. The psychosocial experiences of parents with children who have ASD need to be understood as unique and dependent on the context they are found in.

In conclusion, arguments have been presented around differential experiences of parenting children with developmental/mental illness states. Whilst generalizability of experiences cannot be assured due to the differences in psychosocial adaptation regarding conditions mentioned above, it would be of great value to investigate lived experiences of parent/s of a child with ASD so as to: 1) identify similar forms of adaption when compared to managing a

child with other forms of disabilities and 2) identify unique forms of adaptation that parents subscribe to in a given context.

2.6 PARENTS EXPERIENCES/ CHALLENGES INTRINSICALLY RELATED TO THEIR CHILD'S ASD

2.6.1 Behavioural Problems & their severity in ASD

Research suggests that increased behavioural problems and greater severity of ASD behaviours are associated with increased perception of parenting stress (Davis & Carter, 2008; Estes et al., 2009; Estes et al., 2013; Hastings, 2003; Huang et al., 2014; Lecavalier et al., 2005) and have been identified in a number of other studies as a significant predictor of parental mental health problems (Gray, 2003; Lecavalier et al., 2005; Jones et al., 2013; Tomanik et al., 2004; Weiss, 2012).

As mentioned above, parents face a number of challenges because of their child's ASD. One would assume these would be directly related to the child's behaviour and difficulty managing it or coping with it. Meadan et al. (2010) suggest that its highly probable that ASD behaviours have an impact on the family. Studies have investigated whether ASD behavioural problems emerge as a prominent stressor and challenge for parents of children with ASD (Davis & Carter, 2008; Estes et al., 2009; Estes et al., 2013; Gray, 2002; Hastings, 2003; Jones et al., 2013; Lecavalier et al., 2005; Pottie & Ingram, 2008; Tomanik et al., 2004; Weiss et al., 2012) and found that a number of studies suggest that behavioural problems in children with ASD were significantly correlated with parental mental health problems and psychological distress such as stress, anxiety and depression (Gray, 2002; Estes et al., 2013; Weiss et al., 2012).

On the contrary, some research has disputed that mental health issues in parents are predicted by ASD symptom severity in the child rather than behavioural problems (Duarte, Bordin, Yazigi, & Mooney, 2005; Hastings & Johnson, 2001; Hastings et al., 2005; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010), with some suggesting that ASD symptom severity was the most consistent and highly correlated predictor of parental stress in their findings.

Table 2.2 Research findings showing behavioural problems as prominent stressors in parents

Author/s	Findings
Davis & Carter, 2008; Estes et al., 2009; Estes et al., 2013; Gray, 2002; Hastings, 2003; Jones et al., 2013; Lecavalier et al., 2005; Pottie & Ingram, 2008; Tomanik et al., 2004; Weiss et al., 2012.	A number of studies have have investigated whether ASD behavioural problems emerge as a prominent stressor and challenge for parents of children with ASD
Estes et al., (2013)	Findings reported that child problem behaviour was found to be strongly predictive of higher levels of psychological distress and parenting stress in mothers of toddlers with ASD and DD.
Gray (2002)	A longitudinal study investigating the psychological adaptation of parents of children with ASD, highlighted the significant role of challenging behaviour in parent well-being. This study found that the psychological well-being of most of the parents improved over time, however, in cases where children presented with challenging behaviour, higher levels of stress and less improvement were reported.
Jones et al., (2013)	Findings suggest that behaviour problems were found to be more significant than ASD symptom severity in predicting well-being of parents in their study.
Meadan et al., (2010)	Suggest that its highly probable that ASD behaviours have an impact on the family.
Weiss et al., (2012)	Findings indicate that behavioural problems in children with ASD were significantly correlated with parental mental health problems and psychological distress such as stress, anxiety and depression.
Research findings showing severity as prominent stressor in parents	
Author/s	Findings
Falk et al., (2014)	report that several authors have disputed that mental health issues in parents are predicted by ASD symptom severity in the child (Duarte et al., 2005; Hastings & Johnson, 2001; Hastings et al., 2005; Lyons et al., 2010)

Falk et al. (2014) argue that these studies may not necessarily be generalisable as the participants were recruited through specialised support services, impacting sample population generalisability (Davis & Carter, 2008; Hastings et al., 2005).

Despite contrasting results, both child behaviours and symptom severity emerged as strongly correlated to the experience of parent stress (e.g., Brobst et al., 2009; Ekas, Lickenbrock, & Whitman, 2010; Estes et al., 2009; Hastings et al., 2006; Lecavalier et al., 2006; Tomanik et al., 2004) and maternal stress and well-being (e.g. Abbeduto et al., 2004; Allik, Larsson, & Smedje, 2006; Bromley et al., 2004; Hastings, 2003b; Hastings & Johnson, 2001; Herring et al., 2006; Tomanik et al., 2004).

These findings emphasise the relationship between ASD behavioural problems, their severity and parent well-being as the pervasive and lifelong deficits present in ASD continue to be associated with decreased parent well-being and high stress levels. In other words, high stress levels are not only present in the initial phases (although this period certainly has its own psychological and emotional challenges for the parents) but rather ASD behavioural problems continue to present challenges to parent well-being many years after diagnosis. Understanding whether this is the case for South African parents may be a key factor in informing supportive interventions for parents of children with ASD.

2.6.2 Specific deficits in ASD

Researchers have also attempted to understand whether specific deficits or behavioural difficulties commonly present in ASD are predictive sources of parenting challenges and stress. The results have varied and been inconsistent however, this may make intuitive sense as ASD occurs on a spectrum and thus clinical presentation often varies between individual cases, inherently impacting individual family experiences. There are so many variations of combinations of deficits, behavioural phenotypes and the severity of each individual variation that it may be hard to pinpoint common factors amongst individual cases.

Previous research (Alli et al., 2015; Brown et al., 2011; Davis & Carter, 2008; Gray, 2003; Hall & Graff, 2011; Huang et al., 2014; Ingersoll & Hambrick, 2011; Karst & Van Hecke, 2012; Lecavalier et al., 2006; Lee, 2008; Lyons et al., 2010; Tomanik et al., 2004) has reported on common factors that are associated with stress in parents of children with ASD.
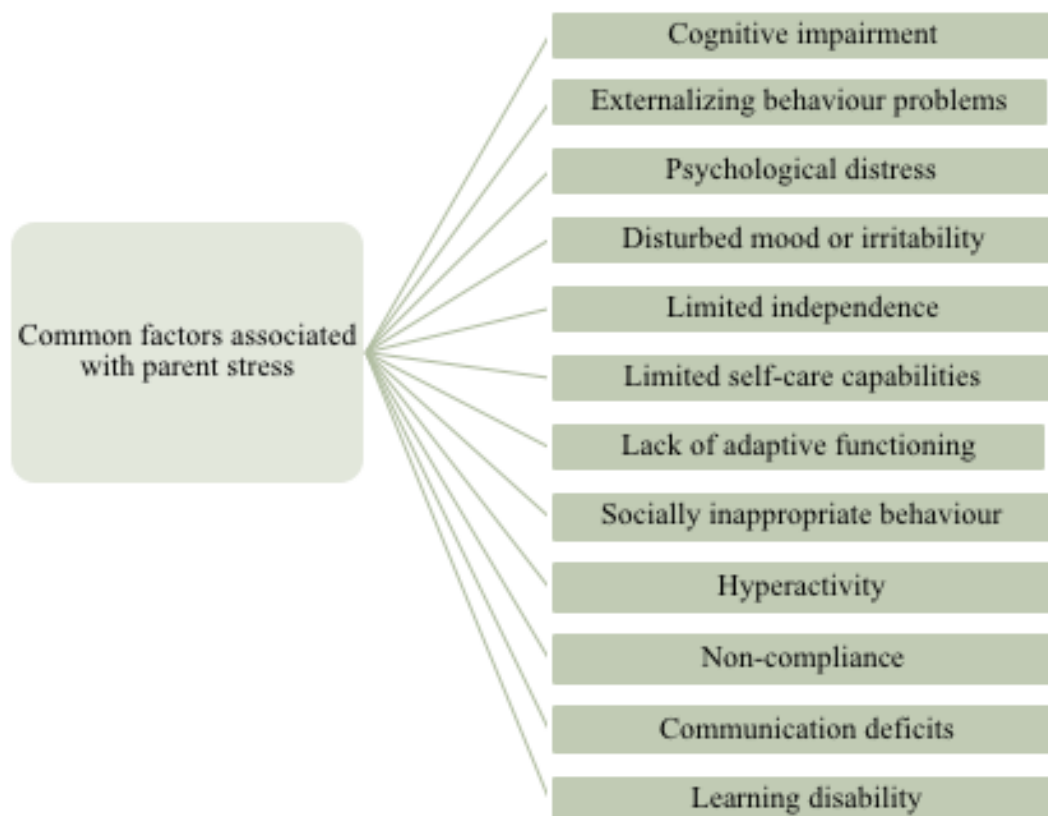
Figure 2.2 Showing common factors associated with parental stress

As shown in the summary figure above (figure 2.2), various factors in child behaviour have been identified as associated with parent stress. Some studies have explored the role of specific core ASD behaviours of the child in parenting stress, including social reciprocity and communication deficits as well as repetitive and stereotypic behaviours. In their study, Davis and Carter (2008) found that deficits in children's social relatedness and communication were associated with overall parenting stress.

Alli et al. (2015) reported that all respondents in their study indicated experiencing challenges in both the receptive and expressive language domains of communication, with communication in social settings emerging as the most challenging. However, these were not indicated as the most stressful behaviour, more that it was affirmed as difficult for all parents in the study.

Mothers of children with ASD reported that their stress levels were highest "when their children were irritable, lethargic and socially withdrawn, hyperactive/non-compliant, unable to take care of themselves, and unable to communicate or interact with others" (Tomanik et al., 2004, p. 24). This was supported by Huang et al. (2014). This finding is consistent with other studies that have demonstrated a relationship between the behaviour of children with ASD and

parental stress levels, however it appears understandable that these behaviours would impact any mothers stress levels, regardless of whether the child was autistic or not.

Research findings suggest that behaviours that are difficult to cope with or stressful for parents are mostly centred around the child's inability to function independently, inappropriate behaviour in social settings and impaired ability to communicate. The mixed results suggest difficulty ascertaining whether parenting stress is predicted solely by core ASD behaviours or whether their co-existing emotional and behavioural problems compound the impact of these core behaviours on parents' stress (Huang et al., 2014).

In other words, evidence has shown that ASD behaviours are distressing and challenging to parents however, focusing solely on this would do an injustice to the parents as it would overlook the multitude of challenges and difficulties they face within their daily lives as well as within their family unit, occupational functioning, social support networks and on a psychological level.

2.7 PARENTS EXPERIENCES/ CHALLENGES: EXTRINSIC FACTORS

Experiences of parents of children with ASD are filled with a diverse assortment of challenges and stressors that are both directly related to the child's characteristics (i.e. behavioural difficulties) as discussed above and indirectly related- brought about or amplified by their child's diagnosis (Benson, 2006; Kiami & Goodgold, 2017; Meadan et al., 2010). Parents face the demanding task of caring for a child with ASD alongside system stressors such as difficulties regarding diagnosis, challenges accessing services, daily life obstacles and the impact ASD has on the family unit and parents themselves.

PARENTS EXPERIENCES/ CHALLENGES: EXTRINSIC FACTORS
- Experiences Relating to The Diagnosis Phase
- Pre- diagnosis & pattern of onset
- Professionals & delays
- Receiving a diagnosis and post-diagnosis
- Empowered but alone: the journey has just begun
- Experiences Relating to Accessing Care
- Inaccessible and ill-equipped
- Economic 'Burden' of Care
- Parents as advocates
- Experiences Relating to Social Support

2.7.1 Experiences Relating to The Diagnosis Phase

Figure 2.3 Showing parental experiences related to the diagnosis phase

2.7.1.1 Pre- diagnosis and pattern of onset

Karst and Van Hecke (2012) suggest that parent and family distress related to ASD occurs prior to a formal diagnosis is received. As mentioned previously, most parents noticed and recognised something atypical in their child's behaviour and development early on and began to seek professional guidance (Altiere & Von Kluge, 2009; Carlsson et al., 2016; DePape & Lindsay, 2015; Estes et al., 2013; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014).

Studies (Altiere & Von Kluge, 2009; Carlsson et al., 2016; DePape & Lindsay, 2015; Estes et al., 2013; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014) indicate that parents reported either atypical development in their child from early on or a regression in functioning and development after a period of "normal" development. Thus, although the pattern of onset may vary, typically within the first year of their child's life these parents encountered one of the two scenarios that causes considerable distress. Altiere and Von Kluge (2009) argue that comparing the two is almost impossible as in one scenario "a family's excitement about a new child changes to confusion, anger, resentment, and guilt when they discover that their child has little interest in them" while in the other scenario, "a child's normal development suddenly disintegrates leading to confusion and despair" (p. 144).

2.7.1.2 Professionals and delays

Although parents may have recognised atypical development at different points, studies suggest that families sought guidance from healthcare professionals before the child was two years of age (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Jónsdóttir et al., 2011; Mitchell & Holdt, 2014). Despite this and the evidence indicating that a diagnosis is possible by age two, the period between recognition of developmental concerns and attaining a formal diagnosis was typically long and filled with frustration and confusion (Altiere & Von Kluge, 2009; Crane et al., 2016; Estes et al., 2013; Mitchell & Holdt, 2014). Some studies found that parents saw an average of four and a half practitioners with a waiting period of three years or more for a diagnosis however in the study by Mitchell and Holdt, (2014), it was found that in South Africa, the number of practitioners seen ranged from six to eleven and years until diagnosis varied between two and seven years.

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Studies suggest that attempts to get answers and guidance often left parents trying to convince healthcare professionals- usually general practitioners- that their concerns were valid and required further investigation. Parents in various studies have reported that their concerns were dismissed and brushed aside by both practitioners and friends or family members (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014). Many parents reported that numerous healthcare professionals assured them that their child would 'grow out of it' or alluded to poor parenting ability as the root cause.

Research suggests that parents perceived practitioners as being unwilling to take heed of their concerns and reluctant to diagnose their children (Mitchell & Holdt, 2014). Parents felt the reasons for this unwillingness to diagnose included a lack of understanding and professional knowledge of ASD, as well as a lack of familiarity with the necessary assessment tools and insufficient time to conduct appropriate assessments (Mitchell & Holdt, 2014). The lack of unambiguous markers of ASD meant that diagnosis (or the acknowledgement of the need for further specialised assessment) was (and remains) reliant on the healthcare practitioners' professional knowledge and understanding of ASD (Mitchell & Holdt, 2014). The above factors in combination with the heterogeneity of ASD often led parents and professionals along incorrect diagnostic paths- while the common misdiagnoses compound parental experiences of distress and confusion as they hope for answers (Altiere & Von Kluge, 2009).

Reports indicate that delays in accurate diagnosis and the dismissal of parents' concerns contributed significantly to parent distress during this process as their child's psychological and physical health declined, and their own anxiety and distress increased (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014). An awareness that dismissals by practitioners was delaying intervention for their child was reported by parents (Mitchell & Holdt, 2014). In other words, parents reported that each appointment that did not result in answers or a diagnosis, meant further delay in intervention for their child. Thus, parents reported a perception that the dismissal of their concerns was adding to the amount of delay until intervention for their child. Studies also suggest that parents had difficulty understanding the child's behavioural problems without a diagnosis and many began to question themselves as parents (Carlsson et al., 2016; Mitchell & Holdt, 2014).

2.7.1.3 Receiving a diagnosis and post-diagnosis

Consistently throughout the literature, parents reported that a diagnosis of ASD was a "life-altering event" (Altiere & Von Kluge, 2009, p. 145).

Many parents indicated that receiving a diagnosis provided a label for their child's behaviour and difficulties giving them a platform to understand their child's behaviour and to explain it to others as well as begin to access support and implement strategies to assist functioning (Abbott, Bernard, & Forge, 2012; Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014).

Parents agreed on the benefits of a diagnosis however the experience of receiving a diagnosis was a strenuous ordeal for families that had a profound impact on the whole family unit. Studies indicate that the emotional impact on parents was profound, often diverse and remained long after the initial shock (Abbott et al., 2012; Altiere & Von Kluge, 2009; Carlsson et al., 2016; DeGrace, 2004; DePape & Lindsay, 2015; Estes et al., 2013; Gray, 2003; Mitchell & Holdt, 2014).

Multiple studies suggest that a varied, and often contradictory range of emotions was experienced by parents receiving a diagnosis for their child including relief, a sense of empowerment, grief, loss, guilt, blame and anger (Abbott et al., 2012; Altiere & Von Kluge, 2009; Carlsson et al., 2016; Estes et al., 2013; Degrace, 2004; DePape & Lindsay, 2015; Gray, 2003; Mitchell & Holdt, 2014).

Relief and a sense of validation was reported by most parents as they received affirmation for their efforts to convince practitioners of the severity of their concerns and a sense that there was now a label, a guide, equipping them to take action (Abbott, 2012; Altiere & Von Kluge, 2009; Carlsson et al., 2016; DeGrace, 2004; DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

Findings of multiple studies indicate that despite parent's suspicions and concerns about their child's functioning being atypical, the experience of actually receiving a diagnosis still brought with it shock, devastation and a sense of grief (Altiere & Von Kluge, 2009; DeGrace, 2004; DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

After receiving a diagnosis of ASD, parents' "quality worlds collapse - they pictured healthy and full of life children in them and now these pictures are slowly being replaced by pictures of 'disabled', 'Autistic', 'challenging', 'unmanageable' children" (Trigonaki, 2002, p. 13). This illustrated quote captures some of the meaning attached to this experience.

Parents reported a sense of loss and even grief as the reality of their child's diagnosis set in and they began to process the repercussions for their child's future. Parents encountered an experience of having to process the loss of the child they envisioned and the hopes they had

for the child's future as well as their future as a family. In some studies, parents compared this loss to the death of a family member (Altiere & Von Kluge, 2009; Gray, 2003; Mitchell & Holdt, 2014).

Estes et al. (2013) suggest that once the child received a diagnosis, a number of substantial personal adjustments had to be made by the parents such as "recalibrating expectations for their child's current and future functioning, and working to ameliorate the impact of ASD on personal and family life" (p. 134) while having to process and work though their own emotional response and psychological dynamics regarding their child's diagnosis.

2.7.1.4 Empowered but alone: the journey has just begun

The benefits of a diagnosis for parents and the child emphasise the stress and difficulty of the periods without it. Research suggests that after a long, often frustrating and confusing period between recognising difficulties in their child and actually formally receiving a diagnosis, the relief parents felt was short lived in some respects as the challenges continue post diagnosis, and they then encountered a variety of other challenges and obstacles.

On the one hand receiving a formal diagnosis brings closure to the journey of identification of state, but on the other hand, parents then face the often difficult journey of intervention and support to manage their child's difficulties and needs. The diagnosis may adjust parent's expectations regarding their child's future, however uncertainty (intervention and support) may contribute to a sense of disempowerment as there may be an absence of a 'concrete' plan of action or way forward. Without a plan or way forward, parents face the mammoth task of facing and navigating a system that is ill-equipped to cater for and support ASD children and their families.

Carlsson et al. (2016) argue that this period brought about a sense of being "empowered but alone" for parents (p. 333) as parents felt left without enough guidance or support to navigate the practical and emotional demands following a diagnosis of ASD.

2.7.2 Experiences Relating to Accessing Care

With little guidance, families were often left navigating a confusing domain that they are completely unfamiliar with, usually with heightened awareness that further delays would impact their child's prognosis even more (Karst & Van Hecke, 2012). Findings from multiple studies indicate that parents reported numerous challenges while attempting to access care or

services for their child (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014; Woodgate et al., 2008).

Studies have shown that in many cases, parents reported perceptions of the system as inaccessible and insufficient due to dismissive professionals, a lack of appropriate and professional knowledge of ASD and inadequate resources (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014; Woodgate et al., 2008).

Long waiting periods, inefficient communication and the financial implications of treatment were reported by parents as other challenges faced in relation to accessing services for their child (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

Having to pay out of pocket was reported as a major stressor for many parents (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Mitchell & Holdt, 2014). Parents faced a multitude of unexpected expenses and many reported financial strain.

Findings indicated that many parents reported having to step into a role of advocating for their child- and essentially fight for access to appropriate services for their children (Boshoff et al., 2016; Carlsson et al., 2016). Parents reported realising that they would need to fight and advocate for their child in each new encounter and throughout the education system (Carlsson et al., 2016).

2.7.2.1 Inaccessible and ill-equipped

The negative perception of an inaccessible and ill-equipped system was echoed in both the healthcare setting as well as the education system. Parents described teachers with inadequate training and limited understanding of ASD, and schools that were unsupportive (DePape & Lindsay, 2015).

Parents also reported a concerning shortage of adequate facilities and services available for children with ASD (DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

Findings indicate that many parents reported having to educate the schools and teachers about ASD as well as implement their own strategies in order to ensure adequate education for their children (DePape & Lindsay, 2015; Mitchell & Holdt, 2014). Some parents did so by employing personal facilitators or starting their own educational facilities (Mitchell & Holdt, 2014), ultimately adding the role of educator to their already large burden of care.

The impact of attempting to cope with the challenges prior to and in obtaining a diagnosis, compounded by continuous obstacles even once a diagnosis has been given may be extremely stressful for parents. Parent reports highlight the lack of adequate facilities and interventions for their children and in turn, the need for parental support at the same time.

A number of NGO's focused on ASD have attempted to provide support to parents of children with ASD by providing a number of online resources and guidelines. One NGO offers training programs for parents of children of ASD.

NGO's play important roles in providing support, guidance and psycho-education for parents, especially in low resource contexts where accessibility of adequate services and guidance is often limited. The NGO's mentioned above report attempting to advocate for those with ASD as a further attempt to provide support and acquire adequate services.

Table 2.3 Showing South African NGOs who are providing support to parents of children with ASD (Retrieved from www.au2know.co.za; www.autismwesterncape.org.za; actioninautism.org.za; www.elsforautism.org)

AUTISM SOUTH AFRICA	
ASD background information and facts	
Autism Specific Government Schools	
Regional Autism Organizations	
Understanding Autism - clinical description	
Information for Parents:	- The Super Useful Guide To Managing Meltdowns - ASA ZFolder - Low support needs ASD 100 Day Kit for Newly Diagnosed Families - Why does Chris do that? - Bullying and how to deal with it - Classroom and Playground Support - Dietary Intervention - Asperger Sibling Brochure 10 Tips for Parents - Developmental Milestones Chart
Info for professionals and family members	
Autism-Specific Adult Services	
AUTISM WESTERN CAPE	
Autism facts and information	
Resources for parents:	- Diagnosis, what now? - Your rights and the rights of your child - Social grants - Support groups
Resources for professionals	
List of service providers in the Western Cape	
Support groups:	- Offer a number of parent support groups. - The groups meet monthly. "Support groups provide parents and caregivers an invaluable support network where they have the opportunity to meet and socialise with others who are experiencing similar challenges".
ACTION IN AUTISM	
A Walk in Resource and Support Centre	- Aims to provide a comprehensive service to families. - This includes information booklets on ASD, a list of health care professionals that are able to assist, and a comprehensive list of schools for those with ASD. - Action in Autism also aims to support families in accessing a diagnosis, accessing a social grant, and accessing an

2.7.2.2 Economic 'Burden' of Care

Limited appropriate care for children with ASD was associated with high costs for the few interventions that were available and, in many cases, even greater costs as parents eventually had to employ their own strategies in order secure appropriate intervention for their child.

In the South African study by Mitchell and Holdt (2014), the significant lack of facilities and the high costs associated with appropriate intervention was emphasised by all the parents in the study. The authors also highlighted the fact that for the majority of South Africans these costs are impossible to even consider- leaving a large number of families unable to afford adequate intervention for their children.

Parents have consistently reported that having a child with ASD was associated with substantial financial burden and changes in career in multiple contexts (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Falk et al., 2014; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014; Nealy, O'Hare, Powers, & Swick, 2012). Research argues that many parents reported intense financial pressure and thus opted to work more or change their occupational setting in order to accommodate these pressures.

Due to the high demand of caring for a child with ASD, many parents reported having to decrease their work hours, change shifts or stop working entirely (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Falk et al., 2014; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014; Nealy et al., 2012). This impacted family income as well as decreased social and emotional support structures (Karst & Van Hecke, 2012).

Findings in the South African study by Mitchel and Holdt (2014) echoed the above-mentioned findings. Their study found that all the parents emphasized immense financial costs of care. Six of the mothers in their study had stopped working due to the demands of time and input required to care for the child. Altiere and Von Kluge (2009) found that mothers tended to report greater adjustments to their careers than fathers. In their study, the majority of the mothers were no longer working.

It was found that due to the financial pressures and demands parents faced, many reported having to take out loans or access various other forms of social support (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014). Altiere and Von Kluge (2009) reported that parents sold assets and property in order to manage the financial requirements they encountered. Mitchel and Holdt (2014) found similar trends amongst the South African parents in their study however

highlighted that most of their sample consisted of middle-class individuals who were able to access these financial supports for healthcare, therapy, medication and facilitators for their child. These findings emphasize concerns around socio-economic status and adequate health care services for children with ASD, especially in low resource communities (Altiere & Von Kluge, 2009; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014). The parents in this study had the means to access financial supports should they need to, and yet still reported feeling financially strained, highlighting the gravity of the financial burden of care for ASD children.

"If parents with the financial means (as in this study) have experienced the difficulties involved in diagnosis and recruiting adequate support for their ASD child, where does this leave the majority of the South African population, who are unable to afford these services?" (Mitchell & Holdt, 2014, p. 59). The provided quote, stresses the reality that the current financial implications associated with obtaining a diagnosis and adequate intervention is beyond the realm of possibility for the average South African, essentially continuing the cycle of children with ASD being undiagnosed and untreated.

2.7.2.3 Parents as advocates

Treatments associated with ASD are considered intense and multi-faceted and many parents reported a sense of playing 'catch-up' after lengthy delays in the diagnosis process. Parents reported that they felt overwhelmed by the number of treatments required, the logistics of attending multiple therapies and often, their own role in implementing these interventions. Research indicates that a large amount of effort and commitment from the parents was involved in interventions (Woodgate et al., 2008). This can be seen in the role parents played in implementing interventions and techniques within the home however above this many parents report taking on the role of advocating and fighting an unsupportive system in order to access appropriate care for their child.

Several studies (Carlsson et al., 2016; Falk, 2014; Woodgate et al., 2008) describe the emotional and psychological impact of having to advocate and fight for access to services for their child. The time and energy spent on caring for a child with ASD was draining and demanding in itself, however advocating and having to fight for their child's needs compounded this and contributed to overall distress (Carlsson et al., 2016; Woodgate et al., 2008).

The fear of "letting the window of opportunity pass them by" combined with an "unsupportive system" where professionals lacked knowledge and expertise in dealing with the needs of families greatly added to the pressure placed on parents- increasing the sense that they are required to take on everything alone- whether it be fighting for interventions for their child or doing it themselves. There is a sense that the stakes were so high, that any moment not spent advocating or implementing some form of intervention for the child is a moment lost (Woodgate et al., 2008, p. 1080).

These challenges and internal dynamics are important to explore and understand as they give insight into what seems to be a high pressure, demanding context in which parents are a key player. The high risk of mental health concerns in many parents of children with ASD is also highlighted here as this may reduce their capacity to cope and navigate these challenges as well as implement the necessary interventions (Falk, 2014).

2.7.3 Experiences Relating to Social Support

Most parents began by seeking formal support to guide and assist them, and then seek informal social support from family members, friends, and support groups (Altiere & Von Kluge, 2009). Families that received adequate informal support from their social networks and formal support from healthcare practitioners had a higher likelihood of positive adjustment (Falk et al., 2014; Hastings & Johnson, 2001; Meadan et al., 2010).

However, a common stressor reported by parents was the low levels of support received (Falk, 2014; Meadan et al., 2010). This is a concerning trend as social support has been explored as one of three main factors studied regarding predictors of parental well-being and mental health problems (Catalano et al., 2018; Falk, 2014; Lamminen, 2008; Sharpley et al., 1997).

Studies suggest that shifts within support networks of extended family and friends were often mentioned by parents of children with ASD (Altiere & Von Kluge, 2009; Nealy et al., 2012; Woodgate et al., 2008). Parents indicated that many extended family members had difficulty understanding ASD and were perceived by the parents to be unwilling to learn (Altiere & Von Kluge, 2009; Nealy et al., 2012; Woodgate et al., 2008). This suggested that the responsibility often fell on the parents to educate family members which would involve energy and time that they didn't have to spare- instead of extended family members taking action to learn and therefore provide support.

Parents also indicated that heavy time and energy demands as well as newfound responsibilities impacted their social interactions and their ability to maintain contact with social networks (Altiere & Von Kluge, 2009). For some parents, isolation was an inevitable consequence as social interactions were perceived as tedious with their child's potential outbursts and inappropriate behaviour (Altiere & Von Kluge, 2009; Woodgate et al., 2008), alongside social networks with little understanding of ASD.

An increasing sense of isolation and lack of support in the reports from parents remains concerning as studies have shown the importance of social support in positive outcomes for the family and the child (Catalano et al., 2018; Meadan et al., 2010; Mitchell & Holdt, 2014).

