Parents' experiences of accessing education for autistic learners in primary school

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Declaration

I hereby declare that this dissertation titled: "*Parent's experiences of children diagnosed with Autism Spectrum Disorder in accessing education for their children and the learning models currently available to educate their children*" is my own unaided effort. All sources have been duly acknowledged and referenced according to the American Psychological Association (APA) 6th edition reference style.

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Date:

Acknowledgements

List of abbreviations and tables

Abbreviations

ABA	Applied Behavioural Analysis
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CDC	Centre for Disease Control
DSM V	Diagnostic Statistical Manual for Mental Disorders 5th Edition
GVM	GemIIni Video Modelling
LPS	Learning Preferences and Strengths Model
MDGs	Millenium Developmental Goals
TEACCH	Treatment and Education of Autistic and Communication Handicapped Children
UN	United Nations
USA	United States of America
WHO	World Health Organisation

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Abstract

Background: Autism Spectrum Disorder is neurodevelopmental disorder which is estimated to currently affect 1 in 10 children in South Africa. Children diagnosed with this disability are required to attend schools that are specialised to cater for their needs within the South African education system. Currently autistic children receive education in special needs or inclusive schools.

Aim: The aim of this study was to explore the experiences of parents with autistic children in how do their children access education and the efficacy of the learning models, which are used in schools to educate autistic children.

Methodology: A qualitative research design informed the study. One focus group with six participants was conducted, followed by semi-structured interviews with individual participants. Data was analysed using thematic analysis as per Braun and Clarke.

Findings: The results indicated that parents experience continuous difficulties in accessing education for their children. Accessing within this context refers to the ability to gain entry into educational institutions. The difficulties were prevalent from early childhood education. Parents' difficulties include having limited number of schools with the required resources or facilities, which could cater for their children's needs. This was primarily attributed to systemic challenges such as limited resources and poor policy implementation. Furthermore it was observed that there was limited supported available to assist in accessing education. The study findings were not able to ascertain the efficacy of learning models within the South African context. The results indicate that there needs to be resource review to explore how institutions can assist parents in accessing education for their children.

Conclusion: In conclusion, parents of autistic children experience systemic challenges in accessing education for their children. Furthermore there is a lack of systemic support for both parents and their autistic children.

Key words: autism, access, inclusive education

Contents

Chapter One

Introduction

1.1.   The orientation of the study

The study aims to explore the experiences of parents with autistic children in accessing education for their children and the applicability of the learning models which are used to educate them. The rationale for undertaking this topic was there is currently very little research conducted which focuses on autism spectrum disorder and the experiences of autistic individuals, their families within the South African context. The research was conducted from a qualitative framework and a systems theory was used to understand the research topic. It is hoped that the findings of the research will assist in the development and improvement of educational interventions which are not only applicable but also sustainable within the South African context.

1.2.   Background and context of the study

The study is the result of a growing need to understand autism spectrum disorder within the South African education context. There has been an emphasis placed by the Department of Basic Education that educators need to familiarise themselves with Autism Spectrum Disorder in order to be equipped with the necessary skills to address autistic learner's needs.

There is a dearth of schools available to children who have been diagnosed with autism spectrum disorder within the South African context. It was previously reported that there are only nine schools available for children within the South African context (Bateman, 2013). However, this is not unique as it has been documented that special needs schools currently do not have the requisite resources to cater for the myriad needs of those who attend these schools (Department of Basic Education, 2001). Institutionally, government has proposed the implementation of inclusive education approach within the educational system. However, implementation of an inclusive approach has not seen fruition. Due to these systemic challenges this has resulted in the exclusion of autistic children from the school environment. Exclusion from the school environment has resulted in many autistic children in certain cases being placed on a waiting list for up to five years in order to receive an education. In order to have a better contextual understanding the manner in which autistic children access education the researcher aimed to:

- Provide the theoretical framework informing the study.
- Inform the reader of the research methodology utilised in the study.
- Provide the findings of the study generated from the data.
- Provide recommendations which are applicable as per the study's findings.

1.2.1. The development of an understanding of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with symptoms presenting in the early developmental stages of children. ASD is characterised by children having difficulties in communication, emotional regulation and performing restrictive and repetitive behaviours (American Psychological Association, 2013; Stone & DiGeronimo, 2006). Individuals who are diagnosed with ASD are often referred to as being autistic or autists. For the purposes of this research study the term autistic will be used to refer to individuals diagnosed with ASD.

Autistic children are often described as appearing to live in their own world due to their limited ability or inability to interact with others including members of their respective families. These behaviours are often viewed as abnormal and socially inappropriate. ASD is categorised by many as a disability but unlike many conditions where the disability is visibly physically, autistic children appear to be normal and thus people often misinterpret their behaviours as being naughty, oppositional or spoilt. This in turn makes autistic children subjected to social rejection, isolation and exclusion (Stone & DiGeronimo, 2006). The social isolation is not restricted to the autistic children but also applies to their familiars particularly their parents. ASD is often misdiagnosed or under diagnosed due to lack of understanding by healthcare professionals or their hesitation to diagnose young children with the disorder (Bateman, 2013). This is further coupled by lack of understanding of the aetiology of ASD which remains largely unknown. Studies have been conducted to determine the aetiology of ASD and have found that children with the family history of mental illness are presented with a higher risk because of certain genetic and environmental factors (Bateman, 2013; American Psychological Association, 2013).

1.2.2. Prevalence of autism spectrum disorder

The World Health Organisation (WHO) estimates that 1 in 160 children in the world have ASD (World Health Organisation; 2014). The Centre for Disease Control (CDC) in the United States of America (USA) estimates that 1 in 68 children can be identified as having ASD in the USA (Bateman, 2013). It is estimated that ASD is 4.5 times likely to occur in boys than girls. Studies conducted in Asia, Europe and North America identified that individuals with ASD as averaging

1% to 2% of the population (American Psychological Association, 2013; Bateman, 2013; Midence & O'Neill, 1999). In South Africa there is not a single national estimate of the prevalence of ASD in the population but reports from the Red Cross Children's Hospital, Lenteguer Hospital and the Tygerberg Hospital, all located in the Western Cape state that the three hospitals had a collective ASD diagnosis of 10 children per week (Bateman, 2013). It is alarming to note the rate of diagnosis and the lack of statistics from other provinces and the national government. Although there is an estimate that 2% of the South African population is affected by ASD, it does not provide information on the prevalence of ASD in this country (World Health Organisation, 2014). The WHO in May of 2014 during the 67th World Health Assembly adopted a resolution titled the *Comprehensive and coordinated efforts for management of Autism Spectrum Disorder*. This resolution which was supported by member countries of the WHO such as South Africa, urges the WHO to collaborate with member states and participating agencies to strengthen national capacities to address ASD and other developmental disorders (World Health Organisation, 2014). With an estimated cost per year for children with ASD in the USA to be between 11.5 billion to 60.9 billion, it is important for governments of both developed and developing countries such as South Africa to pay more attention to ASD (World Health Organisation, 2014). The cost mentioned above encompasses direct and indirect costs such as medical care required by the children, specialised education and lost parental economic activity.