A systematic review by Catalano and colleagues explored interventions supporting the mental health of parents of children with ASD (2018) and found that the most beneficial interventions were those that involved support groups for parents. These resulted in a reduced sense of isolation and the validation of parent experiences.

2.8 PARENT EXPERIENCES WITHIN THE FAMILY

Having a child with ASD profoundly impact all aspects of family life including shifts in the roles and responsibilities within the family as well as family relationships and interactions (Alli et al., 2015; DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Meadan et al., 2010).

A family with a child with ASD has to make significant adjustments to their lives at a logistical level as well as psychosocially, in order to cope and function adequately (Altiere & Von Kluge, 2009; Estes et al., 2014). The family as a whole face a number of challenges however parents are at the forefront of managing the impact on the family and caring for the child with ASD. Changes in daily life, financial stress and the impact on relationships within the family were common themes mentioned across a number of studies in a metasynthesis by DePape and Lindsay (2014) and in a number of other studies (Mount & Dillon, 2014).

Studies suggest that daily life changed in a number of ways for the parents and siblings of children with ASD causing frustration and a feeling of being overwhelmed. Parents reported feeling unsure about how to manage behaviour problems or how to cope with the increased demands on them. Some parents also reported deterioration in marital satisfaction (Rogers, 2008, cited in Falk, 2014), strains on relationships with their other children, limitations on social ability of parents and the family as a whole, and increased financial strain due to costs of treatments as well as provision of care (Davis & Carter, 2008; DePape & Lindsay, 2014;

Glazzard & Overall, 2012; Huang et al., 2013; Jones et al., 2014; Mount & Dillon, 2014; Tehee, Honan, & Hevey, 2008).

Having a child with ASD often resulted in decreased family quality time and time for recreational activities (Altiere & Von Kluge, 2009; Meadan et al., 2010; Nealy et al., 2012; Schlebusch et al., 2016).

Families often have concerns about socially inappropriate behaviour which results in restrictions on the activities the family can get involved in as well as limiting the possibility of spontaneous family leisure activities (Nealy et al., 2012). These factors demonstrate the number of ways general family life is affected.

2.8.1 Daily life/ continuous care

According to studies, parents reported realising early on that caring for a child with autism was a 24-hour, 7-days-a-week task (Altiere & Von Kluge, 2009) involving the need to plan and schedule every aspect of each day (Carlsson et al., 2016). Caring for a child with ASD impacted every aspect of daily life for parents and the whole family (Carlsson et al., 2016; DePape & Lindsay, 2015) as families report that the majority of their day revolving around autism and the child's needs (DeGrace, 2004; Woodgate et al., 2008). Studies suggest that children with ASD require attention from a family member continuously thus demands of care are relentless and at times overwhelming (Alli et al., 2015; Altiere & Von Kluge, 2009; Carlsson et al., 2016; DePape & Lindsay, 2015; Woodgate et al., 2008).

Literature suggests that for parents with a child who has ASD there was a level of continuous and unremitting management that filled their daily lives. This experience is described succinctly in a study by DeGrace (2004):

> *The families describe their days as "insane" and "hectic" where "every second counts." From the time the children rise until the time they go to sleep, they require the attention of a family member. For example, the children require prompting and assistance to get dressed, to get a bath, and to brush their teeth. This was best captured by the Greens, who referred to having a child with autism as being "like having an infant." (p. 545).*

Having a child with ASD impacted the way a family unit functions, its overall well-being and harmony as much as it impacted the individuals within the unit (Hayes & Watson, 2013;

DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014).

Caring for a child with ASD is a 24/7 endeavour that absorbs and drains most of their time and energy, leaving little room for leisure activities or the energy for either of these. This continuous care is reported to have an impact on relationships within the family, including relationships with spouses as well as other children in the family.

2.8.2 Challenges in parent's marital relationships

Findings regarding the impact of having a child with ASD on caregivers' marital relationship have been mixed. Some studies report higher divorce rates amongst parents of children with ASD (Falk, 2014; Karst & Van Hecke, 2012; Nealy et al., 2012).

Understandably, there is evidence that having a child with ASD may have a negative impact as some parents reported strained relationships, low levels of happiness and increased conflict (DePape & Lindsay, 2015; Falk, 2014; Jones et al., 2014; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014; Tehee et al., 2008). DePape and Lindsay (2015), found that some parents reported conflict around roles within the family and perceived levels of support that impact marital harmony. In contrast, some studies suggest that parents report positive effects on their relationships such as increased closeness (DePape & Lindsay, 2015; Meadan et al., 2010).

Having a child with ASD placed increased demands on the entire family unit without much time for parents to process the diagnosis or grieve the loss of their expectations for their child and their own future. Parents have to recalibrate their roles and responsibilities "on the go" and when parenting a child with ASD, research suggested that parents have little time for themselves- one can imagine this would impact the marital system in the same way.

2.8.3 Siblings

Parents reported that their relationships with their other children was affected by the burden of care associated with having a child with ASD as parents struggled to balance each child's needs with limited free time to spend with their other children (DePape & Lindsay, 2014; Glazzard & Overall, 2012).

The lifelong burden of ASD inevitably impacted the siblings of the child with ASD however findings on whether this impact was purely negative have been inconsistent (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Meadan et al., 2010; Van der Merwe et al., 2017).

Typically developing siblings may experience difficulty interacting with the sibling with ASD as deficits may impact their ability to connect and relate (Van der Merwe et al., 2017). Siblings may also have difficulty with the unequal division of attention in the family as their daily lives revolve around autism and the affected siblings needs (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015). Some studies have reported positive effects on siblings such as higher levels of maturity (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Hastings, 2003a; Meadan et al., 2010; Mitchell & Holdt, 2014). These internal dynamics relate to parent experiences as they constitute an additional stressor on the parents as they attempt to navigate the needs of the child with ASD and their typically developing sibling.

Despite inconsistent reports on outcomes for siblings and a lack of clarity regarding positive versus negative outcomes, the stress of having a sibling with ASD (and in turn living in a household caring for a child with ASD) should not be dismissed (Pilowsky et al., 2004, cited in Meadan et al., 2010).

Meadan et al. (2010) found that some studies have suggested that demographic factors may be predictive of adjustment in siblings of children with ASD (e.g. Kaminsky & Dewey, 2002; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006). This was supported by Macks and Reeve (2007) who argue that the presence of demographic risk factors impacted the siblings ability to cope emotionally and psychologically with their autistic sibling. They argued that siblings of a child with ASD were more likely to be affected by certain demographic factors such as birth order (being older than the child affected by ASD), being male, only having one sibling and low socioeconomic status of the family (Macks & Reeve, 2007; Meadan et al., 2010).

A recent study in South Africa by Van der Merwe et al. (2017) shedding light on the attitudes of siblings of children with ASD found that sibling attitudes became more positive over time despite reports of ongoing obstacles in interactions with their sibling with ASD. This study suggested that siblings developed greater understanding and empathy for their affected sibling however still continue to be challenged by daily difficulties related to the ASD. This is mirrored by research suggesting that over time some parents are able to move towards acceptance and more positive perceptions of their child affected by ASD. Both parents and siblings have been

shown to report greater difficulties when the child affected by ASD presents with higher levels of behavioural problems.

Parents ultimately have to attempt to balance providing care for siblings and the child with ASD, which is often difficult as families often report having to orientate family life towards the needs of the child with ASD. Thus the adjustment and coping of their typically developing children may constitute an additional stressor for many parents.

2.9 EXPERIENCES RELATING TO THE SELF

Studies found that parents reported feeling overwhelmed, stressed and exhausted, indicating that caring for a child with ASD left them physically, psychologically and emotionally depleted (Altiere & Von Kluge, 2009; Chong & Kua, 2017; DePape & Lindsay, 2015; Mitchell & Holdt, 2014; Woodgate et al., 2008).

Research has shown that high levels of parenting stress and psychological distress have consistently been reported amongst parents of children with ASD (Dabrowska & Pisula, 2010, cited in Xu, Neece, & Parker, 2014). Kiami and Goodgold (2017) reported that 77% of the mothers of children with ASD in their study, met criteria for clinically significant stress levels.

As discussed, while facing a multitude of challenges and stressors daily, parents of children with ASD are also at an elevated risk for developing mental health problems.

A parent's role in every step of the child's development, intervention and daily life is crucial. Elevated parent mental health concerns, poorer well-being and higher levels of stress can impair the parent's functioning, which in turn may reduce parental potential to deal with the challenges guaranteed to occur when raising a child with ASD (Altiere & Von Kluge, 2009; Huang et al., 2014; Meadan et al., 2010). Furthermore, as considered previously, parents play a significant role in implementing interventions and if functioning were to be impaired, this may negatively impact a child's development and the effectiveness of a given intervention (Altiere & Von Kluge, 2009; Huang et al., 2014; Meadan et al., 2010; Osborne et al., 2008).

2.9.1 Emotional challenges

Research consistently indicates that parents experienced a diverse range of emotions and psychological experiences related to parenting a child with ASD. These in included: anger frustration, helplessness, discouragement and disappointment, hopelessness, despair and embarrassment (Chong & Kua, 2017; DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

2.9.2 Psycho-social challenges

Parents faced a number of psychological and psycho-social challenges in relation to parenting a child with ASD. These internal challenges intermingled with the plethora of daily practical, logistical and emotional challenges parent face presents an environment rife with parental mental health risks.

2.9.2 A) Normality

Studies have shown that parents report difficulty maintaining a sense of normality within their family (Altiere & Von Kluge, 2009; Woodgate et al., 2008) as their experience shatters many of their preconceived ideas or expectations of what parenting 'should be'.

2.9.2 B) Permanence

As discussed, ASD is one of the most severe neurodevelopmental disorders, with deficits that are pervasive and lifelong, thus the burden of care extends far beyond the duration one would expect for a typically developing child. Studies suggest that the realisation of the permanence of their child's condition has been reported to be stressful for parents throughout the child's life.

2.9.2 C) Anxiety about the future

Parents also reported ongoing concerns about their child's future and the extensive care they would need for the rest of their lives- many reported making extensive plans for future care of their child (Falk, 2014; Meadan et al., 2010; Mitchell & Holdt, 2014). This sense of fear of the future and having to over-prepare in order for their child to be taken care of, accentuated the anxiety and stress of many parents. For some parents, this meant they felt the need to work more in order to earn more and meet the financial demands of caring for a child for the rest of their lives (DePape & Lindsay, 2015).

2.9.3 D) Lack of acceptance, general lack of awareness and going out in public

Literature indicates that the lack of acceptance of their child's diagnosis and behaviour by family members and the general public or society was a stressor for parents (Meadan et al., 2010). Parents expressed feelings of isolation because of the general public's lack of understanding of ASD and the level of care involved in parenting a child with this diagnosis (Woodgate et al., 2008).

This sense of isolation was also linked to a limited understanding of parental experiences, the loss of a sense of 'normal', disconnect from extended family and friends, and a system that was perceived to be unsupportive of the parents and their children (Woodgate et al., 2008). Thus, reports suggest that parents perceived others as not understanding but also as unwilling to attempt to understand or provide support. This was especially so in the context of parents needing to fill the role of advocate for their child within the healthcare system as well as in their daily lives.

2.9.3 E) Judgement and criticism

Another factor related to this sense of isolation, was the experience of parents being judged and criticised by extended family members and members of the general public for a lack of discipline or poor parenting ability in response to their child's behavioural difficulties or outbursts (DePape & Lindsay, 2015; Gray, 2002; Neely-Barnes, Hall, Roberts, & Graff, 2011; Woodgate et al., 2008). Parent reports indicate that their children were often perceived as disobedient and wilfully disruptive.

2.9.3 F) Parenting sense of self

This not only resulted in parents avoiding social interactions or going out in public, but also impacted parenting self-esteem and appraisal of parenting ability. During the pre-diagnosis phase when parents didn't have an answer or context of understanding for their child's behaviour it is likely that they may have internalised these comments and criticisms from strangers (and extended family members) regarding their patenting ability or lack thereof. During the pre-diagnosis phase, when parents began to express their concerns to clinicians, the dismissal of these concerns and at times, implications regarding parenting ability from clinicians, further impacted parents sense of self and parenting ability (Carlsson et al., 2016; Karst & Van Hecke, 2012).

Thus it is essential to maintain awareness that a parent's mental health and well-being ultimately impacts the entire family unit and of course, impacts the child with ASD.

2.10 RESILIENCE AND ADAPTABILITY

In their synthesis of literature, Meadan et al. (2010) found that in spite of the challenges and high levels of stress experienced by families of individuals with ASD, many are able to cope and manage fairly well. Despite the challenges faced and difficulties encountered, many

parents also reported positive shifts as a result of having a child with ASD (Woodgate et al., 2008).

In their review Meadan et al. (2010) found that several studies reported that the use of reframing (i.e., shifting one's perception of stressors) and social support were the most common coping strategies reported. This was echoed by a number of other studies (Chong & Kua, 2017; Greeff et al., 2013; Hastings et al., 2005).

Parental agency emerged as another factor that was associated with better outcomes for parents and their children (Altiere & Von Kluge, 2009; DeGrace, 2004; DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Neely-Barnes et al., 2011; Woodgate et al., 2008). Parents reported taking action when dissatisfied with information provided and educating themselves as much as possible. This in turn resulted in many parents educating family members, health care providers and schools about ASD. This allowed parents to become efficient advocates for their child (Altiere & Von Kluge, 2009), giving them a sense of control in the tumultuous journey of accessing care for their child.

Gray (2006) found that the coping strategies used by parents changed over time, suggesting that parents may adapt and begin to accept factors that are unchangeable thus requiring less intense coping strategies.

Many parents also reported a number of positive experiences despite the hardships and the overwhelming burden of caring for a child with ASD including, the individual characteristics of their child, their happiness and seeing their successes (Karst & Van Hecke, 2012). Some parents highlighted the importance of embracing their new 'normal' in the journey towards acceptance (DePape & Lindsay, 2015). Others emphasised the benefits of acceptance which included closer relationships with their child and within the family, positive changes in their own behaviour and a level of appreciation that developed (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015).

Bayat (2007) found that "a considerable number of families of children with autism display resilience- reporting having become stronger as a result of a disability in the family" (p. 702). These factors highlight the importance of exploring parental experiences in the context of a tremendously stressful diagnosis as many, despite this, go on to report coping and adapting successfully.

2.11 SUMMARY/ RATIONALE

Being a caregiver of a child with ASD has been shown to involve encountering problems and demands daily that can cause substantial amounts of stress and impact mental health and well-being negatively, more than that of parents of typically developing children or non-ASD disabilities.

Experiences of parents of children with ASD are filled with a plethora of challenges and stressors that are both intrinsically related to the child's characteristics (i.e. behavioural difficulties) and extrinsically related, however brought about or amplified by their child's diagnosis.

Parents face the burdensome task of caring for a child with ASD alongside systemic stressors regarding diagnosis, barriers to accessing services, daily life obstacles and the impact ASD has on the family unit and parents themselves.

Prior to diagnosis parents face growing concerns about their child's development and the arduous task of attempting to access appropriate and supportive guidance from healthcare providers. Parents encounter a tumultuous journey of diagnostic delays, dismissals from practitioners regarding their concerns and a number of misdiagnoses during the lengthy and frustrating diagnosis process while they attempt to understand and managing their child's concerning and disruptive behaviour. This is compounded by socioeconomic divides and stressors that the majority of South Africans face.

The task of caring for a child with ASD is non-stop, 24/7 task and requires a substantial amount of effort and time from care-givers. Parents face daily obstacles ranging from ensuring basic daily care for their child to stepping into the role of educator, advocate and essentially their child's voice. Parents report feeling overwhelmed, exhausted and continuously drained as they take on these tasks alone. This suggests that daily experiences are demanding and taxing on parents and their well-being.

Despite these numerous challenges and stressors parents face, many report positive experiences and positive benefits of having a child with ASD. The ability to adapt and engage with the 'new normal' they are presented with is essential on the path towards acceptance. Parents who were able to employ coping strategies that effectively changed their perception of the situation reported greater adaptation and family harmony.

This emphasises that it is possible to adapt and embrace the multitude of obstacles and stressors of having a child with ASD. In order to assist parents and provide adequate and appropriate

supportive interventions, practitioners need to understand the dynamics and under-workings of this unique parenting experience.

Karst and Van Hecke (2012) argue that despite the evidence suggesting the importance of parental experiences and in turn the impact of parents on the child, there is an insufficient collection of research on interventions designed to help individuals with ASD and their families. Greater external support is needed for families who have ASD children. Furthermore, increased public awareness of ASDs is also needed. Interventions directed at parents also need to recognise autistic traits which may be present in some family members and be designed accordingly.

An understanding and awareness of the difficulties of raising an ASD child may provide a greater supportive and facilitative environment for parents (Mitchell & Holdt, 2014) and in turn impact child prognosis.

Despite a recent 'growth spurt' in available research on ASD in South Africa, the dearth of literature available on the incidence, prevalence and impact of ASD within a South African context remains problematic as the majority of the literature emerges from upper-middle class countries, lacks appropriate sample characteristics and therefore is limited in its applicability to a South African context.

The current South African research that is available is limited but suggests that ASD continues to be under-identified, access to services is incredibly difficult without abundant financial resources (problematic even with these resources), and there is an overall lack of support from healthcare practitioners. These contextual factors serve as factors further compounding what has been shown to be an extremely strenuous and demanding task.

With this is mind, this study aimed to generate an understanding of contextually relevant circumstances that contribute towards parents' experiences and difficulties in relation to managing a child with ASD. By investigating the psychosocial experiences and challenges that impact parental functioning, this study aimed to highlight these stressors and obstacles so as to inform future intervention in the area of psychosocial adjustment for parents of children with ASD.

CHAPTER THREE

METHODOLOGY

Chapter 3 will include six subsections. The first subsection will include conceptual understanding and discussion of the Resilience Model. The next subsection will discuss the research design including the importance of qualitative designs, the use of semi-structured interviews and thematic analysis as well as describing the procedural steps involved. This section will also discuss objectivity and the role of the researcher, followed by a subsection on dependability and credibility. The research methodology section will begin with the methodological approaches of previous South African studies, followed by participant selection, sample description, data collection and analysis of the current study, concluding with reflexivity. The final subsections will include possible limitations and ethical considerations.

3.1 CONCEPTUAL UNDERSTANDING
3.1.1 The Resilience Model

The Resilience Model focusses on a family's potential to cope, by highlighting their strengths and capacities (Holtzkamp, 2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; Patterson, 2002). It also proposes that families actively engage in order to rebalance their strengths and capabilities with the demands they face and by doing so, engage with the family's sense of meaning in order to proceed to a level of adaptation (Holtzkamp, 2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; Patterson, 2002).

Families face many demands that build up and may result in crisis if the family's capabilities are unable achieve homeostasis after a stressor. According to McCubbin and Patterson (1983 a crisis creates disorganisation and demands a change in a family's functioning (Holtzkamp, 2010) requiring families to edit and adapt their familiar and established patterns of functioning.

Adaptation and coping is seen when families are able to engage with this actively in order to achieve homeostasis between their capabilities and the demands placed on them. The role of meaning is emphasised in many resilience theories as this impacts a family's appraisal of the situation and in turn their coping (Holtzkamp, 2010; Patterson, 2002).

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Table 3.2 Conceptual framework key definitions

Term	Definitions	References
Stressor	A demand placed on a family that has the potential to create systemic changes	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015
Vulnerabilities	Life stressors that restrict and undermine the family unit capacity for adapting. Influences that impact of the initial stressor.	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015
Established patterns of functioning and family typology	Behavioural and cognitive repertoire of coping responses within a family.	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015
Resistance resources	Social, psychological, biological, and other competencies that could potentially provide support and encourage family adaptation	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015
Appraisal	Perceptions of the stressor; aspects that provide a sense of meaning to adverse experiences	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015
Family problem solving and coping	Family approach and problem solving approach to stressor	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015
Pile up	"Cumulative risk based on one or more family stressors and the efforts to manage the resulting demands"	Hall et al., 2012 (p. 25)
Adaptation	The level of competence in individuals, family subsystems, and family-ecosystem after addressing significant stressors	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015; Patterson, 2002;
Bonadaptation, (positive adaptation)	Adequate family system functioning and individual competence after significant risk; generally, at or above pre-crisis level	Greeff & Van der Walt, 2010; Greeff & Nolting, 2013; Hall et al., 2012; Henry et al., 2015; McCubbin & Patterson, 1983
Maladaptation, (negative adaptation)	How family system is functioning within the ecosystem after significant risk-inadequate coping	McCubbin & Patterson, 1983

Families face many demands that build up and may result in crisis if the family's capabilities are unable achieve homeostasis after a stressor. According to McCubbin and Patterson (1983 a crisis creates disorganisation and demands a change in a family's functioning (Holtzkamp, 2010) requiring families to edit and adapt their familiar and established patterns of functioning. Adaptation and coping is seen when families are able to engage with this actively in order to achieve homeostasis between their capabilities and the demands placed on them. The role of meaning is emphasised in many resilience theories as this impacts a family's appraisal of the situation and in turn their coping (Holtzkamp, 2010; Patterson, 2002).

Figure 3.1 a Phase 1 (Adjustment) adapted from McCubbin and McCubbin (1993)

Figure 3.1 b Phase 1 (Adjustment) adapted from McCubbin and McCubbin (1993)

3.2 RESEARCH AIMS

3.2.1 Aims

This study was an exploratory investigation of the psychosocial experiences and difficulties that parents of children with Autism Spectrum Disorders (ASD) encounter. A study of the factors that impact parenting stress and overall psychosocial experience facilitated an understanding of some of the challenges that parents of a child with ASD face and also shed light on the different/similar coping strategies that emerge in their contexts in order to help families adapt to the challenges of caring for a young child with ASD. Ideally, factors can be identified that broaden understanding of parents' experiences with ASD and are plausible targets for intervention and efforts to support parents (Davis & Carter, 2008).

The study examined these difficulties qualitatively, through semi-structured interviews and analysed the results using thematic analysis. The results were discussed within the theoretical context of the Resiliency Model of Family Stress, Adjustment and Adaptation proposed by McCubbin and McCubbin (1993). The Resiliency Model focuses on a stressor, the family's efforts to use resources, their appraisal of the situation and their coping patterns, as well as attempts to maintain function while dealing with a stressor.

The study intended to gain a greater understanding of the experiences of parents of children with ASD in relation to their psychological, social and occupational functioning. The study objective was to shed light on the difficulties experienced by parents directly in relation to their child's diagnosis as well as the challenges indirectly related to their child's diagnosis. A further aim was to inform supportive interventions for parents. In doing so, it was hoped that the current research would add to the very limited body of knowledge and literature in the domain/ area of psychosocial experiences and difficulties of parents of children with ASD within a South African context.

3.2.2 Research question

"What are the psychosocial experiences and difficulties of parents of children with ASD, prior to diagnosis and post diagnosis?"

3.2.3 Objectives

- Compare the challenges intrinsically related to their child's diagnosis to those extrinsically related. What causes greatest psychosocial difficulties for parents?

- How has having a child with ASD impacted the family dynamics? How are they coping?

- What does "coping" really mean in the context of lifelong burden of care?

- Which experiences are particular to specific participants and which are common to the experiences of the whole group?

- Parental psychosocial experiences within a South African context

3.2 THE RESEARCH DESIGN
3.2.1 Qualitative research

Qualitative research employs a "naturalistic approach" which aims to generate an understanding of a phenomenon within the context in which it is found (Golafshani, 2003, p.600). Qualitative research supports the role of the researcher as involved and immersed in the research and engaged as the primary research instrument or tool (Golafshani, 2003). Qualitative research design allows a holistic picture and understanding of the individual to emerge without the confines of quantitative constraints. This allows "rich, detailed data" to be generated. In alignment with this philosophical principle and the aims of this study, a phenomenological framework was used to guide the data collection of this study.

An advantage of qualitative design, and one which is especially relevant to this study, is the provision of the opportunity for the perspectives of participants to be fully and dynamically explored. According to Anderson (2010), qualitative research is able to "vividly demonstrate phenomena or to conduct cross-case comparisons and analysis of individuals or groups". The design encourages the exploration of the participant's personal, lived experiences and the ways in which they make sense of these (Smith, 2008).

Phenomenological research is a design of inquiry coming from philosophy and psychology in which the researcher describes the lived experiences of individuals about a phenomenon as described by participants. This description culminates in the essence of the experiences for several individuals who have all experienced the phenomenon. This design has strong philosophical underpinnings and typically involves conducting interviews (Giorgi, 2009; Moustakas, 1994).

A focus on understanding the phenomenon from the perspective of the participants is a core feature of qualitative research and is well supported by the phenomenological framework. The

framework and research design allow for the participants to be heard and engaged with on an empathetic level thus allowing a greater depth and richness of data to be obtained.

3.2.2 Semi structured interviews

The research employed semi-structured interviews for data collection. Semi-structured interviews allowed for greater flexibility and enabled the researcher to adapt the interview process based on the participants (Flick, 2009) which is in alignment with the philosophical positioning of qualitative research. This provided opportunity for unforeseen topics or data to emerge spontaneously from the participants- further honouring the aim of holistically exploring the participants' perspectives.

3.2.3 Analysis: Thematic analysis

The analysis of the interviews was done using thematic analysis. According to Braun and Clarke (2006), qualitative research methods are "incredibly diverse, complex and nuanced" and so thematic analysis should be understood to be a "foundational method for qualitative analysis" (p. 78). Thematic analysis is a qualitative method that identifies, organises and details the given data set (Braun & Clarke, 2006). The process allows patterns to emerge and be examined in parts and as a whole.

The thematic analysis steps provided by Braun and Clarke (2006) were followed:

Figure 3.2 Thematic analysis steps (Braun & Clarke, 2006)

3.2.4 Procedural steps

The following steps were followed:

- Interviews.
- Transcription.
- Immersion
- Thematic analysis
- Data Checks

These four specific design features aided in providing the evidence necessary to address the research questions.

3.2.5 Not objective

It is recognised that the qualitative process is not an objective one or at least one that is not without subjective influences (Morrow, 2005). Therefore, the data gathered in this study aimed to be representative of the subjective experiences of the participants from their perspective and with the meaning they place on these experiences. The aim of this research was not to generalise the findings but rather to use the data gathered to possibly aid in gaining a greater understanding of the subjective experiences of parents of children with ASD within a South African context and more specifically in the Western Cape.

3.2.6 Role of the researcher

Within this understanding of the process as a subjective one, the role of the researcher, described above as one that is involved and immersed in the research, is critical. The researcher was required to maintain reflexive stance throughout the research process, acknowledging their own role and subjective experiences and how these might influence the interpretation of the data. In alignment with qualitative research principles, the researcher was required to confirm with the participants that the interpretations made are felt to be accurate reflections of their experiences (Morrow, 2005). By doing so, in the current study the researcher aimed to maintain the focus on the participants' subjective experiences and accurately depicting these.

3.3 DEPENDABILITY AND CREDIBILITY OF THE DATA

The research concepts of validity and reliability are conventionally very significant quantitative concepts. These concepts remain important to a qualitative researcher however they are conceptualised differently (Golafshani, 2003; Seale, 1999). According to Healy and Perry (2000, cited in Golafshani, 2003), a study's quality should be measured according to its own paradigms terms. Thus in order to measure quality, the study addressed issues of dependability, rather than reliability and similarly, looked at credibility rather than validity (Babbie & Mouton, 2004; Golafshani, 2003).

Within qualitative research, replication of a study may be difficult and improbable, and so dependability becomes more of a focus. This means that generating a more in-depth understanding which can be used to inform and guide other settings forms the intent, rather than being able to generalise the findings (Leech & Onwuegbuzie, 2007). Dependability parallels reliability in a sense as it refers to the effort and degree to which care is taken to safeguard that the research is dependable and complies with the rules and procedures of qualitative research (Flick, 2009). In order to ensure dependability, the study provided

descriptions of the steps of the research, the theoretical positions of the study as well as its design and methodology (Babbie & Mouton, 2004).

Credibility within qualitative research refers to the level of confidence that a researcher is able to place in the research findings, which are validated by rich narrative data and felt to be truly representative of the phenomena they are trying to understand (Whitemore et al., 2001). In qualitative research, validity and reliability are related to research that is credible however within qualitative research, credibility depends on the ability and effort of the researcher (Golafshani, 2003).

3.4 RESEARCH METHODOLOGY

3.4.1 Methodological approaches of South African research studies on parental experiences of ASD

The methodological approaches of the South African studies on parental experiences of ASD included semi-structured interviews, self report questionnaires and surveys. Sample sizes ranged from six participants to 180, with eight studies reporting less than 15 participants. The majority of the studies were qualitative with smaller sample sizes while the few quantitative studies had larger sample sizes.

Of note, many studies reported limitations regarding sample size and the bias of convenience sampling. Some studies also reported the possibility of limited generalisability due to the makeup of their sample population. One study reported that due to the demographics of their sample (upper, middle socioeconomic brackets) their results were not necessarily representation of the entire population.