In South Africa there is a growing interest to understand ASD and the effects it has not only on the families of autistic children but also on the different institutions which autistic children and their families access (Bateman, 2013). Although there is a growing body of research internationally which not only explores the aetiology of ASD but also explores the experiences of parents with children, there is very little research conducted in South Africa in this area. Therefore in order to develop our institutions to be more accessible and supportive of autistic children and their families, it is important that we understand the parents' experience in order to create interventions which are sustainable, effective and easy to utilise by the above mentioned groups

1.3. Problem Statement

With a burgeoning interest in autism spectrum disorder internationally and locally, few studies have been conducted in South Africa. There is an even further lack of knowledge on the presentation of autism spectrum disorder in the South African educational context. Currently there has been little documentation of how parent's access education for their autistic children

and documentation of their experiences. Furthermore, although there is myriad of learning models currently utilised with the South African context to educate autistic children, their applicability from the perspective of parents have not been fully explored. Therefore, this study intends to explore the experiences of parents regarding accessing education and applicability of learning models used to educate their autistic children.

1.4.   Statement of purpose

The purpose of this study is to capture, using a qualitative approach, the experiences of parents in accessing education for their ASD children and their experiences of the learning models which are currently used to teach their children. Explore the current literature available regarding parents' experiences of accessing education for their autistic children and the learning models which are currently available to educate them within the South African context.

Currently there are very few public and private schools available to educate children with ASD. It was previously reported that nationally, there were less than ten schools that specifically cater for the needs of autistic children (Bateman, 2013). However there have been efforts by the government to remedy the current accessibility challenges facing autistic children. This includes the provision of schools specifically designed for autistic children. Unfortunately these schools have been concentrated within the Gauteng province. The lack of schools that cater for the specific needs of children diagnosed with ASD makes it difficult for parents to access education for their children.

In South Africa there is a myriad of learning models which are made available to parents. The models currently being used are the Applied Behavioural Analysis (ABA), Early Childhood Learning Model, TRIAD Teaching Model, TEACCH Model, Early Start Denver Model and the Learning Strengths and Preferences Model. Little research has been conducted on the applicability and efficacy of these learning models within the South African context. These learning models require multiple resources and studies have not been ascertained the parents' experiences with these learning models. Furthermore the study provides an opportunity to reassess whether the interventions that are being utilised are effective and what other interventions that can also be developed in accessing education for children with ASD which are applicable within the South African context. This would benefit various stakeholders from parents, teachers and those within different administrative roles. Thus the study wants to explore parents' experiences of accessing education for their children and the

current learning models being used to educate children with autism spectrum disorder, their effectiveness thereof as per the parents' appraisal and the interventions that can be developed to improve these models within the South African context.

1.4.1. Objectives of the study

1) To explore the experiences parents have with accessing education for their children and the learning models currently available for children diagnosed with Autism Spectrum Disorder.

2) To explore how parents understand the effectiveness of the current learning models for children with Autism Spectrum Disorder

1.4.2. Research questions

1) What are the experiences of parents whose children were diagnosed with autism spectrum disorder in accessing education for their children?

2) How do parents explain the effectiveness of the current learning models within the South African context?

1.5. Rationale of the study

As an educator currently teaching at a primary school in the foundation phase, I have encountered and taught children with developmental disorders and learning difficulties. This became the impetus for me to further my studies and specialise in inclusive education for my honours degree. I had previously observed and read from various studies that with the requisite skills and training, children who had special education needs can be incorporated into the mainstream schooling system. My first encounter with autism was interacting with the grandchild of a friend. During our first encounter he presented with sensory and social difficulties which his grandmother explained as part of his symptoms. This resulted in me watching documentaries and reading various articles and books that developed a growing interest for ASD. Furthermore I was curious to learn if within the South African context was there utilisation of an inclusive approach to teaching children diagnosed with ASD, possible challenges parents experience in accessing education for their children and what models are currently used to educate children with ASD. Undertaking this research provided the opportunity for me to acquire knowledge which will not only be beneficial to me but also to other educators, parents and stakeholders who are interested in learning how parents of autistic children access education for their children and how education can be made more accessible for autistic children. This provides the necessary information to educators and

other stakeholders, which can be utilised in the development of accessible and sustainable early interventions, which are applicable within the South African context.

1.6. Definition of the key concepts

The following section discusses the key terms that will inform the study.

1.6.1. Autism Spectrum Disorder

ASD can be defined as a neurodevelopmental disorder that is characterised by a child having difficulties with communication, emotional regulation and presenting with restrictive or repetitive behaviours, which can possibly injure the child. These symptoms often present during the early developmental stages of the child. The difficulties often cause distress for the child and impair or impact their social and academic functioning (American Psychological Association, 2013). ASD is a lifelong condition and can vary in severity throughout the lifespan. After continuous research into the three disorders which were autism, aspergers and pervasive developmental disorder. Observations showed that the three are not inherently different from each other but are rather representative of behaviours that can be placed on a spectrum. This led to the incorporation of the three disorders into a single diagnostic condition (American Psychological Association, 2013; Stone & DiGeronimo, 2006). Individuals, who had been previously given the diagnosis of autism, aspergers and pervasive development disorder are now diagnosed as having ASD as per the Diagnostic Statistical Manual for Mental Disorders V (DSM V) criterion (American Psychological Association, 2013).Understandably research conducted prior to the incorporation refers to the three disorders separately but many healthcare practitioners and other professionals still refer to the above mentioned disorders separately and do not use the ASD term. For the purposes of this research, the term ASD will not be restricted to research conducted after the incorporation of the disorder but will refer to research conducted prior to the incorporation.

1.6.2. Learning models

A learning model is a framework which outlines how learning can occur within the classroom. Learning models are designed to cater to the specific needs of a particular group (Ruble, Dulrymple & McGrew, 2013; Stone & DiGeronimo, 2006). In their very foundation or premise learning models are developed to counter the shortfall experienced within the current educational system. These shortfalls can be ergonomic, stimulation and pedagogical orientation (Billington, McNally & McNally, 2000). The development of learning models can be argued as reactionary process to the systemic failures of different educational institutions. More often than not,

learning models are specifically created to address the needs of children who are considered as not fitting within the confines of mainstream schooling (Ruble, Dulrymple & McGrew, 2013). This includes children who present with neurodevelopmental disorders such as specific learning disorder, attention deficit/ hyperactivity disorder, intellectual disability and ASD to name a few. Those who present with physical disabilities are also an impetus for the development of learning models to address the learning needs of the above mentioned children. Learning models often utilise a multi resource approach. A multi resource approach will include technological devices, human resources and specifically designed learning material (Billington, McNally & McNally, 2000; Ruble, Dulrymple & McGrew, 2013; Stone & DiGeronimo; 2006) However, it is evident that learning models do not adequately address all the needs of special needs children. Learning models in this respect can be understood using the analogy of a spectrum. At different points of a spectrum each learning model will be equipped to cater for those who cluster within that point. This highlights the necessity of continuous assessment when utilising learning models. Continuous assessment ensures that the child is placed within a learning environment suitable to their learning needs throughout their schooling career.

1.6.3. Inclusive Education

Inclusive education is an educational approach which advocated that education should not be stratified into mainstream and special needs education (Bjorg & Hanssen, 2016). Advocates of inclusive education state that the delineation of education within these two streams is discriminatory and perpetuates the othering of those with special needs (UNESCO, 1994). Furthermore they have argued that special needs education from the initial and current conceptualisation does not address adequately address the needs of those with disabilities. The term inclusive education has been coined since the late seventies but gained traction following the United Nations Educational, Scientific and Cultural Organization Salamanca Convention (UNESCO), (UNESCO, 1994). At this convention the merit of inclusive education was presented from financial, structural to entrenching pro diverse values within society. Since the convention the process of implementing an inclusive approach within certain contexts has not been successful. These will be further explored within the upcoming chapter.

1.6.4. Access to education

The United Nations (UN) Declaration of International Human Rights states that all individuals have the right to an education (UNESCO, 1994). The right to education encapsulates individuals being provided with the opportunity to access education when an individual is of school going

age. This pertains to people who are able bodied and those with disabilities. The UN has championed access to education through global initiatives such as Millenium Development Goals which championed universal access to education (Statistics South Africa, 2015). As a member of the United Nations South Africa participated in the Millenium Development Goals programme were able to achieve above ninety percent access to primary education for those of school going age (Statistics South Africa, 2015). It is not certain if this percentage includes individuals with special needs. Access to education for those with special needs is still a pervasive point of concern with an estimated ten thousand children with disabilities living in South Africa not receiving an education. In order for an individual to access education the process requires an amalgamation of different institutional resources. The institutional resources refer to legislative, policy, financial, human and infrastructure. Lack of the above mentioned resources results in probability of access to education decreasing significantly. Within the South African context it has been identified that a lack of infrastructure and human resources was one of the key factors contributing to the lack of access in education.

1.7.   Synopsis of methodology

The study was conducted from a qualitative research perspective with the focus group method being utilised for data collection. Qualitative research has been described as an approach aimed at capturing the individual's life experience as accurately and authentically as possible. The qualitative research approach advocates that the lived experience cannot be reduced to numbers. This research approach utilises interviews both individual and focus groups, field observation and journal notes amongst others as research instruments.

The interviews were semi-structured and recorded with an audio recorder. A semi structured interview is an interview whereby the researcher will formulate a few guiding questions. The guiding questions however are not the sole focus of the interview. During the interview the researcher will attentively listen to the participants' responses and use them as prompts for further questioning and exploration. The utilisation of this interview approach enables for an in depth exploration of the research topic. A semi structured interview further enables the researcher to explore other avenues which the participants might have thought of. Ethical clearance was obtained from the supervising university and participants were informed of the nature of the study and their rights prior to giving informed consent. Thematic analysis was used to analyse and synthesise data.

1.8.   Scope and delimitation

The study will not focus extensively on the parents' experience of accessing education for their children and the learning models available in schools for ASD children. Although there is extensive research being conducted exploring different methods which can be utilised for early detection of ASD there is limited research regarding access of education (Bateman, 2013). The study will further not explore social support structures and parents' experiences of these structures in detail. The rationale for this decision is that this is an extensive area of study which would require the study to specifically explore social support for parents of autistic children study has also been conducted within a single area, which renders the results not generalizable to the entire population. Although the study may not be generalizable, it provides insight regarding accessibility of education for autistic children and further explores the applicability of learning models. This will provide the framework for future studies and further areas, which can be explored regarding the relationship between ASD and education.

1.9.   Significance of the study

The study will assist stakeholders in education to understand the experiences of parents whose children have been diagnosed with ASD in accessing education for them and to comprehend whether the current institutional process regarding educating autistic children has been applicable and efficient. Although there have been efforts placed nationally to facilitate the learning of autistic children during early childhood development up to their formative years, it has not been implemented. This facilitation was first advocated through the Constitution, Bill of Rights and in recent years the White Paper Six on Inclusive Education. There has been little documentation of how the parents experience the current institutional processes which include accessing education and the learning model's suitability for the South African context. By capturing parent's experiences this can provide how we can improve access to education for autistic children and ensure that the learning models provide the platform for autistic children to learn to their potential.

1.10.   Summary of chapters

Chapter One

The chapter provides the reader with an introduction to the topic under the study. This includes informing the reader of the problem statement, research questions and objectives, key definitions, methodology utilised and significance of the study.

Chapter Two

The chapter will provide a review of the current literature available related to the research topic. An outline of what previous researchers have found will be explored, with the researcher proposing the contributions which this study can provide to the literature. This chapter also

details the Bio Ecological Systems Theory. The theory will be utilised to determine the current presentation of the phenomenon under study.

Chapter Three

The chapter details the methodology to inform the study. This includes the research paradigm, sampling of participants, formulation of research questions and attainment of ethical clearance amongst others.

Chapter Four

This chapter is a presentation of the findings as per the data findings. The chapter will include direct quotations from the participants to elucidate the findings. Pseudonyms were used by the researcher in order to protect the identity of the participants.

Chapter Five

Chapter six will provide the reader with a discussion of the research findings as they relate to the literature review and theoretical framework. Furthermore, it will explore the research questions and objectives in relation to the findings.

Chapter Six

The chapter will provide a summary of the findings, recommendations and limitations. This chapter also includes within the recommendations section areas for possible research.

1.11. Conclusion

ASD is a neurodevelopmental disorder that has been largely researched in other disciplines with little attention paid to the field of education. This is of particular concern as despite the call by the Department of Basic Education for educators to equip themselves with the necessary knowledge and skills in order to be able to engage and teach autistic children. Currently there is a dearth of research exploring issues of accessibility of education and the applicability of the learning models currently in use. In order to better understand applicability of the current framework being utilised it is important to capture the experiences of parents as they are the first line consumers of the services provided. The current chapter provides the reader with an introduction to the topic under study. This chapter orientates the reader to the applicability and

the merits of the study. The upcoming chapter will review the literature to highlight the current shortfalls within the research. This includes the areas where the research could provide valuable contribution.