The majority of the qualitative studies had smaller sample sizes however reported that the in-depth understanding of each case provided insight that contributed to a growing understanding. Smaller sample sizes may be due to the nature of parental experiences as many parents report being extremely busy, fatigued and thus unable to spare time to participate in research. Some studies attempted to ease this by using electronic questionnaires or surveys however this may have been at the cost of face to face interaction despite possibly being easier in relation to the demands on parents. Thus, there is a need to assess the advantages and disadvantages of each approach.

In the context of parents of children with ASD, although electronic surveys may be easier to conduct, the opportunity to build rapport and engage with the participant on a deeper level

would likely be lost. This rapport may play a crucial role in providing the necessary environment for parents to respond more openly and honestly regarding experiences that may be difficult to verbalise.

In the current study, the benefit of a more in-depth engagement was prioritised over greater sample sizes or the convenience of electronic surveys. The role of rapport was viewed as essential in this study with the understanding that parents required a held, secure interaction in order to honestly respond to questions.

3.4.2 Participant selection

The study aims were to explore and understand the psychosocial difficulties of parents with children who have ASD. For this reason, purposive sampling was used for participant selection. Non-random sampling was used as the study required a specific population group that have been through this particular experience. Participants were recruited via a gatekeeper who distributed an invite to participate to parents linked to an ASD support group.

The literature suggests that a minimum of three to five transcripts is necessary for a thematic analysis and in order to identify themes. Thus, this study aimed to accept at least 4 to 10 participants. The sample selection aimed to be as representative as possible however due to restrictions and the qualitative nature of the study, the findings may be considered representative of the individuals participating in the study.

3.4.3 Sample description

Purposive sampling was used for participant selection.

- Parents with at least one child who has been diagnosed by a medical professional as having ASD.
- Living in the Western Cape, South Africa.

Sample demographics can be seen in Table 3.3 a, while characteristics of the children of the participants can be seen in Table 3.3 b.

Table 3.3 a Demographics of sample

Part.	Gender	Marital status	Ethnic/ racial background	HLOE	Employment (self)	No. of people in household	No. of children
A	F	Married; (2nd marriage)	Caucasian	Honours degree	Self-employed	4	4 (1 biological, 3 step-children)
B	F	Married	Caucasian	Hotel Management Diploma	Part time employed, teaches Child B 2 at home	5	3
C	F	Married	Caucasian	Uknown	Unemployed	2	2
D	F	Married	Caucasian	Unknown	Unemployed, Stay-at-home	4	2
E	F	Married	Mixed ancestry	Nurse	Employed	4	2

Table 3.3 b Showing characteristics of participants' children with ASD

Part.	Child's age (yrs)	Child's age at diagnosis (yrs)	Child's current diagnosis/ ASD 'category'	Child's other diagnosis/es	No. of diagnoses prior to ASD	Diagnoses prior to ASD
A (Child A)	13	9	"Aspergers"	ADHD; "PDA" (Pathological Demand Avoidance)	2	Sensory processing disorder; ADHD
B (Child B1)	22	16	"Aspergers"	Dyslexia	1	Dyslexia
(Child B2)	11	3	ASD	ADHD	0	
C (Child C)	25	5	"PDD"		0	
D (Child D)	9	4	"Aspergers"		0	
E (Child E)	13		ASD (Severe)	Metabolic syndrome	0	"Mild delay"

3.4.4 Data collection

Semi-structured interviews were used as the primary means of data collection in this study. Semi-structured interviews allowed for greater flexibility and unforeseen information to emerge (Flick, 2009). The parents involved were asked to reflect on the difficulties they have experienced in relation to having a child with ASD. This study recognises that these interviews were based on the subjective experience of each parent however this was acknowledged from the start, as was the reflexive role of the researcher.

Each participant was interviewed once. The interviews lasted approximately forty-five to sixty minutes. In one case, where both parents were present at one point in the interview, questions were presented to them together. Probes were used to explore further when appropriate. As it was understood that many of the participants may have difficulty finding spare time to engage in an interview, participants were interviewed at various locations that suited them. Two participants were interviewed in local coffee shops, one in a public garden and two participants invited the researcher into their homes. Interviews were recorded for ease of reference during the analysis stage.

In order to ensure dependability, participants were contacted where necessary for further clarification during the analysis phase, fulfilling the quality criteria of member checking (Leech & Onwuegbuzie, 2007).

The participants were given a description of the research study and its objectives, as well as a guide to the process prior to the interviews. The participants were only interviewed once the researcher had their informed consent.

3.4.5 Data Analysis/Interpretation

The study was an exploratory cross-sectional design. The data analysis and interpretation were done using thematic analysis.

Consent was obtained in order to audio-record the semi-structured interviews. The audio recordings were transcribed *verbatim* in English. The transcriptions were analysed thematically in order to identify commonalties and variances among the responses of participants.

Thematic analysis was used to observe previously unidentified patterns or themes. Once these patterns were identified, the next step involved classifying or encoding the pattern by giving it

a label, definition or description. The third major step involved interpreting the pattern (Boyatzis, 1998; Braun & Clarke, 2006).

The researcher read and reread the transcripts in order to immerse herself in and familiarise herself with the data. This provided the opportunity to generate a deeper understanding of the data (Morrow, 2005; Smith & Osborn, 2007).

The data were used to build an understanding of the individual and shared experiences of parents in relation to their child's ASD in a South African context.

3.4.6 Reflexivity

According to Smith and Osborn (2007), the research process is an interactive and dynamic process. The researcher attempts to gain access to and make sense of the participants subjective world, however this is influenced and often complicated by the researchers own subjective experiences, beliefs and values (Smith & Osborn, 2007; Willig, 2008). It is recognised that this, in combination with the view of the researcher as the primary research instrument or tool, means that the researcher plays a significant role in the manner in which the data are interpreted and understood (Golafshani, 2003; Merriam, 2002). It thus becomes vital that the researcher acknowledges the influence of their role as well as maintaining a reflexive stance towards their personal biases and subjective beliefs (Golafshani, 2003; Merriam, 2002; Willig, 2008).

This study recognises the researcher's role in the research process and in the description and interpretation of the data, as well as the influence the researcher may have on the findings that emerged. Thus reflexivity is an essential part of the research process. The researcher aimed to apply a reflective approach to her personal involvement and maintain awareness of her personal subjective positions throughout the research process. Engaging in reflexivity encouraged the researcher to use personal reflections to aid in gaining a deeper understanding of the participant's experiences which availed previously unrealised insights to emerge.

3.5 POSSIBLE LIMITATIONS

A possible limitation of this study was that parents who have children with ASD may not have been willing to volunteer to participate for a number of reasons. Children with ASD often require a number of therapies and interventions, thus parents may feel too busy to participate. It is for this reason that the researcher did her best to accommodate parent's time needs and keep the interview as short as possible – as well as set appointments for when parents are available. Another possibility may have been that parents may have difficulty discussing their

personal difficulties in general however even more so if these are difficulties in relation to their child. Thus, it was important to discuss positive aspects as well as difficulties to ease parental discomfort.

It is possible that parents may have concerns about personal information and experiences being documented and recorded, however for this reason it was emphasised that anonymity and confidentiality were and remain of key importance to the researcher. Another possible concern was the possibility that interview transcripts did not yield enough data from which to make interpretations, thus where required, follow up phone calls with participants for further information was considered however email contact was preferred.

Another possible limitation that has been considered is the potential for unclear or insufficient data relating to the parents psychosocial difficulties in relation to specific ASD deficits. Further research into this specific topic would prove useful in future studies.

As ASD research in the Western Cape has increased in recent years, another limitation was that support groups or participants often felt "over-researched" and thus were unwilling to participate.

3.6 ETHICAL CONSIDERATIONS

Prior to commencing the interviews, ethical clearance was applied for and obtained by the researcher, ethical clearance certificate number: HSS/1606/016M. Ethical protocol was followed throughout the research process. This study placed emphasis on fully informing the participants prior to obtaining consent, maintaining the confidentiality of information shared and the anonymity of the participants. To protect participants from being identified, demographic information was kept to a minimum and participants assigned an alphabetical code for reference. Participation in the study was voluntary and all participants were fully informed of the studies aims and purpose and were asked to sign a consent form confirming their understanding.

The participants were recruited from an ASD support group thus this it is recognised that this may have limited confidentiality to a degree as many of these groups interact. Thus it was be important to keep identifying information to be kept to a minimum and refrain from directly naming specific support groups involved. Should any participant experience any distress from the data collection process, he/she will have access to therapeutic services for further assessment and management.

CHAPTER FOUR

FINDINGS

4.1 INTRODUCTION

An analysis of the interviews revealed a number of significant themes which offer insights into the psychosocial experiences of parents of a child with ASD as well as the factors that impact family resilience and coping. Thematic analysis was conducted extensively with a multitude of themes emerging. In this chapter thematic content and relevant quotes (used as an example of the thematic area) will be presented. The chapter presents pre-diagnosis and post-diagnosis experiences within each main thematic area alongside each other allowing parallels to be drawn between the two. Table 4 indicates the order of the chapter, themes and subheadings.

Tables and figures will be used to visually represent the findings and for ease of understanding.

Table 4.1 Themes and subthemes identified

Life With Child Before Diagnosis	Life With Child After Diagnosis	Greatest Challenges before Diagnosis	Greatest Challenges After Diagnosis	Symptoms (before)	Symptoms (After)	Parenting Ability & Managing Child before Diagnosis	Parenting Ability & Managing Child After Diagnosis	Family Life With Child Prior To Diagnosis	Family Life With Child After Diagnosis	Social Life Changes & Adjustments before Diagnosis	Social Life Changes & Adjustments After Diagnosis
The Pattern Of Onset *Differences Early On Clear Marker Of Post-Immunisation Changes In The Child*	**Assessment & Diagnosis** *Smooth experience Feelings of uncertainty prior to a formal diagnosis Periods Of waiting Greater awareness and understanding of ASD leading to a diagnosis*	**Experience Of Child** *Struggle Due To Difference Confusion Disappointment Questioning The Self Guilt And Fear Loss*	**Consequences For Child Expectations** *Own Future Childs Academics/ Future*			**Parenting Ability**	**Renegotiating Expectations** *Of Parenting Approach Of Child*	**Parent Relationship**	**Parent Relationship** *Expectations Of Relationship "Not Normal" High Pressure On Parent Relationship Importance Of Spousal Support*	**Judgement**	**Judgement In Social Settings** *Judgement In Public Judgement-Extended Family Others Don't Understand Child's Interactions With Peers*
		Consequences For Child *Criticized Misinterpretation Of Behaviour As Purposeful/ Disobedient* **Experiences And Perceptions Of Professional Assessment** *Parental Concerns Dismissed*	**Experiences And Perceptions Of Professional Assessment** *Delayed Diagnosis Impacted Decisions Made Professional Feedback Professional Approach: Authoritative Professional Approach: Listening To Parents*			**Perception Of Self**	**Parenting Approach** *Child as Priority Parenting Team Aiming for Independence Overcompensating or Over-Protecting*	**Family Dynamic**	**Resources** *Availability & Accessibility Agency & Access Expensive Nature Of ASD Interventions*		

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Parental Perception Of The Child Without A Diagnosis	**Responses To Acquiring A Diagnosis** *Cues To Action* *A Sense Of Relief* *Acceptance Of The Diagnosis* *Feeling Hopeless* *Fear Based Reactions To Diagnosis*	*Lack Of Professional Experience* *Missed Signs* *Mis-Diagnosis* *Inadequate Assessment* *Unwilling To Diagnose* *Blame Placed On Parents/ Concerns Dismissed*	**Education/ Intervention** *Inappropriate Teachers* *Lack Of Appropriate Intervention* *Difficulty Accessing Education* *Lengths To Secure Education* *Home Based Intervention*	**Frustration**	**Renegotiation Of Parent Roles** *One Parent As More Prominent Care-Giver* *Trust In Spousal Care-Giving Role*	**Family Dynamics** *Family Roles* *Whole Life Revolves Around ASD* *Not Normal Acceptance* *Split To Manage* *Effect On The Family Members*	**Social Life** *Accepting Friends* *Effect Of Child's Behaviour On Family Social Life* *Invitations* *Restrictions On Family Activities* *Friends With Special Needs Children* *Lack Of Respite Care*
Perception Of Atypical Functioning				**Frustration Leading To Distress**	**Dealing With Frustration**	**Level Of Management** *Management Required And Family Input High Stakes*	
	Perception Of Child With Diagnosis	**Education/ Intervention** *Lack Of Diagnosis Impacting Possibility Of Appropriate Schooling* *Inappropriate Educators* *School Unable To Cope* *Children Unable To Cope*	**Facing The Future** *Future Concerns* *Fears About Future Care*		**Parental Emotions** *Guilt*	**Extant Consequences On Parents/Care-Giver**	
	Perception Of Choices And Sacrifices		**Expectations** *Own Future* *Childs Academics/ Future*		**Parent Emotions Put Aside**	**Sibling** *Sibling Relationship* *Parental Concern About Sibling* *Divided Attention* *Sibling Difficulties* *Sacrifices*	

4.2 LIFE WITH CHILD BEFORE DIAGNOSIS

When examining the interviews experiences of parents of a child with ASD, a key area of investigation included a description of life prior to diagnosis and the experiences parents encountered in relation to their child's state. The impact of not having a diagnosis to contextualise and understand the child's difficult or disruptive behaviour.

4.2.1 The pattern of onset

Findings suggest that although understandings of ASD and its causes vary, the participants responses split into two categories of "patterns of onset": a) Differences early on, and b) a clear marker of change in functioning.

4.2.1.1 Differences early on

For most of the parents interviewed there was an awareness of their child being 'different' from early on despite being unsure of the cause or reason. For these parents there was not necessarily a marker of 'before and after' (or ASD "onset").

Participant A, B, C and D all indicated that their children had been 'different' from early on however may have progressively worsened as they got older. Despite Participant B's children having different phenotypes and diagnostic 'pathways', both presented with their respective deficits from early on. In other words, there was no clear marker or onset for these children.

4.2.1.2 Clear marker of post-immunisation changes in the child.

Only one parent identified a clear marker of change in her child. She reported a clear "onset" of ASD occurring around 18 months' old- just after routine immunisations. Her experience of the onset was one of illness and hospitalisation with a clear change in and "disappearance" of the child she knew.

Participant E went on to describe her experience highlighting her despair.

Findings suggest two different experiences of the "onset" of ASD. One involving an awareness that their child's behaviour was atypical from early on while the second experience involves a period of illness and drastic change in the child's functioning.

4.2.2 Parental perception of the child without a diagnosis

Regarding pre-diagnosis perceptions, findings suggest that prior to diagnosis there was an overriding perception of the child as 'different' for all participants. However, the way in which this 'difference' was perceived varied amongst the participants.

One parent viewed this difference within the context of personality or family genes.

Participant D reported an awareness of this 'strangeness' however perceived her sons behaviour as typical childhood idiosyncrasies.

Participant A later reported that she did not view his behaviour as naughty.

Participant A and D reported viewing their child's differences in the context of personality or eccentricity.

Two participants reported struggling with understanding their children prior to diagnosis. For participant B, her experience of her oldest son's behaviour (B1) prior to diagnosis was somewhat different from that of her youngest child (B2) in terms of the phenotypes of each child and in turn the difficulties encountered.

Participant E described behaviour that was confusing and difficult to manage.

Some viewed this 'difference' in an idiosyncratic light while, for others, this difference had <u>negative</u> consequences in how the child was received or responded to. A common thread amongst the participants was that the lack of an identified reason or cause <u>of</u> the 'difference' in their child resulted in challenges when trying to understand the child's behaviour, despite attempts to do so, as well as impacting the parents emotional well-being.

4.2.3 Perception of atypical functioning

As discussed above- all of the parents realised their child's behaviour was atypical- either from early on or after a clear marker of change in their child's behaviour.

Findings suggest that prior to diagnosis, each parent had concerns about their child's functioning. One parent reported that although they didn't think anything was wrong initially, they were concerned about certain behaviours and so a recommendation from a family member led them to seek professional input.

Table 4.2 Themes and their subthemes identified with supporting quotes from participants regarding life with their child before diagnosis

Secondary theme	Subtheme	Supporting quote
The pattern of onset	Differences early on	You can always pick up there's something different. (Participant A)
	Clear marker of post-immunisation changes in the child	At 2 years he started to lose everything. He had everything- talk, everything, everything, everything, and then he started to lose everything. (Participant E)
		At 18 months, injections on 18 months… that night we were at Hospital E casualty he had fits. Then they said its fever because of the mmr and the polio (injections) and things. So i gave him the mumps, measles, rubella (injections) together and the polio because my eldest daughter had it like that so… so, he developed a fever and then we took him there and then um, get fits, get something for the fever and then he started with vomiting and nausea and the doctor said we think it's the polio drops with the immunisations. This just irritate his bowels, but the vomiting and the diarrhoea was severe, so he was admitted for three days for that... Treated with antibiotics and then sent home... And since he's been home he's stopped... When he came out he just lays there… but he lied there and he there… then spin… it was 18 months… by 2 years old child E was gone…(Participant E)
Parental perception of the child without a diagnosis		So i always knew he was different, but like i say we just thought it was part of the family genes that's how we are…(Participant A)
		So it was, nothing was really picked up except that he, some of his behaviour was very different from the other kids that were around him. (Participant C)
		…and little kids are strange anyway… you now the weird behaviours, socially inappropriate whatever, you know all of that... So how do you, its very hard to judge…(Participant D)
		I know he's not naughty he just doesn't know how to handle different situations.(Participant A)
		We always just thought he, he was, he had a funny personality, was eccentric, the professionals that worked with him never gave me any reason to think otherwise. (Participant A)

		So ya i just think he's an easier kid to deal with and were just lucky… and you don't choose i've got friends with very difficult children… i don't know we just feel quite lucky… and he's just like this happy cheerful little… eccentric little bit of a nutter and we just kind of.. It's very sweet .(Participant D)
		[regarding her oldest son: B 1] um when he was 11, 12, i said to my husband um i didn't… there are nights that i feel like i need to lock my bedroom door because we could be living with an axe murderer. That's how little we knew about this human being. He was just a complete enigma… [regarding her youngest son: B 2] the biggest issue was behaviour- he was like a little wild monkey that just he, he, he either had to fight or he had to run, he bolted he would disappear, and he would run, it didn't matter where we went- he would run. So it was nerve-wracking because [of] safety. (Participant B)
		Don't know, open the fridge, throw the things out, back. You don't know. You don't know why they crying. They crying you don't know why. We up and down. By the doctors. We give this we give… you don't know, you don't, "you have pain?" You just don't know, the child is crying, the child is moaning... And he's 'mos' busy. Hyperactive and, and um… he wants to do what he wants to do. And there's no way… there's not that communication at all. You can't bond. I felt that i felt that it was like an animal in the house a pest. That doesn't understand, when i talk to him he's like just there… (Participant E)
Perception of atypical functioning		Ok, things that you realise- this is not normal, you try not argue that way but you say "none of the other kids does this, there must be something that we missing". (Participant A)
		Geez, like before autism… you know um i think … with child b 1 we always knew something was wrong. (Participant B)
		Cos he wouldn't interact with anybody, he wouldn't interact with the children… and because was anxious he would just walk in circles on the playground flapping… so they immediately 'no-this is definitely not typical'. (Participant D)

4.3 LIFE WITH CHILD AFTER DIAGNOSIS

4.3.1 Assessment and diagnosis

The process of diagnosis varied for each of the participants. Age at diagnosis ranged from 2 years old to 16 years old. The new DSM-5 diagnostic category indicates that all the participants' children fall under the umbrella name of Autism Spectrum Disorder however the children received diagnoses prior to this change and so the parents reported using the previous categories, therefore the parents reference points were used in the discussion below. Three children fall under the previous category of "Aspergers", two in the "Autism" category- one of which was described as "severe" and one in the "Pervasive Developmental Disorder" category.

The pathway to diagnosis was unique for each family however there were commonalities that stood out. An experience that every participant reported was having seen multiple healthcare professionals before receiving a diagnosis, which included paediatricians, developmental paediatricians, paediatric neurologists, occupational therapists, speech therapists, and multi-disciplinary teams.

The process for most parents was a difficult and frustrating one during which parents reported feeling alone and desperate- trying as many avenues as possible to obtain the assistance they needed while attempting to cope with their child's behaviour and difficulties.

4.3.1.1 "Smooth experience"

Only one parent, Participant D, described the diagnosis process as a "*smooth experience*", reporting "*we've just been lucky, we've had a textbook good, positive experience*". Within two weeks of starting at a private preschool, a concern was raised about her child's functioning and, within a short period of time, her son was diagnosed and working with a facilitator. This was however after having been assessed two years prior by a paediatric neurologist who missed the diagnosis.

4.3.1.2 Feelings of uncertainty prior to a formal diagnosis

Participant E reported frustration and an experience filled with desperation. Within the space of six months her family's medical aid resources were depleted after attempts to access assistance for her son- without receiving confirmation of a diagnosis. Themes emerging from her son's diagnostic process were that of uncertainty and 'waiting'.

This sentiment was mirrored by a number of other participants who reported a sense of uncertainty in response to a lack of answers or direction from the professionals they sought guidance from.

4.3.1.3 Periods of waiting

Although the length varied, all the participants reported encountering waiting periods.

Participant C also reported a waiting period before an assessment appointment would be available. Participant C's child was seen by multiple health care professionals but only diagnosed after a full week long multi-disciplinary assessment done by a school for children with ASD in Cape Town.

4.3.1.4 Greater awareness and understanding of ASD leading to a diagnosis

For Participant D and her husband, their response to the diagnosis of their youngest son was to engage in research about ASD, which in turn led to the diagnosis of her eldest son.

4.3.2 Responses to acquiring a diagnosis

A significant aspect of the experiences of parents of a child with ASD is the acquiring of a diagnosis. The findings suggest that a diagnosis brought with it emotional and behavioural responses from all the participants. For many of these parents, a diagnosis that accurately represented their child had evaded them for a lengthy period of time and so understandably brought with it strong reactions.

4.3.2.1 Cues to action

Findings emerged regarding the parent's behavioural responses to the diagnosis indicating different problem-solving behaviours and possibly different coping mechanisms.

The findings suggest that the parents all had fairly active approaches when responding to the diagnosis. One aspect that was evident was the need to learn and understand for themselves what the diagnosis meant- this also highlights the insight that this responsibility fell on them alone.

4.3.2.2 A sense of relief

When examining psychosocial experiences of parents of a child with ASD, the emotional and psychological experience of receiving a diagnosis for their child emerged as an important factor

to explore. The findings suggest that for most, a sense of relief was experienced with diagnosis. This relief may relate to many aspects of receiving a diagnosis and its implications, but of note were the following responses:

Another parent reported relief for herself but also for her child especially regarding how others had perceived his behaviour. The findings also show the impact of these parents feeling heard and attended to by the healthcare professionals they turn to for guidance.

Another parent's experience of relief was related to understanding her son, something which previously had been a challenge.

The findings indicate that for these parents, the receiving of a diagnosis for their child meant that their concerns were being acknowledged and in turn, their parenting was not necessarily the problem and that their child's difficulties were recognised- validating the parental experiences and concerns.

4.3.2.3 Acceptance of the diagnosis

One parent reported that her and her husband responded with acceptance and an openness to guidance informing the next steps.

4.3.2.4 Feeling hopeless

Participant E had two experiences of her son's diagnosis at two different schools with very different perceptions of these interactions. School E 1's interaction with this parent, appeared to leave her in a further state of distress and desperation, after she received what she perceived to be feedback of hopelessness regarding her child's future and functioning.

Her experience of the "relief" that was expressed by the other parents was delayed and impeded by diagnostic feedback that appeared bleak and hopeless with few solutions in it but rather a dismissive comment of "*no you need to be realistic you need to be, you know*". The response she received triggered further desperation and fear rather than providing comfort or guidance.

The second experience for this parent was completely different and thus she continued with them. Her experience and response to the diagnosis from them may have been different because from her reports they made her feel heard and responded to, giving her a sense of hope for her child. Her sense of relief was delayed to after the diagnosis- only once professionals approached her child with solutions and dynamic avenues of intervention.

4.3.2.5 Fear based reactions to diagnosis

Participant C who reported some relief also reported initial confusion and a sense of fear regarding the diagnosis of her son.

4.3.3 Perception of child with diagnosis

After receiving a diagnosis, one parent reported that for her and her husband the perception of her children and their role as parents shifted.

In the context of having a diagnosis, one parent felt validated in her perception that her child wasn't naughty while others reported feeling that having a child with ASD was a privilege.

Two parents perceived their child's ASD as a privilege that provided a unique perspective compared to neurotypical perspectives.

A number of parents mentioned their perception of their child as 'happy'. Participant D gave a quirky description of her sons Aspergers traits.

This parent also acknowledged that her child may be perceived differently outside of the environment they had set up for him.

4.3.4 Perception of choices and sacrifices

Parents reported a sense of contentment when reflecting on their choices and sacrifices they had to make for their child.

After acquiring a diagnosis parents reported a variety of responses including a sense of relief and acceptance, as well as a need to seek further information. For some parents, the feedback they received was perceived as hopeless. Parents also reported how having a diagnosis changed their perception of their child and in turn their choices.

Secondary theme	Subtheme	Supporting quote
Assessment and diagnosis	Smooth experience	So first of all he was at a preschool, where they, a very nice montessori preschool where , really good preschool, where they picked up very quickly that there was something up… and they spoke to us and then because they were so keen on being inclusive they we were juts lovely aaand we actually had a facilitator for him up until grade r because they do a grade R there… And so he started off in his own classroom… and by grade r, he was with a facilitator but with the group… we went from this loving caring environment… had like a very smoooth sort of experience… ya! We've just been lucky, we've had a text book good positive experience. (Participant D)
	Feelings of uncertainty prior to a formal diagnosis	I want like the whole MDT team there. I'm tired of running around like this…and then um we went there... It was the 21st September 2006, they gave us the diagnosis that he might be on the autistic spectrum… and then the one doctor told me about school E 2, so we went to school E 2 for the assessment and they said well he is autistic.(Participant E)
	Periods of waiting	We went [to] the neurologist they suggested, i mean there was like a three month waiting list so... We had to wait three months. (Participant D)
		So then we had the assessment at school E 1 which was about 8 months away, waiting for us to confirm the diagnosis and then we must go for the 2 weeks evaluation… in the mean time we had behaviour… he was running around… climbing bins, no awareness of us... (Participant E)
	Greater awareness and understanding of ASD leading to a diagnosis	Child B 2 was 3 when he was diagnosed and then obviously the first thing- my husband and i are people that need to be empowered with info- so we jumped on to the internet and just learnt as much as we could and as we were learning about autism the red flags started going up regarding child B 1 and we had no… he, he at that time was 15. And then we had him formally diagnosed at 16. (Participant B)

Table 4.3 Themes and their subthemes identified with supporting quotes from participants life with child after diagnosis

Responses to acquiring a diagnosis	Cues to action	I read up a lot… a lot of facebook groups. I try keep it to the more humorous side of things. See the positive side of things so ya. (Participant A)
		The first thing, my husband and i are people that need to be empowered with info, so we jumped in to the internet and just learnt as much as we could... So when you get a diagnosis that's when you start realising there's nothing you could have done differently and then you know it's, it's the knowledge that comes and you need to understand, more and more understanding… (Participant B)
		We very lucky we haven't had to go through… neither of us have been in denial we both been on board you know! (Participant D)
	A sense of relief	…and then yooou… get a diagnosis. And the first thing that happens… when you get that diagnosis- guilt goes away. Because you know this is not my fault. I did nothing wrong. This is literally a combination of genetic, situations, this was, you know, the soil was ripe for this developmental difference and it happened. And that's the, that's, you literally as a parent, sigh relief and say ok this is not my fault. (Participant B)
		For one i was very relieved. I'm so glad someone is acknowledging something. There nothing wrong with him it's actually a name attached to him. He's not being naughty or difficult or immature. He's reaaally struggling. So ya it was a great relief for me and so we could move forward. (Participant A)
		Um it was a bit of a relief ya! Because i'd, we'd kind of wondered why this behaviour or that behaviour… but we'd never really done any reading up on it because we didn't know…uh you know if we'd known it was autism we would have read up on it... But we didn't know why he was doing what he was doing… so we didn't ask anybody… (Participant C)
	Acceptance of the diagnosis	Neither of us have been in denial so we've accepted it so we've rolled with it. (Participant D)
	Feeling hopeless	First of all, i told them my child is 2 years and you're diagnosing him with a life-long disability with no cure and you telling me there's no hope… i again and again and again said that you can't give up on him, he's 2 years old, nobody's trying, nobody's even trying to help him, it's like its doomed that's it, he'll never talk…he's severely mentally retarded, severely autistic on the spectrum…they draw the whole spectrum and there he (is) 'classic

		autistic'. And here's asperger's and there's high functioning and there he 'theeerrre' at the bottom. So, um and then our search begin and we came to school S. (Participant E)
	Fear based reactions to diagnosis	So, then they said to us that Child C has a PDD and my husband and i just looked at each other and said what is that?…it was quite, if i think about it now, i think it was quite frightening to hear the diagnosis and then to realise ok this is autism… or what is that… and to start trying to find out without the internet… (Participant C)
Perception of child with diagnosis		Both [husband] and i, we often have those conversations you know um and its very clear there's a very strong indicator that the two of us should not have had children. Back then that's what we thought. Now that we don't see our kids as broken anymore um, we don't regret having kids. (Participant B)
		He's not being naughty or difficult or immature. He's reaaally struggling. (Participant A)
		And the americans also have a strong um movement towards you not accepting but fixing it- [as if] it's something that needs to be cured something that needs to be remedied, instead of saying you know this is just different form of, just a different [way of thinking] just a different development of the brain different you know um type of person and um, so a lot of the neurotypical guys are not doing a good job of running this planet so…. You know um being neurotypical is not necessarily the best thing out there. (Participant B)
		But a lot of the time so think that we privileged in the sense to have his brain and how he looks at life in our house. People with neurotypical children and neurotypical life and things um i feel miss out. Because there's a lot to learn and there's a lot of um wow moments. I think i always… that if it was duty to teach child e about the world and to educate him and so but you know what as you grow older as you see other children then you realise actually how much can they actually learn from him! How much people can learn from him… (Participant E)
		I don't know i i feel like were very lucky because… hmmm... And he's at a special needs school i, i see people, i've got to know a lot of the moms and their kids are worse off than we are... (Participant D)
		My love for him is so massive, he cannot do anything wrong you knows (laughs). I just adore him so much! And i think to myself my relationship with him would've been different, very different and, and i dont know if i wanted it any different, he really and truly is he is absolutely the love of my life… he's just, just the most adorable thing. There was a time where i couldn't say two words about him without crying because i just i get so overwhelmed with him! (Participant B)

		So in some ways it's not great but in other ways he's just like this really happy cheerful person. So he's just like this happy cheerful little boy and hes your stereotypical 'aspy' so he's like a mad scientist. (Participant D)
		But i sometimes, when we… out of our comfort zone i realise ya man he's, he's a lot stranger than i realise day to day!! (Participant D)
Perception of choices and sacrifices		It's a full-time thing. But to be quite honest i have no regrets when it comes with child e. As the choices i made. If i look at him today and where he was… 10 years ago i would have done it all over. (Participant E)

4.4 GREATEST CHALLENGES MANAGING CHILD PRIOR TO DIAGNOSIS

Parents reported on the experiences, thoughts, behaviours and reactions that lead feelings of distress or helplessness prior to diagnosis. Parents also reported on the process/processes they undertook to assist in developing some understanding of the situation with their child.