Chapter Two

Literature Review

2.1. Introduction

This chapter proceeds from the previous chapter which provided the background of the study. A literature review is achieved by focusing on reviewing the literature with different themes and their respective subthemes. The themes explored are the medical process, social and support services, autism and education, learning models for autistic children, learning models currently used in South Africa. The medical process theme includes the subthemes diagnosis of autism spectrum disorder and access to medical services. Social and support services theme contains the subthemes normal way of life, social rejection and isolation and support structures. The autism and education theme includes the subthemes the right to education, the Salamanca Statement and autism and education in South Africa. Learning models for autistic children includes the sub themes the TRIAD teaching method, the ABA model, the Early Start Denver Model and the Learning Strengths and Preferences Model. The learning models currently used in South Africa theme consists of the sub themes White Paper 6 on inclusive education, GemIIni Video Modelling and the TEACCH model. This chapter also includes an exploration of the Bioecological Systems Theory as the theoretical framework for this study.

2.2. The medical process

The medical diagnosis process is an intricate process which requires a multidisciplinary approach in order to diagnose ASD (Bateman, 2013; Stone & DiGeronimo, 2006). This consists of professionals from a multitude of different disciplines within healthcare. Although the educational professionals are not participants of the diagnostic process, they are most affected as the results of this process determine the nature of learning which educators have to structure for autistic learners. Furthermore, this process is often fraught with multiple challenges for parents who are often not equipped with the knowledge of the medical process and what it constitutes.

2.2.1. Diagnosis of Autism Spectrum Disorder

The diagnosis of a medical condition is often the first step in understanding a medical condition, the condition's aetiology and developing interventions to help treat the condition. ASD presents with diagnostic difficulties for professionals because of the presentation of the symptoms which is often similar to that of other neurodevelopmental and medical

conditions. (American Psychology Association, 2013; Midence & O'Neill, 1999; Stone & DiGeronimo, 2006). These conditions are, but not restricted to Attention Deficit Hyperactivity Disorder (ADHD), global developmental delay, intellectual disability, communication disorders, disinhibited social engagement disorder, fragile x syndrome, deafness and others. Coupled with a lack of knowledge from healthcare professionals, ASD is often misdiagnosed or goes undiagnosed for long periods of time (Bateman, 2013; Tincani, Travers & Boutot, 2009). This causes parents' continuous distress as they usually do not understand their children's behaviour. This is also coupled with the fact that ASD can be comorbid with the above mentioned disorders thus healthcare professionals tend to focus on the other comorbid developmental disorders instead of ASD.

Bateman (2013) noted in his article that medical professionals are reluctant to give the ASD diagnosis to children despite them presenting symptoms of ASD. This is despite the provision by the DSM V for children as young as the age of 2 to be diagnosed with ASD if the symptoms qualify for the diagnosis (American Psychology Association, 2013). It is understandable that healthcare professionals might be reluctant to give the diagnosis of ASD as the diagnosis of ASD has historically many negative connotations to it. However, it is imperative that the diagnosis be given as it allows for the applications of the required interventions to assist the child. Perhaps it should be recommended to healthcare professionals that they should rather diagnose children as presenting ASD traits if they may have trepidation with an ASD diagnosis. By taking this route, it will allow healthcare professionals the opportunity to implement the required interventions without giving the child the ASD label.

2.2.2. Access to medical services

Individuals who have acquired knowledge about the condition are filled with hesitation about their children's prospects due to the debilitating effect (at times) of the condition and the specialised care that the child may require. The specialised needs required by the child are not restricted to the medical aspects but also in terms of their school, social and emotional requirements. For many parents, the resources required to help their child improve their functioning and their behavioural difficulties are unavailable due to their financial status. Furthermore, they are at times unable to access these resources as they are geographically far away from them (Bateman, 2013; Glazzard & Overall, 2012; Tincani, Travers & Boutot, 2009). Wetherston, Gangat, Shange, Wheeler, Sayed Karrim and Pahl

(2017) found that sixty eight percent of their sample experienced difficulties in accessing healthcare facilities and interventions for their children.

Some parents being aware of the difficulties mentioned above and discrimination the child may be subjected to often reject the ASD diagnosis (McGregor, Nunez, Cebula & Gomez, 2008). They may also present with denial about the child's condition (McGregor, Nunez, Cebula & Gomez, 2008). This denial renders the child in a position where their condition worsens as they are not able to access the necessary interventions to help improve their condition. Paisley and Smith (2013) found that during the diagnostic process, many parents are subjected to institutional discrimination. This first occurs in healthcare institutions as many healthcare practitioners are not knowledgeable of the diagnosis. The healthcare workers may subject parents to continuous and unnecessary interventions which when questioned by parents, they are perceived as being hostile or difficult (Bateman, 2013; Paisley & Smith, 2013). A similar finding was presented by Wetherston et al. (2017) whose participants stated that during their initial encounters with healthcare providers, healthcare providers were often negative towards helping their children.

The lack of understanding by these professionals and unwillingness to work with autistic children results in parents receiving substandard assistance or assistance which is not of value to the parent or child. They further found that once the child has received the diagnosis the educational institutions such as mainstream schools are not particularly receptive in accommodating children with autism (Midence & O'Neill, 1999; Paisley & Smith, 2008). Many of the schools argue that they do not have the staff with the required teaching skills to teach and cater the specific needs of autistic children. These children are thus referred to schools which are reserved for children with special needs to the dismay of the parent and the child (Ruble, Dulrymple & McGrew, 2013).

2.3. Social and support services

Support structures are instrumental in providing the necessary formal and informal services which are required by families living with individuals who have a disability. The formal services include medical interventions and social services provided by government whilst informal services primarily consists of the emotional support from family, friends and the community (Wetherston et al, 2017). As ASD is largely a misunderstood condition parents often have minimal support from their social circles, which can have a debilitating effect on their emotional and psychological well-being.

2.3.1. Normal way of life

Parents of autistic children often express sentiments or desires of having a normal life. A normal life is described that as one which is characteristic of the values, beliefs, norms and accepted behaviours of a particular group or society. In the research conducted by Woodgate and Secco (2008) parents expressed sentiments of their desire to participate in activities without having to first think or strategise or whether the activity would cause harm to their autistic child. This was largely attributed to sensory integration difficulties that often plague autistic children. These parents also expressed their sadness and frustrations after realising that they would not be able to live a normal life after receiving confirmation of their child's ASD diagnosis (Woodgate & Secco, 2008). This realisation evoked a sense of loss in the parents concerning their future prospects. Furthermore, it resulted in some parents living isolated and exclusionary lives where they have limited support from their communities and primary support structures.

For some parents support organisations are available as a source of support however they were unable to mitigate the parents' needs and desires for social support with those in close proximity to them. It has been suggested that parents need to undergo a mourning process for the loss of their sense of normalcy. These therapists have further reiterated that by grieving for their sense of normalcy this will allow parents to come to terms and accept their child's diagnosis (Paisley & Smith, 2013). Although the grieving process was beneficial in helping parents to accept their child's diagnosis, it did not quell or diminish the parents' desire for a normal life.

In many studies they have largely centred with families who lived with their children, a study conducted by Billington, McNally and McNally (2000) found that parents whose children resided in institutions also expressed the same sentiments as those who resided with their children. Paisley and Smith (2013) found that instead of attempting to assimilate themselves in the accepted conceptualisation of normal, parents need to reconceptualise what normal is for their specific family. This a good coping strategy to help parents in the transition and aiding them in dealing with their children but it fails to take into account that families with autistic children are part of a system. Each system be it the religious, legal or educational has an impact on how we conceptualise and relate to each other (Murray, 2008). If there is not an acceptance or support from the different systems which people engage or interface with, they are subjected to discrimination, prejudice possible rejection and isolation from other members of the system.

2.3.2. Social rejection and isolation

Social interaction is of critical importance during the developmental stage of a child. Through social interaction children learn more about their environment, interpersonal relationships and socially appropriate or inappropriate behaviours. As children with ASD present with social difficulties due to their condition and an inability to effectively communicate, they often have difficulties negotiating social spaces (American Psychological Association, 2013; Billington, McNally &McNally, 2000; Kang-Yi, Grinker & Mandell, 2013). Children with ASD that also present with difficulties with sensory integration have even more difficulties than their counterparts who do not have this particular difficulty. Sensory integration can be described as neurological sensitivity to certain stimuli such as sound and touch (McGregor, Nunez, Cebula & Gomez, 2008). Children with sensory integration will often hear sounds louder than those around them. These children may present with difficulties in walking as the sensory information they receive is uncomfortable and unbearable.

Children with sensory integration difficulties may engage in behaviours such as screaming, crying or walking in abnormal manner in order to relieve the discomfort they are experiencing at the time (McGregor, Nunez, Cebula & Gomez, 2008). Bystanders within social spaces and members of the parents' social circle and even their family can often misinterpret these behaviours. The above mentioned behaviours can be perceived by the social circle as abnormal, rude, unacceptable and socially inappropriate. Parents who cannot control the child's behaviour and have not taught them socially appropriate behaviours are viewed as inept. Paisley and Smith (2013) found that as autistic children do not present with physical disabilities, many individuals fail to understand the difficulties they experience. This leads to both parents and the child being rejected by their social peers and at times family. The social activities, which they can participate in become vastly restricted to those that the children enjoy or that they can engage in with other autistic families.

2.3.3. Support structures

Many parents appreciate the support they access from other parents who have autistic children. However parents may feel restricted and isolated from the rest of the world. Parents also feel that by only having other autistic children as social peers, parents feel that their children's social development is stunted and inadequate (Spies, 2013). It is not surprising to read that mothers of autistic children present with the highest rates of depression (Paisley & Smith, 2013). A study conducted by Jeans (2013) using the Beck Depression Inventory

Scale, as an assessment tool, presented with higher rates of depression compared to mothers whose children did not have a diagnosis of ASD. These mothers stated that the lack of socialisation with other social peers, lack of quality interpersonal relationships with their significant others and the emotional and psychological challenges of having a child with autism left them feeling isolated and depressed (Jeans, 2013). These parents further stated that they feel disconnected from the rest of the world and live on the same planet, which their child often retreats to (Jeans, 2013). These mothers also felt that there was no effort from their social peers and families to learn more about their child's diagnosis and the role which they could play in helping both mother and child (Jeans, 2013). The mothers reported that these individuals relegated this to support groups, which were made available to them to join. This they experienced as othering of them and putting them in a category of undesirables (Benderix, Nordstrom & Sivberg, 2013). Blaith (2016) argues that parents of autistic children presented with greater risk to mental illness due to a limited resources for their own personal therapeutic interventions.

Autism for many families is costly which limits the disposable resources that can be utilised for other needs. It is interesting to observe that although some mothers were adamant that they would not change their child if they had the ability to do so. Other mothers expressed a desire to change their child in order to afford themselves and their children an opportunity to enjoy a normal life (Blaith, 2016; Jeans, 2013). Some of these parents also informed the researchers that if given the opportunity they would place their children in facilities or institutions that would cater for their child's needs (Benderix, Nordstrom & Sivberg , 2013). This would in turn relieve the burden in terms of resources that they were experiencing (Benderix, Nordstrom & Sivberg, 2013). These observations warrant an exploration of the current structure regarding the social support provided to parents of autistic children as many parents still feel the brunt of having a child with ASD. By understanding the current social support services available, perhaps better support services can be provided to parents, their extended family members and other members of the community.

Currently in South Africa there are organisations at national and provincial level which provide support to autistic individuals and their families in South Africa such as Autism South Africa and Action in Autism (Evans, 2016). The support provided by the organisations is not limited to the provision of services for those affected by ASD but also constitutes continuous awareness campaigns for the public at large. These organisations primarily have footprints in the large commercial cities in South Africa but their reach does

not extend to rural communities (Bateman, 2013). This poses a difficulty for those living in rural communities as they firstly may not be aware of the ASD symptoms. This often results in their children not receiving the requisite assessment and appropriate diagnosis. Additionally, for those who are diagnosed they have limited support and consequently experience high levels of isolation and stigma.

2.4. Autism and education

Autistic children have often experienced difficulties accessing education. This is despite that the United Nations and the Constitution of South Africa have enshrined their right to education. Although there are efforts being made to remedy the shortfalls of the past, autistic children still find themselves being deprived of education due to poor systemic understanding. This section will explore the relationship between autism and education.

2.4.1. The right to education

The United Nations has enshrined access to education in the International Bill of Human Rights. The International Bill of Human Rights states that all children regardless of their race, gender or physical and cognitive abilities have the right to education (WHO, 2014). In South Africa, this is further enshrined within the Bill of Rights and the Constitution. Great strides have been made in the provision of education for children yet there are still more efforts required for children with special needs within the South African context. South Africa was a participant of the Millennium Development Goals (MDGs)which aimed to eradicate poverty, encourage access to services such as health and education and help with the socioeconomic issues which plagued both developed and developing countries (Statistics South Africa, 2015). One of the MDGs' goal was to increase access to education for all individuals of school going age. South Africa was able to achieve access and attendance to education up to 96% for a primary education. The same feature was not achieved for secondary education as many learners did not complete their secondary education (Statistics South Africa, 2015). Although this is a commendable result for the educational system, the statistics did not take into account children who have disabilities and the difficulties presented when accessing education.

Children with ASD are considered to have a disability because of their diagnosis and the specialised education that they require in order to learn to the best of their abilities. Yet, many parents still have difficulties in accessing education for their children. This was observed in a recent insert on Special Assignment whereby parents spoke of their difficulties

accessing education for their children (Van Niekerk, 2016). According to parents, when they were searching for schools to enrol their children, the mainstream schools that they approached were not willing to enrol their children and argued that they did not have the requisite resources for autistic children (Van Niekerk, 2016). More often than not, mainstream schools would refer them to special needs schools however these schools would also reject the children. The special needs school would also present with similar reasons to that of their mainstream counterparts. This left the parents in despair, despondent, frustrated and worried about the child's future.