4.4.1 Parental experience of the child

Parents reported on their experiences of their child without a diagnosis. Some parents reported their awareness that their child had difficulty coping sue to their differences. Parents reported experiencing their child's behavior with confusion, at times fear and a sense of loss. Two parents reported distressing experiences of disappointment and internal self-doubt.
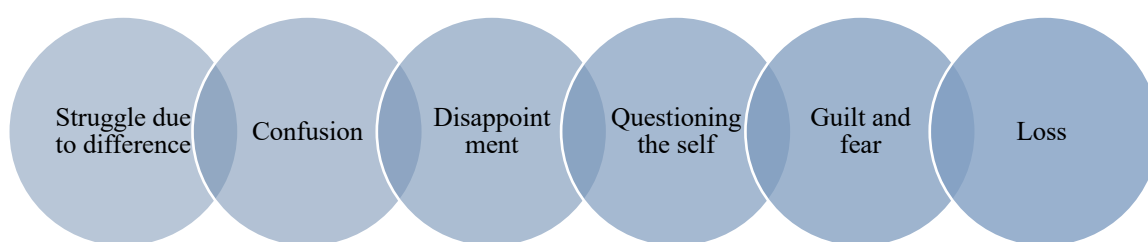
Figure 4. Summary of subthemes: Parent experience of child

4.4.2 Consequences for child

Parents reported that the disruptive and often confusing behaviour that their children presented with was often misinterpreted and in turn, responded to negatively.

4.4.2.1 Criticized

One parent reported how without a diagnosis, her child was perceived as inaccessible and unreceptive to her parenting.

Regarding her oldest son (B1):

4.4.2.2 Misinterpretation of behaviour as purposeful/ disobedient

The same participant also reported that often the child's behavior was interpreted as willfully disobedient or defiant. This was mirrored by other participants.

4.4.3 Experiences and perceptions of professional assessment

In exploring the experience of parents prior to an ASD diagnosis, a common theme emerged regarding professionals and clinicians who missed the ASD indicators in the children of the parents in this study. Parents reports suggest that, in retrospect, their child's symptoms or characteristics were clearly indicative of ASD traits however this was missed by the multiple healthcare professionals consulted. Another aspect to note within this, is that each parent took their child to see *multiple* professionals without receiving clear answers or direction. This appears to be a factor that clearly increased distress and desperation in the parents as they sought answers as well as assistance.

4.4.3.1 Parental concerns dismissed

Parent reports indicate that they felt their concerns were dismissed by the health care professionals they sought assistance and guidance from.

As described above, Participant E reported her experience of her son becoming severely ill after immunisations and their multiple trips to the hospital. Her distress and concern for her child were clear however her perception is that they were dismissed or minimised.

4.4.3.2 Lack of professional experience

Parent perception of health care professionals was that they lacked professional experience and knowledge of ASD and the professional ability to assess and diagnose accurately.

4.4.3.3 Missed signs

Parents also reported that they felt professionals missed significant signs of ASD.

4.4.3.4 Mis-diagnosis

Parents reported multiple diagnoses for their children. One parent discussed her perception of the impact of this.

When participant E's concerns where not addressed or responded to she was sent home. When eventually there was an even greater concern, her apprehensions were again minimised with a report of a "slight developmental delay" and later a second misdiagnosis was given suggesting behavioural problems due to poor parenting ability, both of which turned out to be severe ASD.

4.4.3.5 Inadequate assessment

Parents discussed their perceptions of the assessments conducted by health care professionals-indicating that they felt the assessments were inadequate and lacking in professional understanding.

4.4.3.6 Unwilling to diagnose

One parent described her experience overseas and reported that she perceived the health care professional as reluctant to diagnose her child.

4.4.3.7 Blame placed on parents/ concerns dismissed

One parent reported that a health care professional overlooked symptoms of ASD and instead alluded to poor parenting ability as the cause for her child's behavioural difficulties.

This experience of not getting answers and of professionals who are apparently missing clear indicators was a key factor in parent distress in this study.

4.4.4 Education/intervention

According to these parents, a lack of a diagnosis acted as a barrier to accessing appropriate education and intervention.

4.4.4.1 Lack of diagnosis impacting possibility of appropriate schooling

One parent reported that without a diagnosis it was impossible to accommodate her child as they lacked an understanding or direction of the child's needs.

4.4.4.2 Inappropriate educators

One parent discussed the difficulty of a teacher who was inappropriately suited to teaching her child.

4.4.4.3 School unable to cope

One major theme emerging was the schools inability to cope with the child's disruptive behaviour and the supports parents had to implement in response.

4.4.4.4 Children unable to cope

Importantly, one parent highlighted her child's difficulty coping in a school that was not catering for his needs.

Parents faced several distressing experiences while attempting to manage their child prior to a diagnosis including difficult internal dynamics, distressing interactions in their attempts to seek assistance and their awareness of the impact on their child.

Table 4.4 Themes and their subthemes identified with supporting quotes from participants regarding greatest challenges managing child prior to diagnosis

Secondary theme	Subtheme	Supporting quote
Experience of child	Struggle due to difference	For me it was normal, it's all I knew he's the only child but it was a struggle because he was always different, you can always pick up there's something different. (Participant A)
	Confusion	We couldn't really work out but he would be upset. (Participant C)
		The fact that you don't know what's going (on) in your - our family members nothing you see your child is different and everybody is saying ugly. (Participant E)
	Disappointment	Where I, I looked at this child and thought you know what, um, this is the biggest… disappointment that I've ever had in my life. This child is nothing like how I planned and hoped for him to be…and then and then to have your second child and your third child turns out (a similar diagnosis)… so there's a great sense of loss and great sense of disappointment. (Participant B)
		This is not what I wanted for my child… (Participant E)
	Questioning the self	And I just got lots of questions why my child why this we give everything, I'm not drinking, I'm not smoking you know and… I get this. What did I do to get a child like this? (Participant E)
		I think from a certain perspective you um… that self-loathing and that that disappointment is not with the child, it's with yourself. Because you created something that's broken aaand you must've done something wrong. These things don't just happen…(Participant B)
	Guilt and fear	With Child B 1 - we always felt that we were failing him and we always felt guilty and we were parenting from very much guilt perspective, but the thing is also not understanding him made us scared of him we ended up fearing him because we didn't know him, we didn't know who he was.(Participant B)
	Loss	But he lied there and he there… then spin… it was 18 months… by 2 years old Child E was gone… (Participant E)

Consequences for child	Criticized	Regarding her oldest son (B1): ...and because we didn't have the tools to access his personality or to draw him out and he always ended up being um attacked and, and um criticised and dogged on. It just changed who he was and who he is and it's taken a lot of time (to address), it's taken a lot. (Participant B)
	Misinterpretation of behaviour as purposeful/ disobedient	That type of thing, that was the biggest issue because you, you, and then also you start thinking um he's doing it on purpose and you start blaming and that type of thing…(Participant B)
Experiences and perceptions of professional assessment	Parental concerns dismissed	So, so we, we suspected something but, but then after seeing this neurologist we were like uh ok fine, fine… stereotypy its nothing! (Participant D)
		When he came out, he just lays there, so the paediatrician said he may have a slight developmental delay now because he was severely ill… and things like that so we "must just be patient". (Participant E)
	Lack of professional experience	I think the guy wasn't experienced enough with autism and didn't know what he was talking orrr he felt maybe that autism was over diagnosed… I dont know what his thing was uhm he was an older guy and maybe he just hadn't seen enough autism… because subsequently reading and stuff, I think that someone experienced would have picked it up…and this neurologist we took him to- paediatric neurologist- didn't know what he was talking about.(Participant D)
	Missed signs	Ya, no… and we've been to therapists and you know who and no one ever picked up. The OT, we say her about a year or two after diagnosis, and she like…we told her diagnosed…And…totally missed it. (Participant A)
		But nobody could ever pin point what was wrong… and this is the thing, doesn't matter what we did as parents, we went to see everyone. (Participant B)
		He did say "look if you look up the flapping stereotypy like on Wikipedia you'll immediately see autism… but some of that is out of date- so you could have a stereotypy without him being autistic…" (Participant D)

	Mis-diagnosis	And this is the thing, doesn't matter what we did as parents, we went to see everyone- I had him at a speech therapist when he was tiny and, and, you know this is what's frustrating is the service delivery from professionals. There is just some little (improvement), it's getting better, and in general there's so many misdiagnoses… Um and I think that was the biggest thing that we missed when we took A to all these professionals and that was the major concern and major problem, and is till find it today, I see so many kids in school that are labelled ADHD, um hyperactive whatever and in actual fact, those kids are so totally on the spectrum and they've been misdiagnosed and they struggle their entire lives not knowing what's wrong with them. (Participant B)
	Inadequate assessment	Just to kind of get him assessed anyway at the age of 5 and uh so we, we took my mom-in-laws advice and took him along to Dr C at the Hospital C: "uuuh I could get Child C to kick a ball but I don't have one handy" and we were paying 450 rand!... Paying all that money and he wasn't doing the tests he should have... aaand he didn't have answers for any of that! ummm and he wrote a little... he took a Dictaphone and he did a report and he, he got it typed up and sent to us… and it didn't say anything about Pervasive Developmental Disorder or anything. Certainly nothing about autism. (Participant C)
		But if the guy had done a few more almost like… tests he may have spotted the symptoms/hints… (Participant D)
	Unwilling to diagnose	So, it would have been nice to know… uhm… and maybe he did see something but… because of the different culture there… where everybody is like covering their asses and worried about being sued… maybe he didn't see it or maybe he… uhm… maybe he thought "you know these things will come out in time… don't worry the mother unnecessarily…" I don't know! Uh, I would have like to have known earlier I think...(Participant D)
	Blame placed on parents/ concerns dismissed	Paediatrician did a hearing test so we start with a hearing test, ENT and things like that did the hearing test: "no (it's) behavioural, behavioural problems" so we went for parental guidance to do this and um… basically just said that we… as parents don't know how to um… put down the rules and things because he just breaked everything…(Participant E)

Education/ intervention	Lack of diagnosis impacting possibility of appropriate schooling	Nothing ever is the right (option), because you don't know how to educate, you don't know how to present info for this child to learn, because you don't know what's wrong". (Participant B)
	Inappropriate educators	I think um he was in mainstream until grade 2. And um the teacher he was in class with who was a 60 year old who's husband was deaf so she was loud , She was very…And so totally against what makes him comfortable so I think there was a lot of damage done. (Participant A)
	School unable to cope	We had to wait three months, I dunno how I cant remember I think we may have organised a facilitator for him before then so that they cos. They couldn't… couldn't really manage with him I think… Its not that they couldn't manage him, its just that it was hard to co-to supervise him and other kids cos he was just on his own mission… I dunno…i think. (Participant D)
		To have Child B1 in a school it was always frustrating um he just ya and with Child B 2 we couldn't put him in a -this before diagnosis? - doesn't matter where we took him to whatever preschool he wouldn't last a morning and he would phone me and say please come fetch this boy.
		So that was a big deal with both of them is to find a place. Now if you a working parent what are you going do with your kids?! You have to put them in a creche you have to put them in a day care you have to put them in school and if schools turn around and say listen we don't know how to deal with your child take him away. What are you going to do? (Participant B)
	Children unable to cope	When he started going to school he was just not grasping work and was being left behind a lot of the time. (Participant B)

4.5 GREATEST CHALLENGES MANAGING CHILD AFTER DIAGNOSIS

Parents reports suggest that some of the thoughts, behaviours, reactions and experiences that led to feelings of distress/ helplessness after diagnosis of their child included understanding the consequences of a diagnosis for their child, their experiences and perceptions of professional assessments and facing barriers to education and intervention. After diagnosis, parents also faced concerns about the future of their child and family as well as having to adjust their expectations for both.

4.5.1 Consequences for child

Findings suggest that only once there was a confirmed diagnosis, were parents able to fully grasp the impact of a late or missed diagnosis.

Participant B highlighted the differences between a relatively early diagnosis and a delayed diagnosis.

4.5.2 Experiences and perceptions of professional assessment

Parents reported their experiences and perceptions of professional assessments during the process of acquiring a diagnosis. These included an awareness of the impact of previous delays as well as parent perceptions of the feedback provided by health care professionals.

4.5.2.1 Delayed diagnosis impacted decisions made

One parent highlighted the impact that not having a diagnosis made on her family's decisions.

4.5.2.2 Professional feedback

Two parents discussed their perceptions of the feedback provided. Both parents felt that the health care professionals provided feedback which suggested that they perceived the situation negatively.

Participant E indicated that she still attended her assessment at the initial school, where she received what she perceived to be feedback of hopelessness regarding her child's future and functioning.

4.5.2.3 Professional approach: authoritative

One parent discussed the perception of the health care professionals approach as authoritative.

4.5.2.3 Professional approach: listening to parents

The same parent also felt that professionals who listened had a positive impact on her experience.

4.5.3 Education/ intervention

After acquiring a diagnosis, accessing appropriate and suitable education continued to be a challenge for parents and their children.

4.5.3.1 Inappropriate teachers

One parent mentioned difficulties with an unsuitable teacher who had a poor understanding of ASD. She also reported on her experience in resolving the issue with the school.

4.5.3.2 Lack of appropriate intervention

Parents also reported on the lack of available interventions suited to their child's needs.

4.5.3.3 Difficulty accessing education

Parents reported facing numerous difficulties attempting to access education for their child.

4.5.3.4 Lengths to secure education

A quote from one parent highlighted the lengths parents were willing to go to in order to access appropriate schooling and intervention for their child.

4.5.3.5 Home based intervention

Ensuring that their child received appropriate education emerged as a prominent theme within the transcribed interviews. The findings indicated that parents ensured this through long processes of attempting to source appropriate intervention and eventually either doing it themselves or by actively making sure funding continued so that the child's school could function. Initially prior to diagnosis, participant E implemented her own interventions due to financial constraints. Participant A and B both implemented their own educational interventions for their children.

Two parents reported turning to home-schooling their children while another parent reported ensuring the continuation of her son's school through fundraising. Thus, this was another aspect that filled their daily lives.

4.5.4 Facing the Future

One of the greatest challenges parents reported was their fears and concerns for the future of their child.

4.5.4.1 Future concerns

Future concerns reported by parents revolved around whether their child would cope without them and their concerns about their ability to continue to provide for their child.

4.5.4.1 Fears about future care

Many parents reported their concerns developing into fears for their child's future and their future care.

4.5.5 Expectations

Changes in expectations was notable in each parent's story and experiences. The life, family and future they had envisioned completely shifted and radically changed with a child diagnosed with ASD.

4.5.5.1 Own future

Parents reported changes in their expectations of their own futures including career paths and retirement. They discussed the impact having a child with ASD had on their future expectations.

4.5.5.2 Childs academics/ future

Parents also discussed the need to adapt and adjust their expectations of their child's functioning and academic ability. One parent indicated that for her, academics became less of a priority while her child's sense of self and happiness became more important.

Secondary theme	Subtheme	Supporting quote
Consequences for child		Child B 1 not receiving the right intervention from a very young age they way that Child B 2 has, his um disabilities or not disability, not the right word, his deficits are much bigger… than Child B 2 and his depression and anxiety is much more acute because of the fact that by the time, when he was diagnosed he's a teenager and um everything that goes with that, and it's damage. There's 16 years of damage that needs to be rectified and you can't just do that over-night. Whereas Child B 2 has lived Child B 2 has been in the position where autism has just um it's like having blue eyes or brown eyes, it's like having or like having big feet or small feet to him it's characteristic if who is. (Participant B)
Experiences and perceptions of professional assessment	Delayed diagnosis impacted decisions made	Because I think he was wrong… also we were living in the US at the time.. and we may have made a different decision about moving back here or not.. so it would have been nice to know… uhm… and maybe he did see something but… because f the different culture there… where everybody is like covering their assess and worried about being sued… maybe he didn't see it or maybe he… uhm… maybe he thought "you know these things will come out in time… don't worry the mother unnecessarily…" I don't know! Uh I would have like to have known earlier I think… (Participant D)
	Professional feedback	Ya you have to change… because clinicians also treat your child as if something is wrong and something needs to be fixed. (Participant B)
		And I still got my School E 1 appointment for my two weeks there, I didn't like what I see there, I had lots of arguments with a lot of therapists because the more they tell me that he is mentally retarded, the more I believe that he isn't… First of all, I told them my child is 2 years and you're diagnosing him with a life-long disability with no cure and you telling me there's no hope. They, they not even going the route, I said this is what I wanted, they like 'no you need to be realistic you need to be, you know'. (Participant E)

Table 4.5 Themes and their subthemes identified with supporting quotes from participants regarding greatest challenges managing child after diagnosis

	Professional approach: authoritative	There's a lot of psychiatrists that um I don't know if you know the one psychologist… we had like a major arguments and I think people those days was still like… they tell you what to do and the expect to, to take that advice if you don't take our advice then we not gonna help you. (Participant E)
	Professional approach: listening to parents	To listen. People and in the medical field, I see that every day. They not tolerant. They can't wait it's a quick fix it's… um so um… that is constant, constant worry. And I'm very worried when he's 14 he's 13 now…who's gonna look after him because she was the only one that listened to me. And um, when, respected my choice and still treated me. (Participant E)
Education/ intervention	Inappropriate teachers	We had one year at School D where they had a completely inexperienced and unqualified teacher and we got… um our sons psychologist to do a classroom observation and she wrote a report and then I was angry… they quickly realise she didn't know what she was doing... more than half the class were boys on the spectrum and she didn't understand what autism was and like sensory issues… like when I came to the classroom it was a cluttered mess… Like visually just totally cluttered… the school handled it quite badly and unprofessional uhm… and we contemplated removing him; um so they knew her even though she was our psychologist and WE called her in and I paid for it! Then they were all upset when she released the report to us! And I'm like im paying for it, she's working for me, I get the report you get a copy of but ya know. (Participant D)
	Lack of appropriate intervention	Um, so that was the biggest thing is education um because that is one of the basic rights that children have is to be educated and if you have a system that doesn't cater for them or understand the way that they learn then you have a problem. (Participant B)
		It wasn't like tailor made for you what your needs they didn't hear what I'm telling or asking them, what I want, they just tell told me this and this and this, this must be done and that wasn't right. (Participant E)
	Difficulty accessing education	After receiving an additional diagnosis of "Pathological Demand Avoidance": So um as soon as that was diagnosed then School C2 said they cant cope (Participant A)
		And this is what we found is there are [is] nobody, there are no services, the schools that are out there are so expensive parents cant afford it people/ parents have to bond their houses to afford it stuff like that. (Participant B)

		And then Child E was 5… 6 and then he needed to go to school and then the same battle... for months I had to hang around department of education, I was in… provincial… I was everywhere. Also, every year I build a class for him… (Participant E)
	Lengths to secure education	Because the only reason Child E is there is because I promised them I will give him a class just give me grounds. I will set up the class/ so you know… if I don't do it then my child is not gonna have a class next year. (Participant E)
	Home based intervention	After attending a homeschooling centre for a short period-- So um ya about three weeks in to the third terms. We said ok no this is not going to work for him. Forced to start home schooling. So we started ok home-schooling and for me it was just its been a rough year until now. I don't really care- as long as he passes English, Afrikaans and Maths. Its ok. (Participant A)
		And that's why we are very much you know this is my child I have the best intentions and the best ability to understand and educate my kid and that's why I'll do it myself. (Participant B)
		And that was just twice a week that was all that we could afford. But what we did, we just went in, get a home program, came home and did the program at home. (Participant E)
Facing the future	Future concerns	The future and will he able to cope on his own? (Participant A)
		He's like a lot weirder than I sometimes realise and then when I realise that I feel sad and very very anxious- is he gonna be ok as an adult? And the problem is the older you get- he's cute now- but the older you get the less, less appropriate, when you've got a tall big strapping boy who is… emotionally two to three years behind his peers and just completely strange and uhm… (Participant D)
		There's a lot of as a parent, every single day you don't pray for money you don't pray for whatever you just pray that god gives you a good health for many years so that you can be there can work for your child. (Participant E)
	Fears about future care	I tend to overreact to school things because I like am projecting into the future… like if you don't start this out now… you know what I mean… so not relaxed. I think that's the biggest thing... you projecting into the future… (Participant D)

		Who's gonna look after him? So that is the reality that you going to get every day. And think if something happens to you tomorrow what's gonna happen to this child? Is somebody gonna understand him? is he gonna end up in a mental institution that is your biggest worry. Every night. Is somebody gonna understand him? Will they know what he wants? When he have a tantrum or things will they know why? Or will they just take…take him gun him down give him some benzos and make him sleep or antipsychotics too. Will they listen to him? Cos' he can actually say what he wants but it takes a whole to calm him down to get his anxiety levels down… (Participant E)
Expectations	Own future	That's… you don't see retiring at early age, 45… everybody's talking around the table… "oooh my kinders is nou klaar leer en studeer ek kan nou aftree" that's not in your world. You gonna work till 56-65! To make sure there a medical aid and then there is provision for your child… there's no early retirements. There's no um when we old we gonna tour and we gonna go on this... Who's gonna look after him? It's not fair. I say I love Child E but he's my prison. Hes our prison. (Participant E)
	Childs academics/ future	Feeling so bad about himself. He would be upset about something and start crying and for a 12 year kid t cry in class they don't accept that for them it's like So he and a really bad self-esteem when we took him and we started home schooling him for me it was getting him in a place …Academics was secondary at that stage. (Participant A)

4.6 PARTICULAR SYMPTOM/S OR EXPERIENCE/S THAT WERE DIFFICULT TO UNDERSTAND PRIOR TO DIAGNOSIS

Parents reported several symptoms that they found difficult to understand and manage prior to diagnosis. these included impulsivity, sensory issues, communication difficulties and obsessions.

Parent reports indicate multiple symptoms or behaviours that, prior to diagnosis (which may have provided context), were difficult to understand and in turn distressing for parents. These included 'typical' ASD symptoms as well as those that are not central symptoms and those compounded by co-morbid diagnoses.

Table 4.6 Themes and their subthemes identified with supporting quotes from participants regarding greatest challenges managing child after diagnosis

Symptom	Supporting quote
Joint attention	And it was because he wasn't showing … subsequently reading and watching video clips, like there's this thing where kids have joint attention.. He wasn't exhibiting that, but of course I wouldn't know that… (Participant D)
Missed milestones of development	The only thing was- but obviously I didn't know this- is that all the other kids by the age of 2 and a half... They would have snack time and all the other kids could sit still and eat their snack… he never seemed to get it. It took him till just before we left to finally figure out that he must sit down at snack… or just like, and be compliant… I think he just just didn't have any idea what was going on … (Participant D)
Meltdowns	Where Child B 2 um melts down and it's a very external experience where Child B1's experience is very internal (Participant B)
	As he got a little bit beyond that 2 year old age he was starting to kind of umm sort of a bit of a break down over trivial things you know... But then as he got older it became more obvious that he was having melt down over something but we didn't know that it was anything out of the ordinary... (Participant C)
	He didn't have meltdowns and freak outs and crying and like you now like some kids have real meltdowns. He didn't really ever have meltdowns… trying to think now… he was just like very much in his own world.. Yaaa always just like happily in his own little fog… (Participant D)
Lack of connection	I think a difficult thing was the fact that there's no connection… he's not listening to you and there's not connection whether we go or come or whatever he would sit there… would spin; There wasn't that… because his eyes was also that… you can see in their eyes how they lost… you can just see it... But they even look at you but, in the eyes, is, I can't explain it to you but you can see that they not seeing you. You not in their world. At all. (Participant E)
Lack of communication	With Child B 1 the biggest um issue, was the lack of um aff- complete lack of engagement. "How was your day?", "Fine", "Did anything happen?" "No.". Then you'd find out from school that a lot happened.

	But he just didn't know how, you couldn't ask open ended questions you had to ask, you know... And we didn't know (Participant B)
	Regarding child B 2: But I think um… understanding him was the big, very frustrating part (Participant B)
Verbal ability	Child B 2 was not verbal at all where Child B 1 had language skill or let's put out this way he had speech, Child B 2 didn't have speech at all. (Participant B)
Difficult behaviour	Like I said in grade 2 the wheels started to come off academically; he was started to slip, there was issues at school. I couldn't just drop him off at school, he'd start screaming there, 'cos I didn't want to go, would leave him with the teacher and run… while he screams (Participant A)
	Child B 1, always had issues with um, well his attention span, low muscle tone, praxis, a lot of stuff like that and then there was a diagnosis of dyslexia at one stage (Participant B)
	And then um he would… he can't talk to you so he would make this sounds and he's in the cupboard [indicates that he would slam cupboard doors] breaks the T.V unit doors, he would kick off… and um he don't know what he wants then you ask "Do you want milk? Dummy?" "you want this?"… gee kind wat hy wil he, maak hom mal oor die tantrum! (Participant E)
	The fact that he didn't sleep...He didn't sleep… he didn't. (Participant E)
When anxious/ new situation	Where Child B 1's sensory issues are not that bad but his anxiety makes him very passive he goes into shut down he shuts down when he's anxious (Participant B)
	And he wouldn't express himself. And he wouldn't cry or anything but he would just walk in circles flapping. And nobody could sort of engage with him cos I think he was just very anxious and didn't know what was going on. (Participant D)
	He had this severe separation anxiety towards me just wanted be with me (Participant E)
Inappropriate behaviour	And the inappropriate behaviour as well (Participant A)
Executive functioning	And then his processing speed is affected his cog functioning his exec function to order and to plan and to get things done I mean he sho terrible (Participant B)

4.7 PARTICULAR SYMPTOM/S OR EXPERIENCE/S THAT WERE SIGNIFICANT AFTER DIAGNOSIS

Table 4.7 Showing particular symptom/s or experience/s that parents were significant after diagnosis

Symptom/ characteristic	Supporting quote
Emotional development	Because he's emotionally behind… (Participant A)
	Its only recently that we've fig- he is able to communicate a bit more and just be a bit more in touch with emotion… so I dunno! (Participant D)
Happy	So he's just like this happy cheerful little boy and he's your stereotypical Aspy so he's like a mad scientist. (Participant D)
Social skills	Well in the sense that he he, they do social skills at school, he's just got a bit more mature so his social skills are a bit better. He still doesn't… know how to interact…Its mostly the social ineptitude- just not knowing how to behave at all in social in a social context. (Participant D)
Medication/ ADHD	So um ya it was... the, the um the ADHD has become a lot less of a challenge in terms of impulsivity for the moment. (Participant A)
	Concentration is an issue like he really and truly is all over the show he literally vibrates an then you cant still. (Participant B)
	Yaa he uh he cant function without being on Ritalin because he has ADHD so at school that's a thing… so he has a to be medicated but that's fine I have no problem with that… (Participant D)
Child's approach/ thinking	Uh i think that he's got very rigid patterns of thinking but that does affect... his... cos he's really really smart but it affects the way he tackles his work and he's a perfectionist and he's sometimes comes at things from a really weird angle so… he sometimes struggles with certain things because he's got a weird way of thinking. (Participant D)
Anxiety	And then he also has terrible performance anxiety where he doesn't want to do something because he's scared, he can't do it right, so then there's a lot of resistance and behaviour um to try and get out the work or whatever the case is so there's a lot of that. (Participant B)
	And then he's very anxious and I have read that you know as they become teenagers and stuff like that anxiety (Participant D)
Internalising	A number of parents discussed how their child began internalizing difficult, negative emotions.
Executive function	Child B 1, his biggest characteristic I think is ooh… gosh.. is just getting started. He cannot get started! His executive function is just so poor [that like firing pin] ya! (Participant B)
Sensory issues	Child B 2's sensory processing issues are are um pronounced- Ummm but he's got basically the whole thing, sensory stuff, his proprioception is bad, hes visually um sensitive to light, his hearing is um [sort of the whole shebang] ya the whole! (Participant B)

Communication/ language	Regarding child B 2: Then it just, his language development just escalated [that's amazing] and his language is now quite um it's ya! Its not the same person. (Participant B)
Improvement with age	He knows the routine for himself and he... routine but his behaviour is very temperamental. Um to you know he has ups and downs within a day... um but as he's getting older I've noticed that he's, he's getting better. Maturing um in the respect that he will be, won't be phased by... in the same way. We went to the spur yesterday, the Spur, with a group… it's an ecumenical group and uh there were about 25 of us, he sat next to me and he was like a gentleman! I had to cut up his food to make sure he didn't stuff his mouth but apart from that his behaviour was fine, you wouldn't have thought that he had any difficulty with noise because he just coped. (Participant C)

Parents reported numerous symptoms and behavioural challenges that continued after receiving a diagnosis including newfound difficulties however some also reported improvements in behaviour and some areas of functioning.