Le Fanu (2014) argues that conventional conceptualisation of educational transitions within the disability framework excludes those who have symptoms, which render them unable to engage in academic work. Le Fanu (2014) further states that many of those living with disabilities have an acute awareness of the societally accepted transitions and by not extending this service, it further highlights their difference. With this in mind, Le Fanu (2014) argues that it perhaps has to do away with the notion of secondary education but rather think of secondary education as sites of vocational training for those with disabilities.

Currently it is estimated that there are 11 769 children living with disabilities in South Africa who are not attending school (Charles, 2017; Levy, 2017). In many cases children living with disabilities are placed on waiting lists waiting to be placed in a school. Placement in school does not always become a reality with many children living with disabilities becoming too old to attend school (Levy, 2017). With similar cases to those of South Africa occurring in other countries in earlier years, analysts argued that the delineation of mainstream and special needs is inadequate (UNESCO, 1994). Analysis indicated that many countries were poorly resourced for this delineation in developed countries and worse in developing countries (UNESCO, 1994). Research further indicated that special needs education did not address the needs of those with disabilities which would assist in their development (Hunt, 2011; UNESCO, 1994). Furthermore, it was observed that those within special needs education sphere often experienced othering. The othering refers to learners being shunned by their peers and facing discrimination in their community. The discrimination was not only limited to learners but was experienced by their educators. Educators reported that their peers often viewed their work as inferior or mistakenly assumed they were afforded resources that their counterparts did not have (Bjorg & Hanssen, 2016; Hunt, 2011).

2.4.2. The Salamanca Statement

The Salamanca Statement of Spain on Inclusive Special Needs Education was developed as a framework to inform the implementation of inclusive education (UNESCO, 1994). The statement was founded following observation that the stratification of education into mainstream and special needs education was not feasible (Hunt, 2011). The stratification had largely addressed the needs of those in the mainstream sector whilst their special needs counterparts lagged behind in their development. It was also observed that special needs education did not adequately equip those with disabilities with the necessary skills to engage with society upon completion of their studies (UNESCO, 1994). An inclusive approach was as mitigating the resource shortfall which countries were experiencing and negating the effects of othering that those within special needs education. The statement first posits the following:

> *"Every child has the right to be educated in a regular school."*
>
> *"Provision should be organised according to student need rather than disability."*
>
> *"Resources and services should be school-based."*
>
> *"Decision making should be collaborative."*
>
> *"All children can learn and be taught."*
>
> *"Integration is a curriculum issue."* (UNESCO, 1994, p.48)

These statements have been formative within inclusive education however there have been barriers stopping the fruition of an inclusive education approach. These were identified as lack of teacher training, limited human and material resources, lack of co-ordination between mainstream and special education needs schools and poor acceptance by society (UNESCO, 1994). The framework argues that this can be achieved through the reframing of the education system. This would include a revision of the curriculum so that it addresses inclusion in appropriately and improved training of teachers.

The above objectives would be achieved through multi stakeholder engagement and a revision of political and legislative framework. It was also argued that inclusive education is a cost effective measure as resources would not be too stretched. This would require a skills and resource audit in the country in order assess feasibility (UNESCO, 1994). There was further emphasis on the inclusive approach which would now also require to equip autistic learners with the necessary skills to transition into adulthood. Learners attending

special needs are often ill equipped for the demands of adulthood. This does not solely refer to vocational skill but also includes social skills. Bjorg and Hanssen (2016) found in a comparative study that the skills of the educators were the critical key in ensuring the success of implementing inclusive education. In their findings they noted that in countries where there were limited efforts to ensure that educators had the requisite skills the inclusive approach had minimal success (Bjorg & Hanssen, 2016).

2.4.2. Autism and education in South Africa

In 2010 South Africa was estimated to have only nine schools which were dedicated to teaching children who have autism (Bateman, 2013). These schools were private institutions and were not funded by the government. This left 135000 children unable to access education that they rightfully deserved (Bateman, 2013). There have been efforts to address the lack of educational opportunities available to autistic children. On the 18th of January 2016 the Thulasizwe School for Autism was opened in Orlando West Soweto, Gauteng which specifically caters for autistic children (Evans, 2016). According to the Gauteng Department of Education, eighteen more schools have been opened and twenty five more were expected to be opened in order to provide the education which these children rightfully deserve (Evans, 2016). The efforts by the Gauteng Department of Education are exemplary and commendable but for children living in other provinces accessing education is still difficult. Autistic children in most provinces have to wait for long periods of time before being placed in a school (Collins, 2014; Muringi, 2015; Ngcobo & Muthukrishan, 2014). This is first tier of experience for many parents that they have in accessing education for their children. Research conducted in places such as Europe found that parents often feel frustrated by the lack of access to education that their children are subjected to (Ruble, Dulrymple & McGrew, 2013; Stone & DiGeronimo, 2006).

The next tier of experience for parents is ensuring that the level of education is of good standard and the child fits within the school culture. A study conducted by Billington, McNally and McNally (2000) found that although parents were relieved and happy that their children were able to access education, they however were not pleased at the limited schools available to their children. They found that culture in many schools did not fit with the needs of the child and the schools focused on the improvement of the children's cognitive abilities. Unfortunately the school placed the development of the child's social abilities in the back burner (Billington, McNally & McNally, 2000). This was viewed as solving one problem but neglecting the other. In South Africa, although there is an increased interest in ASD as

is the case with their international counterparts, there is lack of sufficient research that captures the experiences of parents with accessing the educational system. This is vital in order to develop an education system that not only caters for the needs of autistic children but also ensures that parents are able to easily access education for their children.

2.5. Learning models for Autistic children

Due to the nature of the symptom presentation, autistic children find themselves in a unique position. As there is not a homogenous symptom presentation, different children will be taught using different models. This lack of uniformity in teaching can often be advantageous and disadvantageous to autistic learners. The education of children with ASD is specialised and is not limited to academic learning but also requires the fostering and imparting of social, communication and practical skill and therefore there are various models which specifically target the learning of particular skills. A discussion of a few widely used models will follow.

2.5.1. The TRIAD Teaching Method

The TRIAD teaching method is a teaching approach which utilises an integrated teaching method in order to teach skills to autistic children. Stone and DiGeronimo (2013) state that teaching and learning in autistic children can occur or be approached in three ways; these approaches are adult-directed teaching, child-directed teaching and teaching using visual supports. In adult-directed teaching, the adult decides the activities that will be done, when and how they will be done. The behaviours are taught one at a time and at small, different steps. This method is effective in teaching new skills (Stone & DiGeronimo, 2013). In the child-directed teaching, the child leads the teaching by providing opportunities for learning during activities they have chosen. Teaching using visual supports enables children with autism to use their strengths in visual perception to learn. Visual aids are utilised in order to convey information to children regarding what is expected of them to do. By using all three approaches learning occurs in a holistic manner as the children have agency in the learning process and their strengths are put to use in order to ensure that they are able to learn.