4.8 PARENTING ABILITY IN RELATION TO MANAGING CHILD PRIOR TO HIM/HER BEING DIAGNOSED

Parents discussed their perception of their parenting ability and of themselves prior to their child acquiring a diagnosis. parents reported experiences of frustration and distress linked to their parenting attempts during this period.

4.8.1 Parenting ability

Parents reported various experiences and perceptions of their ability to parent their child prior to diagnosis. One parent reported a degree of understanding of her child prior to diagnosis, despite being unaware of the cause for her child's behaviour. Another parent reported that. A lack of understanding of her child, resulted in her perception that she was failing him.

4.8.2 Perception of self

One parent reported a 'content' sense of self while another reported a negative perception of herself and her parenting role. She also reported on her internal psychological responses to this perception.

4.8.3 Frustrations

Parents reported a decreased frustration tolerance at times, especially in relation to the ongoing task management required and having to repeat instructions.

4.8.4 Frustration leading to distress

Parents reported that the feelings of frustration increased and led to surmounting levels of distress. For two parents this was linked to a level of disconnect from their child and a feeling of "giving up".

Parents reported several areas of difficulty surrounding their ability to parent their child prior to diagnosis as well as their perception of themselves in relation to this. Parents reported feeling of desperation, disappointment and being pushed to their limits of frustration tolerance. Parents felt a sense of failure and guilt in their attempts to parent without a diagnosis with some parents experiencing intense levels of distress and helplessness in relation to these frustrating experiences.

Table 4.8 Themes and their subthemes identified with supporting quotes from participants regarding their parenting ability in relation to managing child prior to diagnosis

Secondary theme		Supporting quote
Parenting ability		As I said, it was just me and him so I, I understood him even though I didn't know there was something else that we working with. I realised change was difficult for him, I realised certain things, so I wouldn't put him in those situations or I would prepare him for situations like that. (Participant A)
		With Child B 1- we always felt that we were failing him and we always felt guilty and we were parenting from very much guilt perspective but that everything is also not understanding him made us sacred of him we ended up fearing him because we didn't know him we didn't know who he was. (Participant B)
Percepti on of self		As I say, I was a single mom so I put everything into him um and I don't know. I was quite a content parent. (Participant A)
		Um… and the amount of disgust and self-loathing that goes with giving up on your child, I cannot explain it to you... I think sometimes death is worse. It's worse than death to say to yourself in your heart I'm giving up on my child, I literally don't care for your future anymore, I will do what I have to do to make sure that you stay alive and that's it. (Participant B)
Frustrations		I think sometimes I was frustrated because he wouldn't, he wouldn't listen. He wouldn't stop off something he doesn't want to stop I would have lost it. Ya that was challenging… "but I told you not to, I know you're intelligent, why don't you understand what I'm saying to you?". (Participant A)
		So you would tell him a million times to do the same thing and he would get half and get distracted or the executive function just, just the order wouldn't be there. Um so there was a lot of fighting with him a lot of constant: "how hard is it to get up in the morning get dressed and go to school? Why is this something we have to constantly repeat?" so there was a lot of that um so ya those were the two biggest concerns. (Participant B)
Frustration leading to distress		He was all I had, he was all I had, so um I was disappointed in myself when I lost it with him. (Participant A)
		Hmmm… ummm… I think for Child B 1, ok… I'll be very honest with you…I don't think I've ever told anybody this… um I got to a point where I'd given up on Child B1… and this was even, this was even prior to the... diagnosis… I cannot carry on fighting with him anymore. I'm now officially throwing the towel in. I will make sure that he stays alive and I will do whatever I can to provide for him. And that's that.(Participant B)
		I felt that I felt that it was like an animal in the house- a pest. That doesn't understand, when I talk to him he's like just there. I must feed him and dress him and whatever. But that's it. (Participant E)

4.9 PARENTING ABILITY IN RELATION TO MANAGING CHILD AFTER HE/SHE WAS DIAGNOSED

Parents discussed their ability to parent and manage their child after a diagnosis was acquired and whether this resulted in changes in their parenting experiences. Parents discussed their expectations of parenting and of their child had to change. Parents reported on the renegotiation of parenting roles and responsibilities as well as changes in their parenting approach. Parents also explored their experiences of dealing with frustrations and their own emotions after a diagnosis was acquired.

4.9.1 Renegotiating expectations

4.9.1.1 Of parenting approach and of child

Parents reported having to renegotiate their expectations of parenting as well as of their child once they received a diagnosis.

4.9.2 Parenting approach

Parents indicated that after acquiring a diagnosis, their parenting approach had to be adjusted accordingly.

4.9.2.1 Child as priority

One parents quote mirrored the experiences of most of the parents in this study as she described how her child was her priority.

4.9.2.2 Parenting team

In the current study, the majority of the parents emphasised the significance of working as a team within the parental relationship while respecting each other especially with the renegotiation of roles in the family.

4.9.2.3 Aiming for independence

One parent discussed her families aim for their child. They reported wanting to achieve as much independence as possible for their child and for the child's sibling.

4.9.2.4 Overcompensating or over-protecting

Many parents indicated their awareness of the possibility of overcompensating after a diagnosis was received. Many also reported their awareness of their tendency to over protect their child, however many felt validated in doing so.

4.9.3 Renegotiation of parent roles

4.9.3.1 One parent as more prominent care-giver and trust in spousal care-giving role

Acquiring a diagnosis required parents to renegotiate roles between themselves which in turn resulted in a shift in responsibilities and the rules they followed as parents. One parent highlighted the importance of trust in each others ability to adequately fulfil theie specific roles.

4.9.4 Dealing with frustration

Parents reported still encountering levels of frustration despite having a diagnosis.

4.9.5 Parental emotions

Parents consistently reported experiencing a sense of guilt when reflecting on their behaviour and responses in frustration to their child, prior to diagnosis.

4.9.5.1 Guilt and parent emotions put aside

The quote in the table, epitomised the approach that many parents ultimately employed as they had little time to stop and process their own experiences or psychological needs while attempting to attend to their child with ASD and the multitude of stressors that came with this.

Parents reported renegotiating their expectations of parenting, of each their roles as parents and of their child. Parents also reported that acquiring a diagnosis didn't fully exclude them from experiencing periods of frustrations. They also reported experiencing guilt when reflecting on their responses to frustrating experiences prior to a diagnosis.

Table 4.9 Themes and their subthemes identified with supporting quotes regarding their parenting ability in relation to managing child after diagnosis

Secondary theme	Subtheme	Supporting quote
Renegotiating Expectations	Of Parenting Approach	I mean… you basically have to um turn everything you know about parenting upside down because that's what it takes to parent a child with autism everything you think you know about good eating you end up doing a lot of the opposite, because good parenting for neurotypical and good parenting for autistic kids are very different. (Participant B)
	Of Child	We have a lot of conflict surrounding Child B 1 because he's 22 already aaand um… husband still has expectations… that I know he cant meet. (Participant B)
		What I see from observing… ya! And we don't… sort of don't expect him to be normal and we know hes never gonna get better! you know what I mean! This is what it is! So I think we're just a bit more relaxed… (Participant D)
Parenting Approach	Child As Priority	I was like, it's sort of my mission in life to to sort this little boy out and make sure he's happy and he's ok and I tried everything I could. So, I wasn't really, if that what you asking so I wasn't really a point that I felt sad and I could say I feel I failed him in anything. (Participant A)
	Parenting Team	This is the thing- Its always the two of us against them. When there is any form of um whats the word…if theres any issues in the, in the, or or conflict we always together on the same team against them. We never split up and I'm with one of the kids- we don't do that. We, we stick together no matter what- even if we disagree, we stick together. We'll afterwards have a fight but when… ya we always on the same team when it comes to any conflict in the family…because you have to be. So I think from that perspective we knew that from the get go. But um doesn't matter what we need to be on the same…team. (Participant B)
	Aiming For Independence	What I'm giving you is I'm going try make him as independent possibly so that you can one day have a life. So that he is not your person, gonna keep you here and if you decide wow I wanna go we gonna go on a tour or whatever you can take him with because he's got the social skills to go with. It's not that he's gonna pull her back. (Participant E)

	Overcompensating Or Over-Protecting	But it was also challenging all of a sudden you want to over- compensate. … But it was ya, a challenge to not over compensate. (Participant A)
		… because I think to a certain extent we've raised him a bit in a bubble, but in a bubble in the sense of protecting him but also uhhh… fine-tuning the environment to suit autism and not necessarily forcing him to live in a world that's not made for him- we decided to force ourselves to live in a world that's not made for us. So, we've gone 50/50 on that. We force him sometimes to come to our world, but we indulge and enter his world very often as well, type of thing. So that's basically our approach. (Participant B)
		Ya and a bit over protective like I don't know where to draw the line and how much to…[He's] very sheltered… but I have thought: have I got him in this ivory tower where he's so protected and… ya… I do notice as well that you cant help, it you compensate a lot… (Participant D)
		yes there's counter-arguments where people say I'm protecting him… but I say as long as I can protect him I'll try do that. (Participant E)
Renegotiation Of Parent Roles	**One Parent As More Prominent Care-Giver**	So but because I spend the majority of the time I'm much better trained at dealing with them and becoming automatic response everything I did is in preparation and I lose it, but I obviously have more contact with the kids so it's a lot it comes more naturally for me. (Participant B)
	Trust In Spousal Care-Giving Role	...luckily we in the position where [my husband] one hundred percent trusts me as the expert and he takes my lead and we've got an agreement. He goes to work- that's his level of expertise. I do not tell him how to run his company. He can ask my opinion and I'll tell him my opinion but I will not tell him how to run his company. Same way he trusts me as the expert on autism and raising our children and education therefore he will not try… he will give an opinion but... (Participant B)
Frustration		My husband still struggles and they still bump heads on a regular basis. He would like phone me and say you won't believe what he did now again, and I would like… I'd listen hear him out and "but he's autistic" and he would like ya ya.. But did you warn him? did you do this? I do the checklist with my husband and then he's like, "ya you right". (Participant B)

Dealing With		Well sometimes he talks incessantly well often… but he'll talk to himself and sometimes when you tired-ok it bothers my husband less- but sometimes when you tired and he'll like pace… so having someone who never stops moving well sometimes he does but.. ywho doesn't stop going, who paces sometimes like.. if im tired at the end of the day he wont stop talking he talks so himself. He doesn't moderate his voice correct-like he'll be telling me something in the car and his voice will be soft and then hell stand next to me and yell…. It's the not moderating your voice,the moving all.. well not {feels like all the time} ya! (Participant D)
		Sometimes I do get fed up and sometimes I do feel like yes, I as a mom I have messed up. But then other times I have then feel that at that stage at that moment that was the best we could do as a family… um, that was the choice and we need to live up to it. (Participant E)
Parental Emotions	**Guilt**	There's a lot of guilt afterwards 'cos you think back and your kid was so anxious and distressed and you know in such a state of horror And you just left him on the pavement and went to work. So um there was a lot of guilt to deal with… The guilt is always there. (Participant A)
		The, the Child B 1's story is a story of um guilt and, and, and um almost giving up and despair because you feel bad because you didn't know better…and in general there's so many misdiagnoses and I think to a certain extent instead um I suppose we there was no way we could have known. (Participant B)
	Parent Emotions Put Aside	I think that um… you go through all these things and you manage and you survive, push through to do what's best for your child and you just suppress emotions inside yourself. (Participant A)

4.10 FAMILY LIFE WITH CHILD PRIOR TO DIAGNOSIS

4.10.1 Parent relationship

Each parent mentioned the impact of ASD on their spousal relationship. A quote from Participant E provided a 'snapshot' into their daily life and highlighted the impact on the parental relationship.

4.10.2 Family dynamic

Two parents reported their experience of the shifts in family dynamics prior to a diagnosis. one parent reported that her husband was more aware of her sons difficulties than she was, while another parent described her role in soothing her child in order to avoid disrupting the rest of the family.

Table 4.10 Themes and their subthemes identified with supporting quotes from participants regarding family life with their child prior to diagnosis

Secondary theme	Subtheme	Supporting quote
Parent relationship		…and I think that the strength of the relationship um is tested way beyond anything that ever um could be throw at a couple. (Participant B)
		[It] causes a lot of relationship problems for people… its never been an issue. often dad wont accept it or family members wont accept it or something weve never had that problem! (Participant D)
family dynamic		For my husband, it was very difficult obviously he could see the difference way better than I could, cos he couldn't, his kids wouldn't do that… And I just thought we raised them differently, raising different kids you don't realise there's reasons why. (Participant A)
		I always tried to keep him quiet if he woke up in the early morning, which he often did… then I would keep try and keep him amused or quite but try and get him back to sleep. Was the first things he didn't disrupt the whole family. so his behaviour was very disruptive... either shouting during the day or shouting during the early hours of the morning… if he was unhappy. (Participant C)

4.11 FAMILY LIFE WITH CHILD AFTER DIAGNOSIS

A theme that emerged from parent reports was the effect of the child's sate on family life after diagnosis. Subthemes included the impact on the parent relationship, the role of resources and their availability after a diagnosis, family dynamics including the role the child's needs played in determining the daily life of the entire family unit, high levels of management required and the level of exhaustion reported by the parents. The impact on the child's sibling was also discussed.

4.11.1 Parent relationship

The parent relationship was a significant subtheme that was affected by the child's diagnosis.

4.11.1.1 Expectations of relationship

After diagnosis,. parents reported a need to adjust and renegotiate their expectations of their relationship.

4.11.1.2 "Not normal"

Participant E described the impact on the parent relationship and highlighted the lack of normalcy they experienced.

4.11.1.3 High pressure on parent relationship

One parent discussed the level of pressure and tension placed on the parent relationship and that this was unlike any other obstacles families may face in life.

4.11.1.4 Importance of spousal support

One parent highlighted the importance of support within the spousal relationship.

4.11.2 Resources

The subtheme of resources included logistical and financial resources as well as internal resources of the parents.

4.11.2.1 Availability & accessibility

Participant B highlighted the effect of different amounts of resources available on her children. Participant D indicated her awareness of the possibilities of financial burden of ASD. She

discussed the impact of availability of financial resources for her family. Participant D further reported on the role of access to information as a beneficial resource as well.

4.11.2.2 Agency & access

Internal resources also emerged in this subtheme as one parent discussed her awareness of her capacity to actively engage difficult situations and her availability to do so.

4.11.2.3 Expensive nature of ASD interventions

Financial strain and the expensive nature of interventions for ASD were consistently reported factors amongst all the participants.

4.11.3 Family dynamics

Each parent described a number of ways in which their roles within their families and within their daily lives had changed due to having a child with ASD. Their career roles had changed, their parental roles and their spousal roles shifted as well.

Parents became educators as well as intervention implementors. Some parents took on the roles of educating others as well. Within parental relationships, one parent became the "expert on autism" which allowed her to teach her spouse and guide him where necessary.

4.11.3.1 Family roles

Family roles shifted and adapted into roles based around the needs of the child with ASD and the family unit. Parents reported on the multiple roles they played within the family and in their child's life as well as the roles within specific subsets within the family unit.

4.11.3.2 Whole life revolves around ASD

In exploring the psychosocial experiences of parents who have a child with ASD, a central theme that emerged was the sense that the entire family's life revolved around ASD.

4.11.3.3 Not normal

Parents highlighted that having a child with ASD resulted in a family life that was "not normal".

4.11.3.4 Acceptance

Accepting the state of their family life was mentioned by several parents.

4.11.3.4 Split to manage

Having to split between the children- divide and conquer- was reported by most parents as the only way to manage the needs of all their children. The participant reports in the current study suggested that family time was difficult to co-ordinate or was often restricted due to the needs of the child with ASD.

4.11.3.5 Effect on the family members

The impact on each family was clear, requiring the family to readjust their expectations for their future, their roles and responsibilities as a family unit and as individuals.

4.11.4 Level of management

4.11.4.1 Management required and family input

These parents dedicated every part of their day to their child. Findings indicate that each family's life and lifestyle was navigated around the needs of the ASD child/ children. This was seen in the amount of daily management required.

All participants described having to engage in daily management of their child's needs beyond what may be expected, and more than their neuro-typical children. Two participants compared the level of management required for their sons to that of a toddler /reporting that "like a little toddler". This sentiment was echoed by the other participants. This description provided an indication of the level of dependence and amount of management the participants' children required.

4.11.4.2 High stakes

Intertwined with high levels of management, was the sense of high stakes as each moment was spent providing intervention or aiding the child with ASD in some way, often with fears of the consequences of not maintaining this high level of management..

4.11.5 Extant consequences on parents/care-giver

Each parent in this study described how the non-stop nature of caring for a child with ASD resulted in a sense of continuous fatigue. A quote from Participant E epitomized the sense of exhausted in many of the reports from other participants.

One of the clearest and most unwavering in its presence in each participant's reports was the theme of continuous and unrelenting management that filled their daily lives. Each family described days that revolve around the managing the needs of the child with ASD.

4.11.6 Sibling

Parents reports also highlighted that although the child with ASD was often the focus of their family activities and daily lives, many of them were concerned about their typically developing child and the impact ASD had on their lives as well.

4.11.6.1 Sibling relationship

Parents discussed the unique interactions between their child with ASD and their other children. The importance e of this relationship was highlighted as well as the difficulty in navigating this interaction as it was an atypical sibling relationship.

4.11.6.2 Parental concern about sibling

Parents reported on their concern for their other children and the impact of ASD on their lives. Most notably concerns about their other child experiencing as much of a typical life as possible without the burden of sibling responsibilities relating to the child with ASD.

4.11.6.3 Divided attention
4.11.6.4 Sibling difficulties
4.11.7 Sacrifices

Changes in expectations was notable in each parents story and experiences. The life, family and future they had envisioned completely shifted and radically changed with a child diagnosed with ASD.

Sacrifices for her child's sibling were also highlighted by participant E.

Table 4.11 Themes and their subthemes identified with supporting quotes from participants regarding family life with their child after diagnosis

Secondary Theme	Subtheme	Supporting quote
Parent Relationship	**Expectations Of Relationship**	A big switch that also takes place is in… what you had as a dream for your life and as a couple… (Participant B)
	"Not Normal"	It's difficult you never a normal husband and wife. (Participant E)
		Child E for yeaaaars had severe separation anxiety so for yeeaaars he would, he slept by me! And it was quite normal for us to make plans to sleep by him, so I would make him asleep and um or he would sleep by me and dad will sleep in his room but then it was normal for us… (father: friends that talk… strange) … And then I realised for years probably, Child E is now 13, ten years we don't sleep together… it's just we cant... Yes and now with me working night shifts I'm off and he (Child E) hasn't got me to come lie by him and make him asleep. Then I'm so tired then I sommer just sleep! (Participant E)
	High Pressure On Parent Relationship	Because um if you are not on the same page then you will not survive… having children that need so much different um um approaches to life… because otherwise you end up working against each other and theres a lot of resentment that comes in and also it's not good for the child if the parents aren't on the same page . (Participant B)
		… I don't know how many times we now 20 years together but I can't tell you how many times we are going to divorce. We now had enough of each other. (Participant E)
	Importance Of Spousal Support	You cant do this on your own and you stupid if you think you can and by the time that you realise that you cant then it's probably too late and you've done too much damage and theres no relationship to carry on with. (Participant B)

Resources	Availability & Accessibility	Where Child B 2 was born into it and he was accepted into it and as we were, Child B 1 [was] much older, so we were younger, a lot younger, [and] didn't have access to info the way we do today when he was small, financially we didn't have the resources when he was growing up the way we do have now so there's a lot of things that are different. (Participant B)
		And then of course we lucky enough to be able to afford all the therapy and afford private schooling and its not like placing this huge financial burden on us…that hat we have a special needs kid! Of course its expensive but… I mean I see families where other family member have to help them out… (Participant D)
		So I mean I had the time… the knowledge cos' I can imagine what if you've got a child on the spectrum and you know you don't have access to the internet and I got a reading list from the psychologist and you cant get half of them here but I just downloaded them on my kindle! (Participant D)
	Agency & Access	Ummm but I guess that… as an example of parents and their experiences, I mean we have the power in this situation in the sense that well I can imagine that if… we could say 'I'm not happy with whats going on here'. Um I don't work so I would come in every morning and check what was going on when I started seeing things I didn't like… (Participant D)
		Like I feel very privileged because I could access anything you know… and then i had I didn't have to work so I could be available to ok.. now I'm gonna sort this out… and then after and then we could afford to bring in our own psychologist and I feel perfectly empowered to… go and take the headmistresses to task… imagine if you um are lower income black person and then you you know first of all its not even your first language, you told about this mysterious thing your child has, you don't understand it you know what I mean… and then there's a power dynamic and then so… ya I just feel very lucky because we, I think had the power in this situation. (Participant D)
	Expensive Nature Of ASD Interventions	And unfortunately, when it comes to autism it is an expensive disorder to have because the facilities and the interventions are one on one makes for it being expensive and specialised so… (Participant B)

Family Dynamics	**Family Roles**	I did mental health for 14 years in clinics, I run the mental health in... until my mom- that helped me a lot with F-died in 2014 and then I had nobody to help me with him and drive him around for his therapists and then I went into night duty so that I can, when I come from night duty, take him to school, I work a little bit with School E 2 and then I come back and… then he is at School E 2 and teacher drops him, then I sleep (while he is at school) so when he gets home then I'm here. Then I can help him and she's (daughter) is here and then at night the father is here. (Participant E)
	Whole Life Revolves Around Asd	She's 15 years old and she grew up with Autism. All she knows is autism… we talk autism…she's like I don't wanna go there…So that is also a choice you make. Your life becomes very isolated and our life becomes autism. (Participant E)
	Not Normal	This is my normal and um it's not always nice; it's as if I can't separate the two and I'm, um I never blamed him or felt that I blame him if I can't.. or get mad because we have to leave early it's just… "Not normal" but this is our normal. (Participant A)
		You don't have a normal family life. So… its nothing…people are ashamed of it but I say its there's nothing [to be ashamed of]... this is our life. This is our life. (Participant E)
	Acceptance	You just need to accept this is your life. We different, this is our family unit. Its different than other family units but it doesn't make us less happy as a family we also have out moments of joy funny things and so we go out as a family... to holiday resorts but we not typical family. At all. (Participant E)
	Split To Manage	For Child C was to do things in 2s or 3s you know so that there's always one with him uhhh… either myself or my H or both of us, but just do it in 2s or 3s and you know share the load a bit… ya {guess} as opposed to just me and Child C... Ya huhh... Cos' I was inclined to take a lot of it on myself and then I would try and always try and be pacifying him and always be trying to be making it easier for my daughter and never doing much with her because I was always having to consider Child C… (Participant C)
		She (daughter)… we must go to parent meetings… we can't go - we can't go to concerts as a family one parent needs to go… (Participant E)
	Effect On The Family Members	This is what people don't understand with having a mental ill person in, a family - is it doesn't affect that person at all and they are so happy and they are living in their own world this one (indicating Child E) is in his own world. They don't care... It's the family the people the family unit that falls apart because of this one person that they must caring. (Participant E)

Level Of Management	Management Required And Family Input	And I just mean the amount of management theres so much management in going in to him getting through a day and getting through school and getting through life in general. That is, is exhausting! Child B 1: He just, you just have to tell him everyday and constantly be on him because he just cannot get himself ordered and managed. He cannot manage himself to get these thongs um sorted so that is probably the biggest frustrating and challenging behaviour um… that we have.. (Participant B)
		So ya, and then Child E's um progress was phenomenal. They were shocked at Hospital E and those places but that was 24-hour work! My husband didn't work for 7 years! My mommy helped. It was like every hour it was, brushing, it was rolling it was like this the whole time.(Participant E)
	High Stakes	And the minute you don't management and the minute you drop the bvall it all goes to shit! Si that, that is um… one of the biggest challenges! Because there are days where you just want to say (gestures hands up), and you cant… you just cant. It just it just does so much damage. (Participant B)
		I read this very nice article and one of the thingst hye said is just relax and enjoy the moment… where as you normally taking eveyr moment as a learning opportunity so you never have any fun… but ya… (Participant D)
		And it worries if one of us fall ill then this whole family will ne fall. If he needs to go for operation or thimng something tomorrow then it's like the whole unit is panic. Because there's a routine. He takes her to school I take him, and its, and people don't understand that. People don't understand that. That they just can come in here and come and visit and things like that because there's routines there's, we need to do things now so…so it is difficult. (Participant E)
Extant Consequences On Parents/Care-Giver		I just don't have the emotional energy to resist it. Let him be for the moment. (Participant A)
		it's like the level of of.. interaction with him is like the level of interaction in a toddler.. which is exhausting! Imagine having a toddler for the rest of your life! And I mean hes nine already! (Participant B)
		Ya I was always exhausted (laughs) that's what my friends noticed most… when J went to Vredenburg it was like "sho" relief. I could just be me! I could get some time to myself.. and do things that I put on hold… (Participant C)

		Because hes being teased and… which is fine I mean its kids… but at the same time its like … tiring and tiresome. Uuhm… I dunno. Its just more that ya… (Participant D)
		And you know then it's like and I'm also tired you know things like that and when he was at home that time working with Child E full time… I would come out of the work tired, but he would be tired as well because h and F for the whole day and working and running around but I'm also tired. (Participant E)
		We fight a lot, because every year I started now already with fundraising and things by September - October I'm burned out then I cry then he's like "I told you! (laughing) leave this stuff! Just let uhhtrgr" but I said F! "no you don't have to!" who's gonna do it? If I don't do it who's gonna fight for my child? Who's gonna spread awareness? Who's gonna? Who's gonna?? (Participant E)
Sibling	**Sibling Relationship**	Parents reports also highlighted that although the child with ASD was often the focus of their family activities and daily lives, many of them were concerned about their typically developing child and the impact ASD had on their lives as well. (Participant B)
		He has a fantastic relationship with his brother...Some kids want friends he doesn't but hes got his brother and theyre extremely close in age and theyre extremely close… so i can see he gets, I think he gets a little sad when his brothers got friends and his brothers gonna diverge more and more from him and then where's he gonna be? cos his brother [is] his buddy soo… I dunno if he'll look for anybody else but he'll just be lonely and not understand why, potentially… (Participant D)
		And I always, always tell her you must remember you will be the one significant longest significant meaningful relationship in his life. The rest of his life. Cos when he opened his eyes you were there and we gonna pass on but you gonna walk that road with him… so sometimes she tells me that she's tired of hearing that like I'm, its worrying her… because I'm putting this load on her. But that's the reality. That unfortunately, that is the reality. (Participant E)
	Parental Concern	My concerns for her are sometimes much greater than they are for my boys because it's just this is just sooooo not what she signed up for… I think out of all of this in the family she struggles the most. (Participant B)

	About Sibling	I told my husband you always see the primary caregiver falling out with the mental health patients, the mom that brings the child to clinic, and then you see the children battling when the mom dies, and then you see the one of the other siblings having to give up their work to look after the mental health patient or bring the patient in every month to come get the medicine and things like that. Because that person is not independent enough you know. So that was my thing. When I and k husband, when we not here… then I don't want him to be her…[responsibility]… (Participant E)
	Divided Attention	And then also having two brothers that get so much attention that get so much um um whats the word- attention and she's the one that does everything right but shes always got to take the backseat type of thing. (Participant B)
		You know and… she [daughter] develop her own things her own little things, still... she would tell us we love Child E more, we give more attention to him, um everything that's about him you [the researcher] also coming to visit again its about him! People come in here because of him, um he was a few [times] on tv… because of his progress! People come to give donations and things it's because of him so she's always like in the back and all the things we attend is autism things. Training or whatever and so... and half the time I don't know what's going on at the school I don't attend meetings and things I just cant. (Participant E)
	Sibling Difficulties	She tends to have more time for her brother because he's older- the older brother. Because there s a bit of idolising hero worshiping that happens but as she gets older and starting to pick up om the issues with him shes starting to lose her respect for him. With the little one just irritates the life out of her, he just you know, he obviously hurts her or he you know um ya he just hes not the playmate that she expected in having a little brother so for her it's just pure disappointment… (Participant B)
		So it's very difficult. There's rule, her chores is different than his chores, her discipline is different than his discipline. And she still doesn't understand shell still say but why must i?? (Participant E)
Sacrifices		It's challenging, it's ya… was big sacrifice cos it was uh a good paying income that I had to drop to be but that was how it was, all the time… I have to… you have to choose. You either have to choose your career or living the life or investing everything and all your money in your child. It is your choice. Putting him in an institution would have cost us financially… probably better off now and probably better off now and probably I would have had a better career now and climbed the social ladder but… that was a choice we made. We decided to invest in him. (Participant E)

| | | So my argument was that… we not gonna let her carry him! Even if it means we sacrifice our careers and things because she needs a fair chance. For having her own life. I tell her we not gonna leave you money and houses nothing like that but we are giving you a life. So as long as we live, go educate yourself. (Participant E) |

4.12 SOCIAL LIFE CHANGES AND ADJUSTMENTS PRIOR TO CHILD'S DIAGNOSIS

4.12.1 Judgement

One parent reported a more positive reception from family however discussed her awareness that this was not the case for many other parents.

Table 4.12 Themes and their subthemes identified with supporting quotes from participants regarding social life changes and adjustments prior to child's diagnosis

Secondary theme	Subtheme	Supporting quote
Judgement		People get judged by their families the kids just naughty need a good whatever… smack… the parents discipline! The parents are at fault- which they not. (Participant D)
		And the one says he must just be hit and the one says "terrible temper nuh", uh "oooh you gonna struggle with this one neh!", "you must hit him now… 'baie klein' is" things like that. And we were seen as parents that can't discipline our child. (Participant E)

4.13 SOCIAL LIFE CHANGES AND ADJUSTMENTS AFTER CHILD'S DIAGNOSIS

Parents reported various changes to their social lives after their child received a diagnosis. The subthemes emerging included judgement in social settings from strangers and family, the importance of accepting friends, the impact of their child's state on family social life and activities as well as the impact of a lack of respite care.

4.13.1 Judgement in social settings

While exploring the psychosocial experiences of these parents, a theme that emerged was one of social judgement from strangers while in public.

4.13.1.1 Judgement in public

4.13.1.2 Judgement by extended family

The findings also highlighted that over and above judgement from strangers, a number of families experienced harsh judgement from extended family members as well. This included

judgement surrounding the causes for their child's difficulties as well as criticisms of their disciplining and parenting ability.

4.13.1.3 Others don't understand
4.13.1.4 Child's interactions with peers

Each parent reported various experiences of judgement and the resulting sense of social isolation as a by-product of their child's ASD. This experience was seen in public social experiences but more significantly, within extended families and social networks as well.

4.13.2 Social life

Parents reported the importance of friends who accept their child's behaviour however a few parents highlighted the reality that it was easier to have friends who also had a child with either the same disability or a similar one. Parents reported that their social activities were limited in several ways due to their child's behaviour. Parents reported a decrease in invitations to social engagements as well as limitation on the activities that they could engage in due to their child not coping in social settings.

4.13.3 Lack of respite care

Lack of respite care was a theme that emerged throughout the findings. Parents faced non-stop 24-hour care giving without the opportunity of a break or 'time off'.

Table 4.13 Themes and their subthemes identified with supporting quotes from participants regarding social life changes and adjustments after child's diagnosis

Secondary theme	Subtheme	Supporting quote
Judgement in social settings	Judgement in public	So we were we were scold at a lot and we don't know how to teach our child manners at parties he would disrupt the whole party if everybody starts singing happy birthday. I would go come back in tears! (Participant E)
	Judgement-extended family	Uuummm the um my husband's side of the family was ummm they don't accept it. They very religious, we atheist we're not religious at all, don't believe in religion aaand so the first thing was 'it's because you're atheist', 'you're being punished' so there was a lot of that which you know… (Participant B)
		My, our familys been accepting. (Participant D)
		You can't educate somebody if they don't, if out can see their approach. Understand; But they don't wanna open…and I told them if you only knew what a precious lovable child that is. If you can just open your heart to him, he is such a lovable child, but nobody takes the time, they afraid, the autisms in front of him before… and that the sad thing. (Participant E)
	Others don't understand	But I've got a brother and sister, and they were umm.. they were they were like with B they knew they could accept it but with A they struggled to accept because you know 'he looks so normal' so there was that nonsense. (Participant B)
		I, I feel like quite tense… taking him to situations with new people where they might not understand him. (Participant D)
	Child's interactions with peers	Hes got a bit better but when he was little you would go somewhere or bump into kids or go on a play date or something aand… he seems normal at the outset and kids try to engage with him and play with him and then he'll get the wrong end of the stick about what's going on and it usually end up in a fight. Where those kids don't understand this kids being so weird and then they don't like him… or like end up having a fight with him or he'll do something like.. wrong.. (Participant D)
Social life	Accepting friends	Um, I think… I think I early on I accepted that's how it's going to go. I'm not a social person myself [laughs], and so I'm not into big groups. I actually "freak out" in big groups. So, um the friends that I have, that we socialise with, they all sort of accepted… (Participant A)

		like weve got these fantastic neighbours, and my youngest son, they love him, they go over. I always feel tense when my older son goes over because I dunno if hes gonna get bullied and I dunno whats gonna happen. (Participant D)
	Effect of child's behavior on family social life	Ya, there were things I would have liked to attend that I didn't because I knew he wouldn't cope and ya um… It gets to me because I know I will never have that and not having that actually gets to me. (Participant A)
		I think one of the big one of the biggest issues, not issues but biggest differences in family life before and after. Before was the fact that we had freedom- we had freedom to go places, which all of a sudden stopped… (Participant B)
		…but we had to always weigh up, if he was with us, then we had to always weigh up what we did and how we did it and who went. (Participant C)
		Well luckily most peole we know have got kids so… I mean its affected us because we'd like to have a break you know but it hasn't really stopped our social life.. well it affects our social life.. but this happens to anybody in that… (Participant D)
		It was hard for her it was hard; my husband was like fine because it was so tiring for him to go out and to look after F. It was better for him to stay home. (laughs) but I was more social type of person so I missed that really. So we don't have friends coming in and out and so because um not everybody understand him. So that is also a choice you make. 49:20 your life becomes very isolated and our life becomes autism. Your friends is people with autism-with children with autism. So that is how your life change. (Participant E)
	Invitations	...people that invited you because our child would disrupt their house would disrupt the birthday party- we went invited anymore. Quietly we would hear things going on we weren't invited. (Participant E)
	Restrictions on family activities	Restrictions on the activities or events families could engage in was evident in the reports from all the participants. Participant B indicated that for her family, it was impossible to engage in the typical family activities. It is difficult sometimes that you can't to um go to one of these, these Route 44, I don't know if you know Route 44, grab something to eat. He can't cope with that. It's not an option. So it's not nice. Situations like that. (Participant A)
		We had freedom to go places which all of a sudden stopped um when they got to the age where we saw but behaviour is a problem here- we ended up not going anywhere anymore or we'd end up forcing ourselves to go to places alone because we couldn't um take them with us because the behaviour was always such an issue. So, um I think when you look at other people that are forever doing all sorts of things taking their kids skiing overseas and you know we can't even take our kids to the spur without it becoming a massive thing. (Participant B)

		There were things that I couldn't do… we couldn't go to a supermarket with him, without him making a bee line for a lawn mower or maybe a vacuum, but mostly the lawn mower department so he would its like you'd be shopping or busy with him at your side and he's gone! Now where's he gone! And why's he gone but he'd just tear off! And then I'd have to find him and then I'd be frustrated because I'm trying to get things done and he's just wanted to be where the lawnmowers were… (Participant C)
		"so you never have any fun" (Participant D)
		…till he was better for a long time. we couldn't go to restaurants as a family we couldn't go to cinema, we couldn't go the beach um and even when Child E was better- when we would go to a cinema, social skills and things then we would other people's chips he would get up and if they don't have that.. at the beach we were laughing the other time if he wants to go to the beach the water…he runs over the other people's towels! (Participant E)
	Friends with special needs children	Well our friends- best friends- sadly but luckily in a weird way have a son with a sensory processing disorder who's slightly younger and that has… created… divisions between them and other friends which don't exist with us because we understand their son and he gets a long just fine with my kids and obviously my youngest son is used to someone who is clumsy and cant moderate their voice and has poor proprioception so you know is bumping into you and things like that so its fine… so in a way… its brought us closer and then we just hang out with them because we feel most comfortable and they feel most comfortable with us.. we just lucky I think… (Participant D)
Lack of respite care		So and then finding time as a couple to do stuff on our own and then finding people that can look after our kids cos again babysitters tend to get scared because they don't understand and they don't know what's wrong and we also, there, we always had to go find people and explain that this is how it works here type of thing… this is how we do it and you have to stick that type of plan and stuff so that so we could actually just get some time away from it. (Participant B)
		I tried to get him a babysitter beforehand and one of my friends said to me that if it was… my daughter "I would willingly babysit her I can't, I can't look after Child C…" (Participant C)

Like I've tried having babysitters and that and they don't get him… so uhm.. my parents moved down a year ago aaand the boys are a lttle bit older and we have finally been able to like leave them with other people, and I have a neighbour who ive got to know and she has a son who has ADHD so shes very understanding so we sometimes trade babysitting… so I mean for a long time we haven't been able to go away… because we cant leave him… you know go away… haven't had babysitters you now stuff lke that.. ya (Participant D)

CHAPTER FIVE

ANALYSIS AND INTEGRATION OF FINDINGS

5.1 INTRODUCTION

This research study attempted to investigate the psychosocial experiences and difficulties of parents of a child with ASD prior to and after a diagnosis. The findings emerging from the research highlight several themes relating to the experiences of these parents. In order to give meaning to the findings presented in the previous chapter, it is necessary to provide an analysis of these findings within the context of theory and in conjunction with consideration of other applicable, current research. The themes will be discussed within the framework of the Resilience Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1988; McCubbin et al., 1995). The discussion will identify experiences at different phases (i.e. perception of the child prior to diagnosis and after diagnosis), however these will not be described separately but rather in relation to each other where necessary.

The chapter will begin with the interpretation of experiences that emerged as vulnerabilities and then those that involved renegotiations within the family and resources accessed by parents.

5.2 INTERPRETATION OF FINDINGS

Parents faced a plethora of stressors creating vulnerabilities within themselves and the family unit as a whole. These included the pattern of onset, the daily behavioural challenges parents faced pre-diagnosis, ongoing complications regarding acquiring educational environments conducive towards caring for their child's needs and development, and judgement from family members and the public. In their search for answers parents accessed numerous appointments with multiple health care professionals and several disappointments during these attempts. Whilst this process assisted parents/caregivers with regard to contextualizing their child's state as real (diagnosis and prognosis) and necessitating professional care, the outcome also had the undesirable effect of psychologically and emotionally destabilizing the family system in light of the absence of much needed support.

The research has identified valuable experiences (via the thematic analysis) that could not be conceptualized under the existing model. Parental pathways to resilience did not follow a linear structure but instead deviations suggest a process with overlapping phases that is a lifelong process.
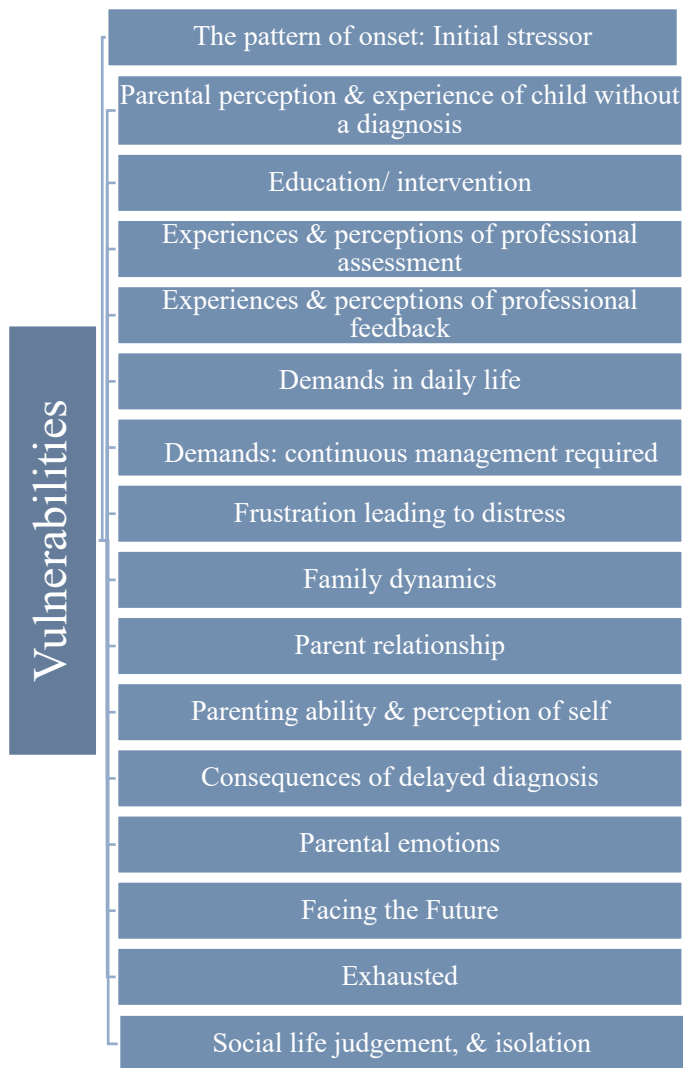
Figure 5.1 Summary of themes identified: Vulnerabilities

The pattern of onset: Initial stressor

Parental perception & experience of child without a diagnosis

Education/ intervention

Experiences & perceptions of professional assessment

Experiences & perceptions of professional feedback

Demands in daily life

Demands: continuous management required

Frustration leading to distress

Family dynamics

Parent relationship

Parenting ability & perception of self

Consequences of delayed diagnosis

Parental emotions

Facing the Future

Exhausted

Social life judgement, & isolation

Vulnerabilities

Figure 5.2 Summary of themes identified: Renegotiations & Resources

Responses to acquiring a diagnosis: Diagnosis as a resource

Parent appraisal of their child's behaviour

Renegotiating expectations

Renegotiation of parent roles

Parenting approach

Parent 'team'

Resources

Perception of choices and sacrifices

Renegotiartions & Resources

5.2.1 Vulnerabilities

5.2.1.1 The pattern of onset: Initial stressor

The pattern of onset was discussed by all participants. For most of the parents interviewed there was an awareness of their child being 'different' from early on however without an understanding of cause or reason for this difference. For these parents there was not necessarily a marker of 'before and after' (or ASD "onset") regardless this represented a clear stressor for all. For one participant her perception of the change in her son was tied to a specific event and with a specific marker, which may have exacerbated the sense of loss she experienced as her child's development degenerated (Altiere & Von Kluge, 2009). Her perception was that within the space of a few months, she lost the child she knew. This was an additional vulnerability compounding the initial stressor and psychological demands experienced, and possibly, speeding up the trajectory towards crisis for this family.

According to a number of studies, this is the case for many parents who report distress relating to ASD prior to a diagnosis, as many report atypical behaviour and development early on (Altiere & Von Kluge, 2009; Carlsson et al., 2016; DePape & Lindsay, 2015; Estes et al., 2013; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014).

5.2.1.2 Parental perception and experience of child without a diagnosis

Parental difficulties understanding their child's behaviour impacted their perception of the parent-child relationship and connection which, prior to diagnosis, had an adverse effect on parenting capacity to cope with difficult and disruptive behaviour.

5.2.1.3 Education/ intervention

This was a significant stressor prior to diagnosis as parents became distressed after many failed attempts to access appropriate schooling and intervention, often with little guidance as to the needs of their child. As seen in previous research, healthcare and education systems were perceived as inaccessible and ill-equipped (DePape & Lindsay, 2015; Mitchell & Holdt, 2014). Parents described teachers with inadequate training and limited understanding of ASD, and schools that were unable to cope with their child's needs as well as troubling limited amount of adequate facilities and services available for children with ASD (DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

Findings suggest that many parents felt they had to educate the schools and teachers about ASD and that many inevitably had to implement their own strategies in order to ensure adequate education for their children (DePape & Lindsay, 2015; Mitchell & Holdt, 2014). Parents responded by employing personal facilitators at their own cost, starting their own educational

facilities or engaging in fundraising in order to ensure the continuation of their child's school (Mitchell & Holdt, 2014). This relates to the problem-solving approach and resiliency of parents however this ultimately added the role of educator and 'funder' to their already large burden of care.

5.2.1.4 Experiences and perceptions of professional assessment

Findings suggests that the majority of the parents in this study faced lengthy and frustrating diagnosis processes which supports findings in previous research internationally and in South Africa (Altiere & Von Kluge, 2009; Crane et al., 2016; Estes et al., 2013; Mitchell & Holdt, 2014).

As seen in previous studies, parents reported that prior to diagnosis their concerns about their child's functioning were dismissed by professionals and they were often left having to convince health care professionals that their concerns were valid and necessitated further inquiry (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014). Studies have suggested that this may be due to a lack of professional knowledge and understanding of ASD (Franz et al., 2017; Mitchell & Holdt, 2014).

Health care professionals were perceived as lacking lack of professional experience and knowledge impacting parent appraisal of the potential resource (Mitchell & Holdt, 2014). Their failed attempts at acquiring a diagnosis and in turn some form of validation of their concerns seemed to leave many of the parents internalising these failures as failures of their parenting ability, impacting their sense of self and their resolve to continue seeking assistance for their child. According to a number of studies, a lack of access to 'gold standard' assessment tools has resulted in the lack of appropriate diagnosis of the majority of the children with ASD in South Africa due to inadequate services and resources such as appropriate and accessible primary, secondary and tertiary assessment and intervention facilitates in South Africa (Bakare & Munir, 2011; Franz et al., 2017; Mubaiwa, 2008).

Parent internal locus of control lead to the parents undervaluing themselves and perceiving themselves as failing in their parenting ability despite the reality that the condition was acquired independent of parenting ability.

Parents in this study encountered further pile up and depletion of resources as they attempted to seek help and instead faced multiple professionals, lack of answers, misdiagnoses, judgement and lengthy delays. Impacting their ability to accept the current situation, parents attempted to contend with a growing awareness and guilt that each delay had an impact on their child's prognosis.

5.2.1.5 Experiences and perceptions of professional feedback

Parent perception of professional feedback was that professionals impressed as viewing their child as "broken" and situation as 'hopeless'. Parents also perceived professionals as unwilling to listen, taking an authoritative stance towards the parents. This impacted the accessibility of these possible resources as parents felt the need to take on a defensive stance in order to advocate for their child. This impaired their sense of trust in the external resources available- once again furthering their sense of having t be self-reliant in order to best care for their child.

5.2.1.6 Demands in daily life

Findings suggest that for many of the families, ASD became all encompassing (Alli et al., 2015; Altiere & Von Kluge, 2009; Carlsson et al., 2016; DeGrace, 2004; Woodgate et al., 2008). There is a sense that every moment of every day was filled adapting in some way to the changes ASD had brought with it. This was true in a practical sense as these parents- if not engaging in tasks directly related to their child- were involved in educating others about ASD or advocating for ASD. On an emotional level, even when there was not necessarily an externally ASD based activity occurring, there is a sense that ASD finds it way in- as these families, try to cope with it or process it internally. This is mirrored in previous research by Greeff and Van der Walt (2010) who found that the needs of the child with ADS 'dictated' family life (Altiere & Von Kluge, 2009; Carlsson et al., 2016; DeGrace, 2004; Woodgate et al., 2008).

5.2.1.7 Demands: continuous management required- little opportunity to rest or replenish

Findings suggest that parents were required to be present (and providing assistance) for every task. Whether assisting in self-care or completing daily tasks; taking their children to or implementing interventions at home; relieving other family members of 'duties' or seeing to other children in the family- everything in the lives of these families was either in response to or adapting for ASD. This unrelenting management constituted a stressor and in turn a vulnerability for most of the families as it was a daily, ongoing occurrence that depleted parental internal resources. Parents report being exhausted which in turn impacted their ability to cope and adjust adequately.

5.2.1.8 Frustration leading to distress

Prior to diagnosis, daily frustrations exacerbated vulnerabilities as parents faced a depletion of resources with no foreseeable change or end to it. The psychological consequences for parents was a sense of depleted of internal resources and ever-growing vulnerability; with parents describing reaching a point of almost "giving up". This had further repercussions

psychologically and emotionally- especially once a reason and cause for the child's behaviour was identified.

Having a diagnosis didn't make parents exempt from natural frustrations- neither did having a positive perception of the child. Although having a diagnosis did however assist in aiding parent capacity to cope and manage with the frustrations on a daily basis.

5.2.1.9 Family dynamics

Having a child with ASD impacted family unit functioning, overall well-being and cohesion (Hayes & Watson, 2013; DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014).

Stressors involving the child's state influenced the way the family functioned and in turn the roles members of the family may have felt obligated to fulfil. The dynamic of feeling responsible for easing the frustration or distress of another family member may be considered a vulnerability as it had the potential to cause resentment and rifts in family cohesion which in turn would impact the family's resilience.

Family quality time was also affected as this was over ruled by the needs of the child with ASD (Altiere & Von Kluge, 2009; Meadan et al., 2010; Nealy et al., 2012; Schlebusch et al., 2016).

5.2.1.10 Parent relationship

A marriage is typically considered a resource for parents as it is a source of support. In this study, it is clear that for many parents their marital relationships are tested beyond typical capacity, running the risk of internal conflict and a further complication in an already complicated family system. There is evidence of an impact on the marital relationship from numerous studies (DePape & Lindsay, 2015; Falk, 2014; Jones et al., 2014; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014; Tehee et al., 2008).

5.2.1.11 Parenting ability and perception of self

Parents faced several onslaughts to their sense of self and parenting ability, which constituted an additional vulnerability.

Parental sense of self and parenting ability was positively impacted in cases where parents had the capacity and available resources to adapt to the child, even without a diagnosis. this however was also influenced by the child's phenotype and presenting behavioural difficulties. However, the majority of the parents reported a sense of failure and internalisation of self-doubt about their parenting ability prior to diagnosis with many identifying "failures" at parenting.

Findings suggest that generational patterns, or patterns of previous experiences of disciplining a child may have been attempted. The parents may attempt to discipline their child in the way they think they should or ways that have worked previously with neuro-typical children. Their understanding of appropriate behaviour may also have been applied to their expectations of their child therefor disruptive behaviours or meltdowns were often viewed as temper tantrums or defiance. Thus, often receiving responses from parents that, although are understandable, resulted in further meltdowns and frustration. This impacted parent-child relationships as well as the perception parents had of themselves and their ability to parent.

Parents also faced external judgement and criticism prior to diagnosis, often directed at their ability to parent adequately- which they may have internalised, further impacting their sense of self and parenting ability. These findings mirror those found in previous literature (Carlsson et al., 2016; Karst & Van Hecke, 2012).

Parents reported highly distressing perceptions of self which further impacted their ability to engage with daily challenges but also their capacity to cope with their child's difficult behaviour- further impacting sense of self.

5.2.1.12 Consequences of delayed diagnosis

Parent awareness that delays in diagnosis had functional implications and consequences for the child. Some children presented with poorer overall functioning and greater functional difficulties that may have been harder to cope with therefore requiring more intensive intervention. In turn this required more from parents, including taking the child to more to therapy, engaging in interventions at home. Parents also faced greater emotional stress, -sense of loss and guilt or self-blame.

A timely diagnosis (which innately would involve attending to and acknowledging the parents reports of a problem) may have meant better prognosis for the child as well as less distress and improved wellbeing for the parents.

5.2.1.13 Parental emotions

Psychosocial dynamics are inevitably complicated in this case however due to the high level of demands placed on parents daily- they often did not have the opportunity to process these and thus, as one parent described "[they] push through… just suppress emotions inside". This may build into greater vulnerability as parents mental health and well-being are at risk. Previous studies found that parents reported feeling overwhelmed, stressed and exhausted, indicating that caring for a child with ASD left them physically, psychologically and

emotionally depleted (Altiere & Von Kluge, 2009; Chong & Kua, 2017; DePape & Lindsay, 2015; Mitchell & Holdt, 2014; Woodgate et al., 2008).

5.2.1.14 Facing the Future (ongoing internal psychological stressor)

Parents highlighted their concerns and fears about the future of their child, their family and their ability to continue to provide adequate care. Findings suggest that parents had enduring concerns about their child's future and the continuous care they would require for the rest of their lives- many reported a need to over-prepare and make extensive plans for future care of their child (Falk, 2014; Meadan et al., 2010; Mitchell & Holdt, 2014).

These included their aims of ensuring their child was as independent as possible, attempting to amass adequate financial backing to continue to support their child and willingly making any necessary adaptations to their expectations of their own futures in order to secure one for their child. These perceptions of the future raised the stakes during present interactions and in terms of acquiring suitable resources to cater for the future, placing additional stress on the parents.

5.2.1.15 Exhausted

The consistent reports of exhaustion from the parents in this study emphasise the impact of the level of management each parent faces daily. This depletion of internal resources may play a significant role in parent capacity to cope with future daily stressors as well as other adverse events.

5.2.1.16 Social life judgement, and isolation

This study found that parents experienced a general lack of acceptance and understanding of their child's diagnosis and behaviour by family members and the general public which is supported by findings in literature (Altiere & Von Kluge, 2009; Meadan et al., 2010; Nealy et al., 2012; Woodgate et al., 2008).). Parents reported isolation and a sense of being ostracised from their previous social circles (Altiere & Von Kluge, 2009; Nealy et al., 2012; Woodgate et al., 2008). This loss of social support and greater social network may be seen as a vulnerability impacting parenting ability to move towards resilience and cope with the demands placed on them. This coincides with a sense that many parents feel that ensuring their child's optimal intervention was their responsibility alone.

Another factor related to this sense of isolation, was the experience of parents being judged and criticised by extended family members and members of the general public for a lack of discipline or poor parenting ability in response to their child's behavioural difficulties or outbursts (DePape & Lindsay, 2015; Gray, 2002; Neely-Barnes et al., 2011; Woodgate et al.,

2008). Parents reports indicate that their children were often perceived as disobedient and wilfully disruptive

5.2.2 Renegotiations and resources

5.2.2.1 Responses to acquiring a diagnosis: Diagnosis as a resource

The findings indicate that for these parents, the receiving of a diagnosis for their child meant that their concerns were being acknowledged and in turn, their parenting was not necessarily the problem and that their child's difficulties were recognised- validating the parental experiences and concerns.

Acquiring a diagnosis had a "ripple effect" as it provided the opportunity for renegotiation of perceptions and understanding of the child, becoming a resource for the parents and the family.

The impact of a diagnosis, subsequent understanding of their child's behaviour and of course guidance received on how to engage with the child, meant that parents were able to release the preconceptions that they may have had of their child and become their biggest advocates. The impact of a diagnosis is seen in how the parents who felt like they were ready to "give up", were able to take active stances in advocating for their child's needs.

This experience was especially important for this parent's sense of self and parenting ability especially in the context of pre-diagnosis experiences of the child.

5.2.2.2 Parent appraisal of their child's behaviour

Parent appraisal of their child's behaviour prior to and after diagnosis played a role in parent capacity to cope and adapt to the child and the stressors they endured. This perception, in some cases, allowed greater room for understanding and adapting to the child without a diagnosis and in turn may have alleviated some distress during this period. Parent perception of their child's behaviour as part of a personality dynamic may have gained a rudimentary understanding of challenging behaviour, which in turn allowed more willingness to adapt to the behaviour early on.

This may have been linked however to different phenotypes of ASD and behaviour that may have been less disruptive. Parent capacity for these adjustments also played a role in their apparent willingness to adapt to their child without the context of a diagnosis.

5.2.2.3 Renegotiating expectations

For parents, the life, family and future they had envisioned had to completely shift and radically change with a child diagnosed with ASD. The ability of parents to engage actively in this renegotiation of expectations was a valuable resource aiding adaptation.

5.2.2.4 Renegotiation of parent roles

Renegotiation of parenting roles and the trust each parent had in the others ability to meet the required adjustments was an important resource.

5.2.2.5 Parenting approach

Parent approaches that involved making their child the priority and focusing on family/ parent cohesion were considerable resources especially during challenging experiences.

5.2.2.6 Parent 'team'

This was a key aspect of resilience resources for many parents- the most important aspect being that each spousal relationship underwent necessary adjustments and renegotiations of each other's expectations of the spousal relationship and their commitment to working together as a team.

5.2.2.7 Resources

Logistical resources play a key role in parent perceptions of their own capability to manage the demands they face. These assist in encouraging internal resources and parent ability to access them. However, the converse side of this is the impact of a lack of resources which may act as a barrier to coping and adapting. Parents in this study reported feeling financially strained due to the expensive nature of ASD, despite the majority of the families occurring above the low socioeconomic status.

The internal resources a number of parents displayed included agency and empowerment which were key resources involved in their adaptation. These resources aided parents in advocating for their child and sourcing appropriate intervention.