2.5.2. The ABA model

The Applied Behaviour Analysis (ABA) model can be argued as using the principles of behaviourism in learning in order to teach behaviours and skills to autistic children. This is done by using the ABC model in learning and positive reinforcement to teach new skills, shape existing behaviours and reduce problem behaviours which the child may present with

(McKenzie, 2010; Ngara, 2014; Rogers et al., 2010). The ABA model has been the framework for the development of approaches such as the Discrete Trial Training, Pivotal Response Teaching and Early Start Denver Model. The premise of the ABA model is that autistic children are similar to other children in that they learn using the ABC of learning and reinforcement but have three areas which require a greater understanding than their counterparts. These are:

i.   Autistic children are not interested as other children in pleasing others.
ii.   Autistic children have less interest in sharing their experiences with others.
iii.   Autistic children imitate others less than other children of their age do.

Learning models that utilise that ABA model are based on identifying the child's behaviour **(B)**, choosing rewards and consequences of the behaviour **(C)** and identifying the antecedent before the behaviour occurred **(A)** (McKenzie, 2010; Ngara, 2014; Rogers et al., 2010). Thus by parents having identified their ABC, they are able to teach the children new skills and modify existing behaviours. This model is one of the most commonly used models in educating autistic children but has drawn wide spread criticism for the techniques which are used as they at times rely on unorthodox measures of teaching. ABA model has often been criticised for the techniques which are argued as harmful (Evans, 2016). Techniques proposed by ABA are said to encourage conformity of autistic children instead of taking into account their unique individual needs. Despite these critiques the ABA model still enjoys immense popularity as a teaching paradigm for autistic children.

2.5.3. The Early Start Denver Model

The Early Start Denver Model (ESDM) is a learning model developed using the principles of the ABA model of learning in order to teach skills which are specifically aimed at autistic children social, practical and communication skills. Developed by Rogers, Dawson and Vismara, this model does not focus on the autistic child solely but focuses on the family system in order to teach skills to children (Rogers, Dawson & Vismara, 2010). It takes into account that the child is part of a unit therefore in order for learning to occur as well as a positive change in behaviour, all the figures that are part of the system need to be facilitating and reinforcing the learning. The facilitators also need to be supported in order to ensure that the environment is conducive for learning, not harmful or traumatic for the child (Rogers, Dawson & Vismara, 2010).

The ESDM primarily targets early intervention in children with ASD and their families. This is done as there is a belief that the earlier the interventions are placed for children, the higher the probability of negative behaviours with the child. The model focuses on improving behaviour and skills within the following areas: attention, social motivation, use of gesture, imitation and turn talking, toy play as well as daily skills such as eating and bath taking, communication and arousal and sensory activities (Rogers, Dawson & Vismara, 2010). The focus is on these areas as autistic children have difficulties specifically in these areas. The model compromises of steps for parents to identify the child's difficulties and the steps and activities that must be undertaken for the child to have better behaviours and skills within the different areas.

2.5.4. The Learning Strengths and Preferences Model

The Learning and Preferences (LPS) Model is a learning model developed by Heather McKenzie which is designed for children in preschool or early childhood development centres. The model is specifically designed using Gardner's model of multiple intelligences and is also influenced by Jung's personality theory (MacKenzie, 2010). Gardner believed that an individual has a number of different intelligences that can be nurtured to enhance their learning. MacKenzie argues that by focusing on the different intelligences, you not only address the intellectual needs of the child but also other characteristics that influence the individual's behaviour, motivation and thinking (Mackenzie, 2010). The merits of the LPS Model in teaching are to provide the following:

- Allows for positive regard for the child's learning abilities.
- Does not focus on pathology or deficits of the child.
- Approaches learning from the child's point of view.
- Allows for the caregivers and teachers to assess the child's response to different tasks and activities.
- Provides the opportunity to understand the child more quickly.
  Can be utilised with other assessment information.
- Can be used across different settings and encourages involvement of all the people in the child's life. (Mackenzie, 2010)

2.6. Learning models currently used in South Africa

In South Africa the learning models utilised are on par with their international counterparts but there is a marked difference between public and private schools. Within the private school sector, there is a myriad of learning models used whilst in public schools there is an

orientation to utilise an inclusive approach. The utilisation of different approaches warrants the exploration of the applicability of these approaches within the South African context.

2.6.1. White paper 6 on inclusive education

The White Paper 6 on inclusive education with a focus on special education and needs stated that there needs to be an inclusive approach towards education. It proposed that education and teaching should no longer be stratified into mainstream schools and schools catering for those special needs. Rather children who presented with special needs should be included and integrated into mainstream schools (Department of Basic Education, 2001; Murungi, 2015; Spies, 2013). Although this paper was published in 2001, there have been little efforts to incorporate children with special needs into the mainstream schools. It is interesting to observe that within the Millennium Development Goals and the Mid-Term Strategic Framework the successes of the Department of Basic Education in improving access to basic education for children of school going age particularly in mainstream schools is published but very little to nothing is said of children who have special needs (Statistics South Africa, 2015). Unfortunately the current statistical data available indicates that autistic children still have to wait a minimum of six years before getting formal education (Bateman, 2013).

Although White Paper 6 was heralded as a dawn of the new era in South African education, there are currently two schools in Gauteng province which have adopted an inclusive approach (Van Niekerk, 2016). It is unknown if schools in other provinces have also adopted a similar approach. Furthermore, the Gauteng provincial educational department has entered into a robust campaign to ensure that autistic children are not enrolled in schools that have not utilised the inclusive approach but relegated these learners to special needs schools (Evans, 2016; Van Niekerk, 2016). Donahue and Berman (2015) argue that the failure in implementing inclusive education is contained within the paper itself. They argue that the paper did not detail how this would be achieved. Donahue and Berman (2015) placed emphasis on the issue of skilling educators. The department acknowledged that at the time of publication of the White Paper 6, many educators required upskilling. However, the paper did not address who would bear the responsibility of upskilling the educators (Donahue and Berman, 2015).

Ngcobo and Muthukrishna (2014) found that organisational culture also influenced the success of inclusive education. An analysis of the pilot schools utilising an inclusive approach Ngcobo and Muthukrishna (2014) indicated that in many of these schools the

culture within the school did not shift towards an inclusive approach. Ngcobo and Muthukrishna (2014) further argued that all efforts of inclusive education program to upskill and change infrastructure would be futile if the current organisational culture was not addressed. Nudzor (2012) have argued that the poor governance and resource challenges within education are a direct result of poor policy implementation and conceptualisation. Their sentiments are echoed by Motala, Govender and Nzima (2015) who have found that the poor implementation of inclusive education following White Paper 6 then has been direct result of the policy not being holistic in conceptualisation. Despite identifying the challenges within special needs education, the policy does not detail how to accurately implement inclusive education. Due to this oversight this in a continued stratification of education into mainstream and special needs.