5.2.2.8 Perception of choices and sacrifices

Having a positive perception of their choices and sacrifices was found to be a significant resource for parents. This was aided by awareness of their child's growth and improvement. This was an important resource as it provided parents with a sense of internal validation and accomplishment.

Findings suggest numerous vulnerabilities within family functioning including that of being isolated and alone. Social support has been shown to be a key protective factor (Falk et al., 2014; Hastings & Johnson, 2001; Meadan et al., 2010), however for many of these parents was lacking or insufficient. The internal resources of these parents may also be depleted as they report disrupted sense of self and emotional and physical exhaustion.

Families that received adequate informal support from their social networks and formal support from healthcare practitioners had a higher likelihood of positive adjustment (Falk et al., 2014; Hastings & Johnson, 2001; Meadan et al., 2010).

Having a child with ASD placed increased demands on the entire family unit without much time for parents to process the diagnosis or grieve the loss of their expectations for their child and their own future. Parents have to recalibrate their roles and responsibilities "on the go" and when parenting a child with ASD, research suggests that parents had little time for their own personal needs.

5.3 SUMMARY OF ANALYSIS

The experiences of the parents in this study appear to deviate from the suggested process in the resilience model as they impress as not necessarily always in crisis and yet with heightened levels of pile up that appeared not to fully subside at any given point. The 'route' towards parental resilience in this case, unlike the model's clear phases and pathways, appeared to involve overlapping processes towards resilience. There was little, if any, sense of 'smooth sailing' for any of the parents involved. Normative stressors were indeed still present however often took a backseat with ASD in the centre focus.

Parents experienced an initial stressor occurring long before diagnosis and a significant pile up stressors involving the parent-child relationship, parenting sense of self and negative interactions with others and professionals, as well as disruptive difficult behaviour and an emerging sense of disconnect from their child and the experience they had hoped to have in terms of bonding with him/her. This impacted their sense of self and ability to parent with dismissals of their concerns by professionals further confounding the internalisation of these judgments.

In their attempts to access support, parents encountered resources that were inadequately suited and incapable of assisting them in meeting the demands faced (Holtzkamp, 2010; Greeff & Van der Walt, 2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; McCubbin & Thompson, 1991; Walsh, 2003).

Attempts to connect in the typical manner were unsuccessful and, without the context of understanding that a diagnosis may have provided, these unsuccessful attempts left the parents frustrated and distressed, furthering the feeling of disconnect from the child. This impacted the parent's capacity to continue to cope and adequately manage the child's behaviour. Parents reported experiencing such high levels of frustration and distress at times that they felt they

were ready to "give up"- a psychological experience that parents report brought with it guilt and shame.

In this study, several expectations accompanied acquiring a diagnosis including hopes for a clear direction and in turn a hope for acceptance and adjusted appraisal of their child's difficulties- hopefully aiding the movement forward towards adapting and coping. For all the parents, a diagnosis definitely provided relief and some context for understanding their child's behaviour- which had been a difficulty throughout the previous stages. The reality however involved short-lived relief, alongside grief and loss; a lack of guidance and a great sense of being alone. Therefore, this period brought with it some renewed resources however it also represented a period of further adverse effects and greater pile up factors. External resources were perceived as inadequate including an inaccessible and ill-equipped healthcare system and education services- as well as little if any social support while internal resources remain depleted.

A consistently reported vulnerability was the sense of isolation and ostracism each family faced as a result of their child's state and/ or disruptive behaviour. The sense that each parent took on this journey alone, permeated the parental experiences.

Parents attempted to engage actively in order to address the stressor and pile up of demands. Part of this involved attempts to find meaning as suggested in many resilience theories (Holtzkamp, 2010; Greeff & Van Der Walt, 2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; McCubbin & Thompson, 1991; Walsh, 2003) however for many parents, attempts to reappraise the situation were overshadowed by the difficulty and frustration of this period and the ever-growing pile up of demands. For some parents, viewing their child's behaviour in an idiosyncratic light eased some frustration however did not preclude them from the many demands and challenges faced. As demands piled up, the level of vulnerability of the family increased.

Moving towards resilience, some parents attempted to find new meaning with their focus often redirected to becoming advocates for their child. This provided a direction and purpose for many parents- reigniting previously depleted internal resources.

As the parents attempted to deal with a number of demands, ongoing daily stressors and psychological dynamics, they also faced disorganisation within the family unit. This called for restructuring and reappraisal within the family (Holtzkamp, 2010; Greeff & Van Der Walt,

2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; McCubbin & Thompson, 1991; Walsh, 2003).

Families attempted to restructure in order to meet the demands they faced by renegotiating family life and roles, renegotiating daily life and testing out new problem-solving skills. This required parents to seek out new sources of support. This restructuring was not without stressors as parents attempted to balance the needs of all family members, provide continuous 24/7 care, advocate for their child and re-evaluate their own careers and financial strains.

Parents sought interventions, became therapists, became educators and advocates- fighting every step of the way (Carlsson et al., 2016) with no opportunity to rest or recuperate. The psychological demands of their entire journey and daily encounters contributed to the psychological vulnerabilities occurring for most parents. In turn this had the potential to create an ongoing, underlying build up of unprocessed psychological residue which may have depleted internal resources, greatly impacted parent wellbeing and in turn, their ability to cope with the extensive pile up facing them.

Elevated parent mental health concerns, poorer well-being and higher levels of stress may impair the parent's functioning, which in turn may reduce parental potential to deal with the challenges guaranteed to occur when raising a child with ASD (Altiere & Von Kluge, 2009; Huang et al., 2014; Meadan et al., 2010). Furthermore, as considered previously, parents play a significant role in implementing interventions and if functioning were to be impaired, this may negatively impact a child's development and the effectiveness of a given intervention (Altiere & Von Kluge, 2009; Huang et al., 2014; Meadan et al., 2010; Osborne et al., 2008).

Parents of children with ASD play an incredibly high stakes role in their child's well-being- often beyond the duties of a parent of a typically developing child, and in this case there appears to be no 'path of least resistance as parents report having "fight for every inch" (Carlsson et al., 2016).

A process of structural changes within the families occurred. Many parents reported achieving a point of acceptance of their child as a crucial step to adapting. This required a re-evaluating of what one considered important in life and the letting go of a preconceived idea of family life. These steps moved the family towards a greater sense of meaning and coherence, as well as a sense that the demands they may face are manageable and can be engaged with.

In a sense there are moments of temporary release- or the release in one area of functioning or concern, providing momentary relief until it is replaced with a new concern or daily difficulty.

Many of these families report having "adapted" and to some degree appear to be managing the demands placed on them successfully, in that they are getting things done. However, if we look at the definition of bonadaptation versus maladaptation (Holtzkamp, 2010; Greeff & Van Der Walt, 2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; McCubbin & Thompson, 1991; Walsh, 2003): the adaptation is maladaptive when the demands exceed the capabilities of the families resulting in crisis. A large amount of adapting occurred in each family however the costs appear to be large.

Most of the parents report exhaustion and fatigue, "being too tired to do anything" (Participant E), isolation and social restrictions, ongoing stress and family conflict about roles and responsibilities. Highlighting concerns about parental emotional wellbeing. Therefore, there appears to be a level of adapting however whether this is sustainable is questionable. Thus, the importance of understanding these factors becomes clear. These are the areas where practitioners can step in and support parents- even the ones who appear to have adapted.

CHAPTER SIX

CONCLUSIONS

6.1 SUMMARY OF FINDINGS

A process of thematic analysis was used to explore the dynamic qualitative data that emerged from the interviews. The main themes were identified and paralleled in pre-diagnosis and post-diagnosis experiences.

Analysis highlighted the following themes:
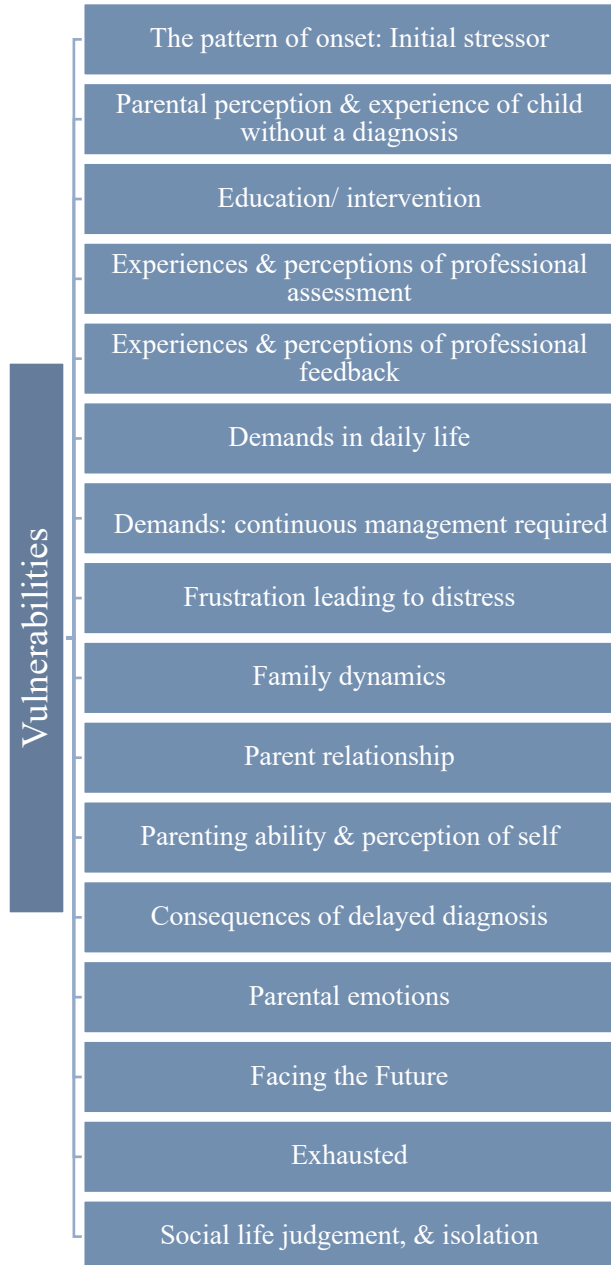
Figure 6.1 Summary of themes identified: Vulnerabilities
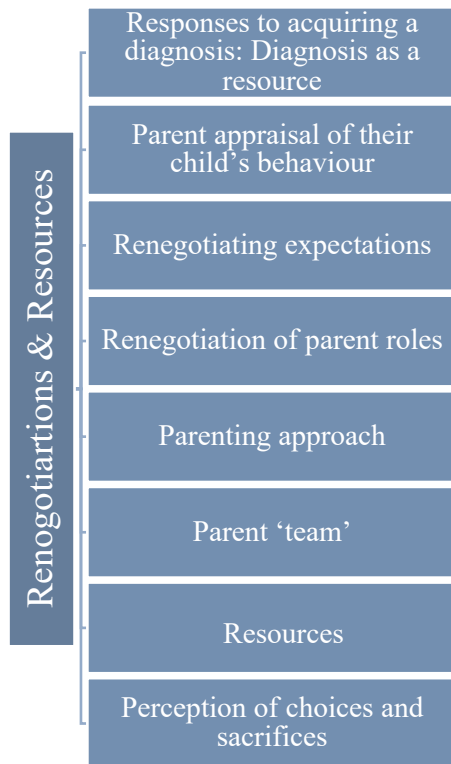
Figure 6.2 Summary of themes identified: Renegotiations & Resources

6.2 CONCLUSIONS

These families experienced high levels of pile up, alongside psychological dynamics, daily demands and navigating a disrupted family life. Many parents adapt or make changes which they report to be satisfactory however they also report exhaustion, isolation, lack of social support and 24/7 demands of care. Thus, as it is clear that these changes are deemed essential by parents, it is just as essential that they be given the support they need in order to cope and adapt as effectively as possible.

A significant factor that emerged, which is supported in a number of resilience theories, is the importance of meaning and appraisal (Holtzkamp, 2010; Greeff & Van Der Walt, 2010; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1982; McCubbin & Thompson, 1991; Walsh, 2003). These parents changed their appraisal of their child to see the value of their child's input, changing their expectations and concept of what is important as they adapted to this 'new normal'. Having a happy child became more important while focusing on their own exhaustion or the challenges they face daily- and will continue face tomorrow- became less important.

It is possible that the key to resilience in this case lies with the following concept: not necessarily not being any of these things- not being tired, or stressed, or isolated, or having a 'perfect' psychological profile, but instead the importance potentially lies with how these parents value each of these things and how hard they've worked to get to a point where they are sacrificing rather than their child having to sacrifice. This may bring in a different level of resilience- an understanding that for these parents, doing what they do, regardless of the fullest impact on themselves, they do it for a specific purpose, and their purpose is their child and children. Whether or not this is sustainable or the most optimal option in terms of their own mental health highlights an important gap for parental support and intervention as well as an area worth further study.

6.3 LIMITATIONS

The current study had some limitations. One limitation may be the generalisability of findings as the current sample had limited variability in race, culture and socioeconomic status of the participants. The small sample size may also impact generalisability. Future research attempts should involve greater sample sizes and a greater heterogeneity of participants.

A lack of comparable literature was another limitation as the researcher found few articles relating to ASD within a South African context and an even smaller amount relating to the experiences of parents of children with ASD. The majority of the published articles were conducted in different social and cultural contexts, providing a limited source of comparison.

6.4 RECOMMENDATIONS FOR FUTURE RESEARCH

ASD research remains limited in South Africa despite growing interest in expanding the research base within this context. This research study provided the opportunity for in-depth exploration of parental experiences and challenges relating to raising a child with ASD in a South African setting. The findings highlight the value further research in this area could hold and therefore emphasises the need for further exploration. Future research should involve detailed exploration of parental experiences at various phases of the family's 'ASD journey' as these parents encounter numerous challenges and obstacles, unique to their role of parenting a child with ASD. Upon reflection, multiple interviews with parents over a period of time may provide an even richer data set for exploration. Further studies may find value in exploring a renegotiation of resilience within the context of having a child with an ASD diagnosis.

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APPENDICES

Figure 1.3 Number of publications per research theme category per African country
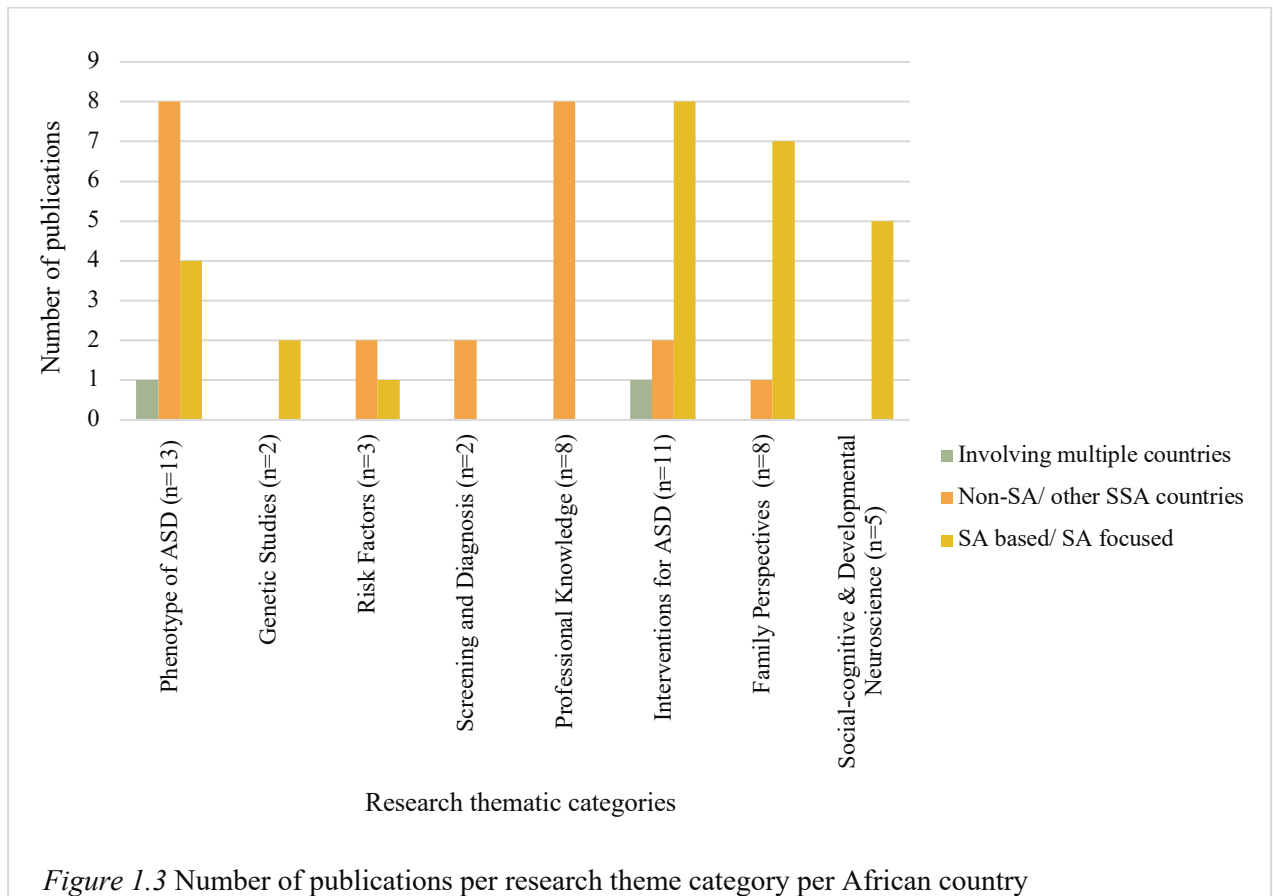
APPENDIX B:

Table 1a: Research on ASD in South Africa, directly related to parental experiences.

	Total	Label	No. per topic	Topic	Authors (date)	Sample size	Method
Psychosocial experiences (focused on parent experiences)	12	A	3	Parent challenges and strategies	Alli et al., 2015	10	Semi-structured interviews
					Fewster & Gurayah, 2015	11	Semi-structured interviews
					Oliver & Ah Hing, 2009	8	Semi-structured interviews
		B	1	Parent experience of diagnosis process	Mitchell & Holdt, 2014	7	Semi-structured interviews
		C	1	Family resilience	Greeff, 2010	34	Self-report questionnaires and an open-ended question
		D	1	Family routines and quality of life	Schlebusch et al., 2016	180	self-administered survey

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			Support sources (informal): social media	Cole et al., 2017	6	Qualitative, phenomenological design
	E	2		Gerber, 2014.	10	Open ended questionnaire (electronic)
	F	1	Transition to adolescent-parent perspective of child	Meiring et al., 2016	14	Semi-structured interviews
	G	1	Regarding father carers	Pottas, A. & Pedro, A., 2016.	8	Semi-structured interviews
	H	1	Regarding treatment knowledge	Wetherston et al., 2017	46	Quantitative, Electronic questionnaire survey
	I	1	Use of medication for their child	Louw et al., 2013	65	Descriptive, quantitative, analytic study using survey questionnaire and the Nisonger Child Behaviour Rating Form (NCBRF).

Table 1b: Research on ASD in South Africa, not directly related to parental experiences.

	Total	Topic	Authors (date)
Psychosocial experiences (not focused on parent experiences)	3	Teachers attitudes on inclusion	
		Assessing baseline knowledge of ASD in teachers	
		Sibling attitude	
Medical	3	Genetic studies	
		Maternal stress as a risk factor for ASD	
ASD research in South Africa/ Africa	3	Regarding current research available/ future goals.	Abubakar, A., Ssewanyana, D., & Newton, C. R., 2016; Catherine, E. R. & Li-Ching, L., 2017; Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G. F., & De Vries, P., 2013
ASD in South Africa	3	Characteristics and demographics	De Vries, P. J., Venter, A., Jacklin, L., & Oliver, C., 2013; Springer, P. E., Van Toorn, R., Laughton, B., & Kidd, M., 2013; Van Biljon, S., Kritzinger, A., & Geertsema, S., 2015
ASD in Africa	1	Commentary	Newton, C. R., 2013.
Multi-country outside Africa	1	SA and South Korea	Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., & Wetherby, A. M., 2012
ASD & other Developmental disabilities	3	Stigma, resilience	Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A., 2015; Greeff, A. P. & Nolting, C., 2013
Focus on other conditions	1	Screening for trauma	Collings, S. J., Valjee, S. R., & Penning, S. L., 2013
Adaptation and validation of screening and	3	2 translating scales; 1 assessing effectiveness	Chambers, N. J., Wetherby, A. M.; Stronach, S. T., Njongwe, N., Kauchali, S., & Grinker,

| diagnostic tools (SA) | | | R. R., 2017; Smith, L., 2017; Travis, J. & Geiger, M., 2010 |

APPENDIX C

Table 2.1 Showing criteria of ASDand examples (adapted from DSM-5, APA, 2013)

Main category	Sub-category	Aspects within this	Examples
Social communication & social interaction deficits	Social-emotional reciprocity	Abnormal social approach	Language often one-sided, lacks reciprocity, used to label or request instead of commenting sharing feeling or converse.
		Failure of normal back-and-forth conversation	
		Reduced sharing of interests, emotions or affect	
		Failure to initiate or respond to social interactions	Difficulty processing and responding to social cues: when and how to join a conversation, appropriate things to say
	Non-verbal communication behaviours	Poorly integrated verbal & nonverbal communication	Difficulty co-ordinating non-verbal with speech: present as odd, wooden or exaggerated.
		Abnormalities in eye contact & body language	Absent, reduced, or atypical
		Deficits in understanding/ using gestures	Impaired joint-attention: a lack of pointing/showing/ bringing objects to share with others, failure to follow others pointing/ eye gaze.
		Total lack of facial expressions & nonverbal communication	May learn a few functional gestures, lack of spontaneous use of gestures.
	Developing, maintaining & understanding relationships	Difficulties adjusting behaviour to suit social contexts	Difficulties understanding deeper complexities of social behaviour (and language)
		Difficulties in sharing imaginative play or in making friends	Preference for solitary play, desire for friendships but a lack of realistic understanding of what friendship entails.
		Absent/reduced/ atypical interest in peers	Rejection of others, passivity or inappropriate approaches-seeming aggressive or disruptive.
Restricted, repetitive patterns of behaviour,	Stereotyped or repetitive motor movements, use	Simple motor stereotypies	Hand flapping, finger licking
		Lining up toys or flipping objects	Spinning items, lining up toys

interests or activities	of objects or speech	Echolalia or repetitive speech	Echolalia: delayed or immediate parroting of heard words, use of "you" when referring to self.
		Idiosyncratic phrases	Stereotyped use of words, phrases or prosodic patterns.
	Insistence on sameness, inflexible adherence to routines or ritualised patterns of verbal/ non-verbal behaviour	Resistance to change	Extreme distress at small changes: changes in packaging of a favourite food, insistence on adherence to rules, rigid thinking patterns; Need to take same route or eat same food every day, greeting rituals
			Difficulties with transitions
		Ritualised patterns of verbal/ non-verbal behaviour	Repetitive questioning, pacing a perimeter
	Highly restricted, fixated interests that are abnormal in intensity or focus	Strong attachment to or preoccupation with unusual objects	Attachment to a pan, or preoccupation with vacuum cleaners, spending hours writing out timetables.
		Excessively circumscribed or perseverative interests	
	Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment	Apparent indifference to pain/ temperature	
		Adverse response to specific sounds or textures	Extreme responses to specifics; extreme reaction to or rituals involving taste, smell, texture or appearance of food or excessive food reactions.
		Excessive smelling or touching of objects	
		Visual fascination with lights or movement	

APPENDIX D:

Table 3.1 Methodology approaches of South African research studies on parental experiences of ASD

Authors	Sample size	Method
Alli et al., 2015	10	Semi-structured interviews
Fewster & Gurayah, 2015	11	Semi-structured interviews
Oliver & Ah Hing, 2009	8	Semi-structured interviews
Mitchell & Holdt, 2014	7	Semi-structured interviews
Greeff, 2010	34	Self-report questionnaires and an open-ended question
Schlebusch et al., 2016	180	Quantitative, self-administered survey

Cole et al., 2017	6	Qualitative, phenomenological design: specifics unknown
Gerber, 2014	10	Open ended questionnaire (electronic)
Meiring et al., 2016	14	Semi-structured interviews
Pottas, A. & Pedro, A., 2016	8	Semi-structured interviews
Wetherston et al., 2017	46	Quantitative, electronic questionnaire survey
Louw et al., 2013	65	Descriptive, quantitative, analytic study using survey questionnaire

APPENDIX E:

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31 January 2017

Ms Charnè Dee Glinski (214579859)
School of Applied Human Sciences – Psychology
Howard College Campus

Dear Ms Glinski,

Protocol reference number: HSS/1606/016M
Project title: A qualitative study exploring the psychosocial experiences and difficulties of parents who have a child with Autism Spectrum Disorder (ASD): Within a South African context

Full Approval – Expedited Application

In response to your application received on 29 September 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and **FULL APPROVAL** was granted for the protocol.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

....
Dr Shenuka Singh (Chair)

/ms

Cc Supervisor: Mr Sachet Valjee
Cc Academic Leader Research: Dr Jean Steyn
Cc School Administrator: Ms Ayanda Ntuli

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APPENDIX F:

1. INVITATION TO PARTICIPATE:

A Qualitative Study Exploring the Psychosocial Experiences and Difficulties of Parents Who Have a Child with Autism Spectrum Disorder (ASD): within a South African context.

The study will aim to explore and understand:

- The psychosocial experiences and difficulties that parents of children with Autism Spectrum disorders encounter.
- The challenges these parents face in daily life; socially, emotionally and psychologically.
- Parents' perceptions of their experiences before and after their child was diagnosed with ASD.

It is hoped that the results of the study could assist with possible future psychosocial parental support interventions. By gaining knowledge around their experiences, clinicians can begin provide appropriate support for parents of children with ASD.

Participation in the study will involve a 50 minute interview and will be on a voluntary basis.

No personally identifiable details will be released or used in the research, and pseudonyms will be used for all names in order to protect participants' identities.

If you wish to participate please contact cdglinski@gmail.com as soon as possible.

Your participation would be greatly appreciated.

Kind regards
Charne Glinski

3. INFORMED CONSENT FORM:

A Qualitative Study Exploring the Psychosocial Experiences and Difficulties of Parents Who Have Children with ASD: within a South African contex*t*.

This research project is about the experiences of being a parent of a child with Autism Spectrum Disorder (ASD) within a South African context. The study seeks to understand the difficulties these parents face in daily life, socially, emotionally and psychologically. This study will also aim to understand whether there are certain deficits that cause more psychosocial difficulties for the parents.

Research participants are parents of children with Autism Spectrum Disorder in the Western Cape. The experiences of both parents is of interest to the study where possible. Participants will be asked to participate in a semi-structured interview reflecting on their experiences and challenges of parenting a child with ASD. The interview will take approximately fifty minutes.

Research participants will be asked to give their contact number and email address for the purpose of a follow up discussion during the research data analysis phase. As part of a Member Checking process, the research findings/interpretations will be discussed with the participants and they will be asked to comment and share feedback on whether the interpretations made are an appropriate reflection of their experiences.

Participation in this study is voluntary. Participants are free to withdraw at any time. The interview will be audio recorded.

To ensure confidentiality and anonymity, only the researcher will have access to participants' personal details. Participants will then be assigned a number, which will be used as a reference by only the researcher and research supervisor. The interview data will only be read by the researcher and the research supervisor.

If there are any areas of concern or questions regarding the studies aim, purpose or role as a participant, the researcher will provide this information. A copy of the final report will be made available to all participants on request.

APPENDIX G:

Sample of interview transcript

INT:	Maybe we can start off with how old is your son?
Participant	I've got two sons on the spectrum, the oldest one is twenty-two (22) and the youngest one is nine (9).
INT:	Ok.. so it's quite a combination?
Participant	Hmm it's very different it presents itself very differently in both of them they have complete types of autism they are very much different, so ya
INT:	Ok… [phone] in what way?
Participant	Well for starters Child B 1 (phone goes off) gosh this can only be…(looking at her cell phone) my husband sending photos of the dogs! (laughs) ha ha ha we've substituted… we've given up on our kids and now we just love our dogs so (laughs)
INT:	(laughing) that's ok!
Participant	Um… basically Child B 1 was was classified how can I put it he was never diagnosed until the little one was born and we discovered some issues with the little one.
	Child B 1 always had issues with um well his attention span low muscle tone praxis a lot of stuff like that and then there was a diagnosis of dyslexia at one stage but nobody could ever pin point what was wrong and um… he was verbal so you know and he spoke so there was no real alarms of it ever being anything on the spectrum and then Child B 2 was 3 when he was diagnosed and then obviously the first thing my husband and I are people that need to be empowered with info so we jumped in to the internet and just learnt as much as we could and as we were learning about autism the red flags started going up regarding Child B 1 and we had no… he he at that time was 15. And then we had him formally diagnosed at 16. Um so the the the label they slapped on him which I'm completely don't use or talk about anymore because it tends to water down the effects of autism and I
	Um… I have a problem with parents that want to use the label of Asperger's, because they think it is "autism light" and the problem is it has a major impact on the person because the services provided for that person, the understanding for that person is much less than it is for the person sitting in the corner banging his head against the wall.
	You know so I my kids are both autistic and um I and and we've um we've explained it to both of them that way and um they do understand that that they is a very wide spectrum so that's basically the two sort of
	Child B 2 was not verbal at all where Child B 1 had language skill or let's put out this way he had speech, B didn't have speech at all.
	Um and I think that was the biggest thing that we missed when we took Child B1 to all these professionals and that was the major concern and major problem, and is till find it today, I see so many kids in school that are labelled ADHD, um hyperactive whatever and in actual fact, those kids are so totally on the spectrum and they've been misdiagnosed and they struggle their entire lives not knowing what's wrong with them. Not to say there's anything wrong as such (but why they're are struggling) but the biggest question people ask them is what's wrong you with instead of saying why are you different um type of thing so that's basically been our experience um obviously with Child B 1 not receiving the right intervention from a very young age they way that bent has his um disabilities or not disability not the right word his

	deficits are much bigger than Child B1 than Child B 2 and his depression and anxiety is much more acute because of the fat that the time when he was diagnosed he's a teenager and um everything that goes with that and it's damage there's 16 years if damage that needs to be rectified and you can't just do that over-night, whereas Child B 2 has lived, has been in the position where autism has just um it's like having blue eyes or brown eyes, it's like having or like having big feet or small feet to him it's characteristic if who is and
	And to him it's not um… because I think to a certain extent we've raised him a bit in a bubble, but in a bubble in the sense of protecting him but also uhhh… fine-tuning the environment to suit autism and not necessarily [meeting his needs?] and forcing him to live in a world that's not made for him, we decided to force ourselves to live in a world that's not made for us. So, we've gone 50/50 on that …We force him sometimes to come to our world, but we indulge and enter his world very often as well, type of thing. So that's basically our approach you know type of thing.
INT:	So quite um different sort of journeys for you both as you know parents towards those two different diagnoses [v diff]. You know pre-diagnosis what was that like?
	Those are two very different stories [ya]
Participant	The the Child B 1's story is a story of um guilt and and and um almost giving up and despair because you feel bad because you didn't know better
	And nobody else… and this is the thing doesn't matter what we did as parents we went to see everyone I had him at a speech therapist when he was tiny and and you know this is what's frustrating is the service deliver from professionals
	There is just some… it's getting better, and in general there's so many misdiagnoses and I think to a certain extent instead um I suppose we there was no way we could have known because I mean [well this key things] exactly and um and I think with B with Child B 1- we always felt that we were failing him and we always felt guilty and we were parenting from very much guilt perspective but that everything is also not understanding him made us sacred of him we ended up fearing him because we didn't know him we didn't know who he was.
	Um when he was 11/12 I said to my husband um I didn't there are nights that I feel like I need to lock my bedroom door because we could be living with an axe murderer. That's how little we knew about this human being.
	He was just a complete enigma and because we didn't have the tools to access his personality or to draw him out and he always ended up being um attacked and and um criticised and dogged on.
	It just changed who he was and who he is, and it's taken a lot of time it's taken a lot
	I mean… you basically have to um turn everything you know about parenting upside down because that's what it takes to parent a child with autism everything you think you know about good eating you end up doing a lot of the opposite, because good parenting for neurotypical and good parenting for autistic kids are very different. My husband still struggles, and they still bump heads on a regular basis
	He would like phone me and say you won't believe what he did now again, and I would like… I'd listen hear him out and "but he's autistics" and he would like yay a ..But did you want him? did you do this? I did the checklist with my husband and then he's like, "ya you right".
	So, but because I spend the majority of the time I'm much better trained at dealing with them and becoming automatic response everything I did is in preparation and I lose it, but I obviously have more contact with the kids so it's a lot it comes more

	naturally for me to um provide um uh a situation where they feel less anxious or whatever the case.
	Where Child B 1 was normal into it and he was accepted into it and as we were Child B 1 much older so we were younger a lot younger didn't have access to in of the way we do today when he was small financially we didn't the resources when he was growing yup the way we do have now so there's a lot of things that are different and unfortunately.
	When it comes to autism it is an expensive disorder to have because the facilities and the interventions are one on one makes for it being expensive and specialised so
	There's a lot of um um differences between the two. How they were raised and that.
INT:	And it sounds like um… you know quite a very active stance with both of them regardless? Before diagnosis from your side as parents it sounds like you really did try to understand whatever way they went different pathways. What did you, um find the most challenging? Between the two before diagnosis? If we had to look at each for Child B 1 for you, what the most challenging before diagnosis?
Participant	Well for both of them it was education.
	To have Child B 1 in a school it was always frustrating um he just ya and with Child B 2 we couldn't put him in a -this before diagnosis?- doesn't matter where we took him to whatever preschool he wouldn't last a morning and he would phone me and say please come fetch this boy.
	So that was a big deal with both of them is to find a place. Now if you a working parent what are you going do with your kids?! You have to put them in a creche you have to put them in a day care you have to put them in school and if schools turn around and say listen we don't know how to deal with your child take him away. What are you going to do?
	[absolutely]
	I was in the with Child B 1 I was working so we didn't have much choice but A was a much more docile where Child B 2 is all over the show so Child B 1's sensory issues were not as acute as Child B 2, Child B 2's sensory issues are very very disturbing to him he has a lot of sensory issues.
	Where Child B 1's sensory issues are not that bad, but his anxiety makes him very passive he goes into shut down he shuts down when he's anxious
	Where Child B 2 um melts down and it's a very external experience where Child B 1's experience is very internal, so to a certain degree we got away with Child B 1 at preschools and creches and stuff, not with when he started going to school he was just not grasping work and was being left behind a lot of the time
	So then the journey starts with where do you find a school that can accommodate him and so on and so forth where you go down roads and try and look at alternatives but nothing ever is the right, because you don't know how to educate, you don't know how to present in for for this child to learn, because you don't know what's wrong.
	Whereas with Child B 2, swimming lessons, with one swimming lesson and it's like sorry can't take him can't cope uh day care I've literally sometimes I drop him and sit outside and wait in the car for them to phone and it was usually like 20 minutes and I would say don't worry I'm here. Um, so that was the biggest thing is education um because that is one of the basic rights that children have is to be educated and if you have s system that doesn't cater for them or understand the way that they learn then you have a problem.

	A big focus that's why I, very much apprehensive with regards you the American system and the American, um I follow the UK and Irish philosophy and research and uh intervention systems and so on and even Canadian but not the American. Because the American have been… there there… I don't know if you have read this [inaudible] boooq*(bomb sound) it is **unbelievable**. Put it in your Christmas list. It is unbelievable. It explains how autism speaks and all these places has hijacked autism for personal again and whatever so I'm sceptical of that.
	The on thine that is very very clear with regards to the difference between the UK and the Americas. Are the fact that the UK focusses a lot on making the parent the prime educator and prime care giver and not has to pay somebody else to do it. Cos the type of thing we have in South Africa were very colonialised
	You have lots of cheap labour that we can employ, and we can teach you and you will raise our child and that's the way it's been in SA cos a we have this benefit of cheap labour, And unfortunately, a lot of parents are looking towards getting someone else to educate and fix their child. And he Americans also have a strong um movement towards you not accepting but fixing it it's something that needs to be cured something that needs to be remedied instead of saying you know this is just different form of just a different [way of thinking] just a different development of the brain different you know um type of person and um
	So, a lot of the neurotypical guys are not doing a good job of running this planet so…. You know um 15… Being neurotypical is not necessarily the nbest thing out there and thtas what I like about the UK is alsos the focus I do a lot of I do training on autism and I work with… And I do a lot training and I see parents.. and the one thing that was comes out is 'so where can I employ someone?"
	Where can I send my child? Who's gonna do this for me?
	And this is what we found is there are nobody there no services the schools that are out there are so expensive parents can't afford it people/ parents have to bond their houses to afford it stuff like that.
	Um treatment and uh I and that's what I like about the British system and especially Ireland because Irelands a… country, people there come to your home and they teach you how to educate and deal and and do the intervention for your child
	I find that south African people are still very much um 'it's not my problem', somebody else needs to does this"
	And that's why are very much you know this is my child I have the best intentions and the best ability to understand and educate my kid and that's why I'll do it myself.
INT:	Absolutely and research has shown that parent-based research is so effective . symptom wise characteristic wise with each of them-what did you find most difficult.
Participant	With um Child B 2-is this pre-diagnosis?
	The biggest issue was behaviour he was like a little wild monkey that juts he he he either had to fighter he had to run he bolted he would disappear, and he would run it didn't matter where we went he would run. So, it was nerve-racking because safety
	He would run in front of cars and he would take the keys
	People would find him in the road luckily we live in a small town, so everyone knew him. That that is you couldn't take your eyes off him because he would literally um put himself in danger. With Child B 1 the biggest um, issue was that lack of um aff.. complete lack of engagement how was your day fine did anything happen? no. then you'd find out from school that a lot of that happened

	But he just didn't know how, you couldn't ask open ended questions you had to ask you know …Did you do maths? Did anything happen in the maths class that was a problem? No. And we didn't know that… Type of thing, that was the biggest issues because you you and then also you start thinking um he's doing it on purpose and you start blaming and that type of thing and just um And then his processing speed is affected his cognitive functioning his executive function to order and to plan and to get things done I mean he…terrible. So you would tell him a million times to do the same thing and he would get half and get distracted or the executive function is just the order wouldn't be there. Um so there was a lot of fighting with him a lot of constant how hard it is to get up in the morning get dressed and go to school ,why is this something we have to constantly repeat so there was a lot of that um so ya those were the two biggest concerns
INT:	And in terms of your family life before diagnosis? What was sort of your experience? What was the effect of each?
Participant	Well Child B 1, we had Child B 1 for 10 years before we had the other kids so uh we've got a daughter as well [in the middle?] ok… and um ya (laughs). My concerns for her are sometimes much greater than they are for my boys because it's just this is just sooooo not what she signed up for and this is just soooo not right we should never have them she should've been the only child so ya [how old is she now?] she's 11.[ok so also a tricky phase as well]. She was tricky when she was born! (laughs) And she's not on the spectrum, but there's a lot of spectrum traits it's not enough to warrant a diagnosis but obviously having two brothers and obviously being a girl there's a lot of autistic traits there's a lot things she does and she doesn't get metaphors and she doesn't get a lot of speech um what do you call it (Afrikaans word) [idiosyncrasies?] she just doesn't get it, and she would come to me and ask are you upset? Because she can't tell. If I speak loud which I often do, because that is the way I am, um she can't tell whether I'm excited or upset or whatever so there's that too.
INT:	Ok and how does she cope with them [her brothers]
Participant	Not well. She hates them they can die as far as she's concerned and that is as putting it as blunt , seriously she she she I I I I , I don't know if… she hates the situation… but I don't think she can tell a situation from the person yet… I think when she gets older shell start realising that… that you know type of thing.. umm ya no. ya she. She just no. she tends to have more time for her brother because he's older- the older brother. Because there's a bit of idolising hero worshiping that happens but as she gets older and starting to pick up om the issues with him she's starting to lose her respect for him. With the little one just irritates the life out of her, he just you know, he obviously hurts her or he you know um ya he just he's not the playmate that she expected in having a little brother so for her it's just pure disappointment but um She's extremely *extremely* smart and she's very authentic and very honest and we raise her that way she's got a very honest .. to us we don't force her to say things she doesn't mean we don't force her, we allow her to say that she hates the brother Then we try and explain her but you can't hate him, you can hate the way um not hate the way he is but you need to you know we try and figure it out for her um but it is it's very very verrry hard for her I think out of all of this in the family she struggles the most .. you cant
INT:	

Participant	And the funny thing is she's joined…
	I don't know if you… I mean they both [Computer game] addicts, so there's this website well not website a server called [Computer Game] which is specifically it's a server that was started in the UK and America for um…
	Because you can play…
	[Computer Game] online and play again people and the rest of the world and there was a lot of bullying and issues surrounding the one servers.
	So a few parents started this server called…
	You it's a white list server so you get audited you have to apply and then you can only go ono to it and if you are allowed on to it there's always and in present you can quickly go call an admin aand they; l'll deal what it
	They have a chill out room for the person and they've therapy and things like that. [amazing]you know calming techniques and stuff and if t=none of that works they'll kick you off and eventually as a last resort they'll do that and …
	Now she's joined that and she loves it and she's got all these autistic friends and she's constantly writing all these autistic um how they're different but not less[slogans?] all this nonsense t-but she cant stand her brothers so I think deep down inside there's an understanding but I think there's also that sibling rivalry
	That you have between neurotypical kids and then also having two brothers that get so much attention that get so much um um what's the word attention and she's the one that does everything right but she's always got to take the backseat type of thing.
INt	And was there a difference for her between the two diagnoses/ like sort of before and after diagnosis with the brother?
Participant	Well she's very, so her older brother was much bigger so developmentally she never noticed anything was wrong so- she was tiny he was ten so [big gap] and then Child B 2, um Child B 2 was very small he's then 2 years apart so to her he's always just the slow little brother because he's younger than her so I don't think she ever realised that there were any issues.
I	So for her it didn't really um there was no marker
p	Definitely not
I	So in general family life before diagnosis can you give me a picture of that?
	Geez like before autism… you know um
	I think … with Child B 1 we always knew something was wrong. But um we was was an easy child and an only child for a long time so we coped well with it um
	I think one of the big, one of the biggest issues not issues but biggest differences in family life before and after. Before was the fact that we had freedom- we had freedom to go places which all of a sudden stopped um when they got to the age where we saw but behaviour is a problem, where we ended up not going anywhere anymore or we'd end up forcing ourselves to go to places alone because we couldn't um take them with us because the behaviour was always such an issue.
	So um I think when you look at other people that are forever doing all sorts of things taking their kids skiing overseas and you know we can't even take our kids to the spur without it becoming a massive thing.
	So and then finding time as a couple to do stuff on our own and then finding people that can look after our kids cos' again baby sitters tend to get scared because they don't understand and they don't know whats wrong and we also, there always had to

	go find people and explain that this is how it works here type of thing. this is how we do it and you have to stick that type of plan and stuff so that so we could actually just get some time away from it.
int	Quite a difficult um sort of setup actually the babysitting thing you know like cos even just explaining to someone who hasn't had experience with an autistic tantrum
P	And that was BEFORE diagnosis so we didn't even know all we knew was we couldn't take our kids anywhere…
P	And with B 2 with B 2's situation, I'm like I'm the shittest parent of this earth and then you get other friends who's kids are just or their kids parenting to them is so easy and their kids are so easy and yooou are dying to get a nights sleep you are feeling terrible
	[go for coffee…]
P	So sick and tired of um hearing everybodys great stories and you having the nightmare of your life with your kids and you love them but raising them is a nightmare and then you start asking yourself the question should I have had children …And that comes up…
I	Quite a heavy…
P	It is! Both husband and I we often have those conversations you know um and tis very clear there's a very strong indicator that the two of us should not have had children. Back then that's what we thought. Now that we don't see our kids as broken anymore um
	We don't regret having kids
I	Absolutely so that's also quite a bit shift actually that can be quite heavy to carry a question like that… but also quite a big shift after diagnosis?
P	Ya you have to change… because clinicians also treat your child as if something is wrong and something needs to be fixed and and I think I think that's why Ben* uses me for training because I am the parent and I say the things that he's not allowed to say as a clinical psychiatrist there's a lot of stuff that he feels he's not allowed to say that because it goes against what he's been taught
	Whereas I say that because… I have nothing to lose type of thing…But the um I was gonna say the….
	A big switch that also takes place is in… what you had as a dream for your life and as a couple… and I think that the strength of the relationship um is tested way beyond anything that ever um could be throw at a couple because um if you are not on the same page then you will not survive (30:24)having children that need so much different um um approaches to life
	because otherwise you end up working against each other and there's a lot of resentment that comes in and also it's not good for the child if the parents arent on the same page
int	[and quite difficult… it seems there have to be quite specific ways of going about things,[part: definitely] that if you aren't on the same page would be very difficult
Part	And that is the amount of consistency between two parents creates a lot of insecurity in the child and I often find with courses and stuff it's always the mothers that that pitch and then Theres a lot dads that say no I was also an active little boy when I was younger and there's a lot of parents that don't accept it either together- Theres a lot of parents that one accepts it and the other doesn't and then what happens is the mother usually becomes the prime care giver because the father took a long time to accept it

	and by the time he accepts it he's so far out of the lop that he doesn't know how to handle the child and even if he tries he's not successful and it's a complete meltdown situation or disaster and then the mother is just steeped with more and more responsibility to be the prime care giver and the father ahs become resentful because not olny has he lost the dreams he ahd for his child, he's lost his wife.

Aand it's just like a complete um crazy situation… |
| Int | Absolutely and you know you mentioned when we started talking now, the change in your view or expectations for your children, I can imagine it's quite an adjustment… how was that experience for you? Between the two boys? |
| Part | Hmmm…]ummm… I think for A ok… ill be very honest with you…I don't think ive ever told anybosy this… um I got to a point where id given up on A… and this was even this was even prior to the..*** dx. Where I I looked at this child and thoughyou know what um this is the biggest ,… disappointment that ive ever had in my life this child is nothing like how I planned and hopef for him to be and I cannot carry on figthjing with him anymore imnow officially throwing the towel in. I will make sure that he stays alove and I will do whatever I can to provide for him.and that's that.

Then ten years later I had a little girl and obviously this was going to be my wonder child and it was great because she was everything that we wanted and then we had another little child which wa B and again B was um… I idnt want boys.. I I didn't wantboys… I was very disapoiinted when I was pregnant with A and found out he was aboy. So wheb I found out I was pregnant with M and she was a girl very very happy and chuffed and then we had the lats one and agiana he was a boy… I had a very difficult pregannay cwith him I was in anf out ofhisptals, there was lots and lots and lots of issues so by the time he was born um we were surspised that he actually was born at all but again thee was a little bit of disappointment that he was a boy cos I would've liked.. but! This was now our third child so weve got the little igrl and you know but now this is and this is now gonna be the son for H that is everything that A wasn't.

And boom!

Soooo… um… and the amount of disgust and self loathing that goes with giving upon your child I cannot explain it to you.. I think sometimes death is wrse.. it's worse than death to say to yourself in your heart I'm givin up on my child I loterally don't care for your future anymore I will do what I have to do to make sure hta you stay alive and that's it and then and then tohave your scond child and your third chuld turns out… so there's agreatsens of loss and great sense of diappoinemtn and then… 3445

Yooou… get a diagnosis. And the first thing that happens… when you get thad dx. Guilt goes away. Because you know this is not ,y fault. I did NOTHING wrong. This is literally a combination of genetic, situations, this was, youknow the soilw as ripe for this developmental difference and it happened. And that's the that's you literally as aaprent sigh relief and say ok this is not my fault and then you start looking at because… I think fom a certain perspective you um… that self loathing and that that disappointment is not with the child, it's with yourself. Because you created something that's broken aaand you mustve done spmething wrong. These things don't just haopen. So when you get a dx thtas when you startrealising thwres nothing youcould have done differently and then you know it's uts the knowledge that comes and you need to undertsnad, more and more understanding…

Aand um and then you come to the point where you say to yourself if there was a magic pill would I give it to my child, and you have to ask yourself that question. If there was a pill I could give my child to be normal, neurotypically normal, would I |

	give it to them… and then you start, most parents would say yes and I'm at the point in my life where I don't think I would…
I	In what way? Why would you not?
P	Want them to be different? Because if o wanted them to be anything different then there's a part of me that's still not accepting who they are now… and that's a problem.
I	That's quite a powerful start or pint to get to 3651
P	Exactly! And the thing is B is… and my H says it and the kids say it.. A says it and even M says it… she says um B is the love of your life… and he is! And they all know. And then they say, my H says to me, you need to stop letting everyone know that he is your favourite and I say I cant! My love for him is so massive, he cannot do anything wrong you knows (laughs) Ii just adore him so much! And I think to myself my relationship with him would've been different very different and and I dont know if I wanted it any different he really and truly is he is absolutely the love of my life I would he's just just the most adorable thing. There was a time where I couldn't say two words about him without crying because I just I get so overwhelmed with him! So um ya… and that's to me complete acceptance [absolutely] of who he is…
	And it seems like you know it hasn't been the easiest journey with both of them but it seems that's quite clear in your response to diagnosis and how you've responded to you know… him) looking around a very exciting classroom and you know you can see the effort you can see the love… how did your um your family life change with that diagnosis?
P	Uuummm the um my H's side of the family was ummm they don't accept it. They very religious we atheist were not religious at al don't believe in religion aaand so the first thing was 'it's because youre atheist', 'youre being punished' so there was a lot of that which you know… we just thought you know what I'm not going to spend my life explaining things to other people , if they want to accept it or not… so there was a lot of things… but we've never been close to our family um well H hasn't… he's not close to them at all. Um and… both my parents are dead so that was not an issue but ive got a brother and sister, and they were umm.. they were they were like with B they knew they could accept it but with A they struggled to accept because you know 'he looks so normal' so there was that nonsense. But they don't live here so we don't have any family that lives her they all like in Gauteng so um it didn't really impact our family life that much We did have a family get together holiday once and I got home and I was in tears and I said to my H this was the worst holiday of my life this was just so stressful and just trying to keep it together… and we decided well never ever do this again-ever! Now people come and visit us and we always make… but there's a lot of contingency plans that needs to be taken care of in order for us to accommodate family. but they all understand and they all respectful. The thing is also both my H and I are very... whats the word… uuum we very… uh… I don't know I wouldn't say dominating but we very assertive people and we um we wouldn't stand for it… um and that's why also we tend to entertain on our turf because I will not out myself in a position where I have to be in someone elses home or somebody elses space and I need them to adapt to fit my needs I I wouoldnt ever do that because I don't think it's far but that why

	when we do entertain or have people or have nay family interactions it's always on our turf so that here I can dictate what goes and what doesn't go and if tou don't like it you can leave When it comes to family we've made it very clear from the begnnings that youe either with us or agaiants us. If youre agaianst us then we cant do this cannot . you need to come around or you need to nugger off. One of the the two. Type thing sooo but ya we…
I	And within your family unit? Between you your H and the kids? Was there ashift in your dynamics? The way things… your experoences.
P	Ya! The thing is H and I have always.. um.. were best friends to the degree that we have very.. honest outlook and we don't don't sometimes too honst like crude honest and wed look and we'd both sit and say we cannot belive we produced this", I mean how? and we joke l about things ike that, so thers a lot of um.. this is the thieng. Its always the two of us agaianst them. When there is any form of um whats the word…if there's any issues in the in the or or conflict we always together on the same team against them. We never split up and I'm with one of the kids we don't do that. [INT: so kind of a team approach?] we we stick together nomatter ehat even if we disagree we stick together. We'll afterwards have a fight but when… ya we always on the samr team when it comes to any confcuit in the family. that I think is the one…bbecause you have to be. You cant do this on your own and you studpid f you think you can and by the itme that tou realise that you cant then it's porbablytoo late and you've done too mcu damage and therwes no realtionsnip to carry on with. So I think from that perspective we knew that from the gte go. But um doesn't matter what we need to be on the same…t eam[yaa]
I	It sounds like quite a team approach. Um in terms of symptoms and experiences within the family what do you find kind of causes the most difficulty? Between the two boys, in the family, for the family essentially?
P	Um I think A um A cant.. causes.. we have a lot of conflict surrounding A because he's 22 already aaand um… H still has expectations… that I know he cant meet. So … if he would have an interaction with A and it would be some form of conflict ill always step in and try and um explain to him that this is why… and then he would get cross with me because he would say I takes sides… but we've stopped doing that now. I leave them let him get it out of his system and then I will go to him afterwards what you did here this this and this and the thing is also it takes a lot for a guy to uh.. it's hard to explain it because.. it's had for a guy to take criticism from the spouse when it comes to… but really take the criticism on board and luckily we in the position where H one hundred percent trusts me as the expert and he takes my lead and we've got an agreement. He goes to work that's his level of expertise. I do not tell him how to run his company. He can ask my opinion an ill tell him my opinion but I will not tell him how to run his company. Same way he trusts me as the expert on autism and raising our children and education therefore he will not try… he will give an opinion but … if I need to know about my finances I'll will go him and say pleas help me with this, stuff he needs to know he'll; come to me. So we've agreed upon what is our field of expertise and we respect that. [yaaa] and we operate within that boundary type of thing.
I	So for.. for A it's sometimes dealing with a conflict that..
P	[there is conflict, because A has also learned to manipulate, he's learnt how to play mom and dad up against one another he would like ask dad for something and dad will say no and hell come to me and pretend that he never asked dad, or he wouldn't even bother to say hell just ask me and I would say to him ya sure no worry and then

	H would like 'he just asked me' andw ill saell y I dindt know that.so he does that. So now my response when he asks me for nayhting my response it what does dad say
	And then he would, cos he wouldn't sya to me ive already asked, I don't knonw if it's manipulation or that's just [omitting the truth?]
	ya I think to a certain degree he doesn't understand that there's a diffrrence. That if dad alreadys said that that should moms decision too anf if she ahd known al the info that would probably have influenced the deciosn but so you know so hmmm.. so that tends to.. to happen.
	With B there's not really um B doesnt really create any conflict, M creates a bit of conflict in the sense where H feels I'm very hard on her sometimes like you know which I probably am but um most of our conflict in our family iuh rise around surroundgin um A. basically
I	And for the two boys are there specific characteristics, or traits specifically spectrum traits that you find also quite difficult to work with? Or still stand out?
P	Hmmm.. um B's… concentration is an issue like he really and truly is all over the show he literally vibrates an then you cant sitl still and… so he constantly needs um breaks and he contasntly needs intervention to get him through a working day and that's um that's challaegig. And then he also has terrible performance anxiety whre he doesn't want to do something becaseu he's scared he cant od it right, so then there's a lot of resistance and behaviour um to try and get out the work or whatever the case is so there's a lot of that but you know I general if we… if we stick to our routines and our preparations and our visual schedules and our systems then he, we usualy have you know very little resistance but it's just… it's like the level of of.. interaction with him is like the level ofinetraction in a toddler.[hmmm] which is exhausting! Imagine having a toddler for the rest of your life! And I mean he's nine already! And I just mean the amount of managenemtn there's sommuch management in going in to him getting through a day and getting through school and getting through life in general. That is is exhausting! And the minute you don't management and the minute you drop the bvall it all goes to shit! Si that, that is um… one of the biggest challenges! Because there are days where you just want to say (gestures hands up), and you cant… you just cant. It just it just does so much damage.
	Ummm.. with A his biggest charcteristc I think is ooh… gosh.. is juts getting started. He cannot get started! His executive function is juts so ppor [that like firing pin] ya! He just, you just have to tell him everyday and constatntly be on him because hejust cannot get himself ordered and managend. He cannot maage himself to get these thongs um sorted so that is probably the biggest frustrating and challangeing behaviour um… that we have..
	And with the two um… symptom-wise, and we've spoken about a few, are there any that we haven't chatted about? That you experience with them? Because they're quite different, quite different little 'spexctrum personalitieis if we could call them that? If you could give your top 5 of each that are most prominent?
P	Ok.. um.. B's sensory processing issues are are um pronounced
	A's is not
	A's executive functioning is very pronounced, B's is better but I think it's more because of intervention from a very young age where he's learned augmented supports to compenasate for a lot of the executive fucntoining deficits umm…
	B's speech was an issues major issue until we went and became English with him, we actually Afrikaans speaking aand.. um A was raised English I don't know why but he was raised English,, and then B was raised and M was raised Afrikaans and then B

	about a year ago- and his speech waa getting ther ebut it easnt what it was supposed to be for his age and his soeech only started coming through about 5 only started speaking when he was 5, and then he just, he wateches a lot of youtube and spends a lot of time on the internet and you know he's a complete youtuber. And he basically came to us about a year or two ago and said um in a very round about way um that he's not happy with being afriakaans and we offered do you want ot be english and he said yes and then it just, his language development just escalated [that's amazing] and his language is now quite um it's ya! Its not the same person. He obvoulsy he, there's a lot of it that's not formed by him there's a lot of he's basically, he speaks with a british or Amaerican accent.. aand it's a lot of words and stuff and phrases that is ibvoulsy just a phrase learnt {like cut and paste] but uses them compeletely accuarately. But when you are, when he's forced to acutally speak um when you ask him a question that he doesn't have a phrase for that he actualy has to think you can see that language is still not easy. But he does get around to expressing himself in a very concrete way soo.. ya.
But I think um… understanding him was the big, very frustrating part. Ummm but he's got basically the whole thing, sensory sruff, his proprioception is bad, he's visually um sensitive to light, his hearing is um [sort of the whole shebang] ya the whole!
Whrre A is not sensory at all but he he's very clumsy and he does have some praxis and then he but his exectuve functioning is proably the biggest symptoms that affects him to order… his day and to do planning you know motor planning and things like that so..
I	Thank you so much! I really appreciate, I'm sitting her thinking the amount of information, you've been able to and willing to give {not a problem!!] it really is, it's so exciting to to, you know I can really hear certain things coming up that are common in quite a few of the conversations but also really different perspectives! And I'm really appreciative of that! Thank you!

Um what I will do, sometimes there may be one or two clarification items that I might need ot get back to you with- is it ok if I email you? And then in the next week ill email you the invite and the 'game plan' and a few sort of demographic questions, if that's ok? |
| P | No problem! |
| | Thank you again! |