Thus the teaching of autistic children is primarily orientated to the use of behaviour modification models even within the South African context. It is important to note that the different schools and centres of education do not use a single model within their programmes. Institutions may use a single learning model or a combination of models as they address different difficulties the child may be experiencing, which other models may be unable to address adequately. It is also important to note that children diagnosed with ASD require a multidisciplinary approach in order to help them with their functioning and development of skills that they require in order to take care of themselves and engage with their communities.

2.6.2. GemIIni Video Modelling

The GemIIni Video Modelling (GVM) is web based tutorial that is used to aid children with ASD in developing their receptive and expressive language communication skills. The programme is not focused only on children with ASD but is utilised with children who present with language and communication delays, dyslexia, Attention Deficit Hyperactivity Disorder, hearing impairments, cerebral palsy and those with severe language delay (GemIIni, 2015). The GVM utilises modelling with a focus on video modelling to teach verbal skills in children. Parents and teachers utilise online tutorials in order to be taught lessons and skills, which they in turn teach the child. The GVM does vehemently advocate that it is not a substitute for speech therapy but must be used in conjunction with speech therapy for effective results. The programme also advocates that the learning should not only be confined to the classroom, therapeutic session or the home but rather also in different environments that the child may engage with.

The programme has been predominantly used in the USA, with a reported 9, 000% increase in language acquisition over the baseline across the population after a week during a clinical trial last year in the Spokane Public Schools (GemIIni, 2015). In South Africa, a study was conducted at the Khuluma Education Centre where 28 pupils were identified as having low verbal skills and abilities during the course of two weeks used the GVM to help develop and acquire communication skills (GemIIni, 2015). After utilising the programme, the pupils presented with a marked improvement in their skills. After achieving these positive results, there is currently a study being conducted with a larger population to explore the efficacy of the GVM programme. It is important to note that there is very little empirical evidence that supports the results that have been presented by the GVM programme.

2.6.3. The TEACCH Model

The TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) model is a person centred evidence based learning model which looks at the individual's characteristics in order to develop a learning programme which be suitable for the needs of the individual (Ngara, 2014; TEACCH, 2014). The programme does not provide interventions at an individual only but is also family orientated, flexible and not rigid. The programme prides in understanding the 'culture of autism which is understood to be the presentation of the symptoms that are required in order to be given the diagnosis of ASD. The model is underpinned by five principles which are:

- Understanding the culture of autism
- The development of an individualised and family centred plan designed for each client rather than using a standardised curriculum.
- The structuring of the child's physical environment.
- The use of visual aids and supports which make the sequence of daily activities understandable.
- The use of visual aids and supports to make individual tasks understandable.

The programme is not restricted to children, can be used to teach individuals of all ages and can be modified to use in mainstream school classroom. Thus, it can be argued that it is a possible to achieve the objectives of providing inclusive education as per the White Paper 6. TEACCH further focuses on developing the individualised programme centred on the person's interests and their strengths. By cultivating or teaching from this approach, the

programme not only positions itself as providing optimum opportunity for learning but also focuses key areas such as socialisation that require development of skills.

2.7. The theoretical framework

This section will provide an understanding of the theory which informs the study. The chapter provides the theoretical premises of the Bioecological systems theory and the applicability it has in understanding the research topic. Furthermore, it will explore how the structuring of educational services and subsequently the learning models utilised contribute to the current relationship between autism and education.

2.7.1. The Bioecological Systems Theory

Urie Bronfenbenner developed the Bio ecological systems theory or the ecological systems theory as it was formerly known, in 1974. The development of the theory was a response to the behaviourist wave that was popular in psychology at the time, which argued that humans or children are born tabula rasa and their behaviour and development in other spheres can be moulded using consistent reinforcement such as rewards and punishment (Bronfenbenner, 1994). Although this bodes true to a certain degree as individuals behaviour can be influenced through the use of certain strategies. The behaviourist theoretical framework underpinning this theory analysed development from a one dimensional point of view. This did not take into account that development is multi-faceted and there are different contributing factors which can account for development.

In his initial theory, Bronfenbrenner argued that children are not merely products of their biology nor the behavioural strategies imposed to mould their behaviour but rather children's development is influenced by the interactions and the interpersonal interactions they have within their environment (Bronfenbenner, 1994). These interactions he posited occurred in different systems, which interacted directly and indirectly with the individual. The theory initially had four systems, which were the microsystem, mesosystem, exosystemic, and macro system. In later years, he added the chronosystem. In the theory's formative years, Bronfenbrenner did not place emphasis on the child's predisposed biological make up which also has an effect on the child's ability to interact with their environment (Bronfenbenner, 1994).

The microsystem is the first point of interaction for an individual; this system consists of the individual's family, community, peers, school and religious bodies that they may interact

with. It is also characterised by the pattern of activities, social roles and interpersonal interactions. There is a bi-directional effect between the individual and the different components of the microsystem. This means that although the system has an effect on the individual, the individual affects the microsystem too. The theory now compromises of a biological component as it was noted that the individual's biological make up plays a role in how the individual interacts with the environment (Bronfenbenner, 2002). Nowhere is this more evident as with autistic children who present with communication difficulties, which plays a critical role in forming interactions with the different components of the microsystem. The means for the microsystem influence can be understood as the result of the individual's membership to different groups within the microsystem. Individuals within their respective community do not have singular membership to one group but have multiple memberships in the community. These memberships provide the opportunity for the individual to influence the different institutions.

The mesosystem consists of the interactions between the components of the microsystem. Although the components of the mesosystem do not directly interact with the individual, the interactions between the different components of the microsystem exert a direct influence on the individual. The exosystem consists of institutions such as the law and the media, the individual does not have an active role in a system or decision-making processes found in this system, the decisions and interactions taken in this system have a direct impact on the individual.

The macro system compromises of the cultural values, beliefs and political systems. These have a more implicit influence on the individual as they inform behaviours and societal norms that are found in the different systems. Although the macro system is primarily implicit it has one of the biggest impacts on the individual as the beliefs and values generated from them are culturally sanctioned and is the primary mechanism that people perceive the world around them (Bronfenbrenner, 1994). The chronosystem refers to time and how time and changes that occur throughout the ages influence the different systems particularly beliefs, values and cultural systems. Although a developmental theory by conception, the researcher believes that the ecological systems theory is best suitable to explain the experiences of parents with autistic children.

2.7.2. Bioecological systems theory in understanding social phenomenon

Bio ecological systems theory is primarily a developmental theory that has been utilised to explain and understand the presentation of various social phenomenon. This is primarily attributed to the theory's focus and emphasis on the various structures within the different systems. It has been argued that Bronfenbrenner provided blue print of society, development of values, beliefs and how each of the structures within impact the development of cultural values and beliefs. This factor is of particular importance in the understanding of social phenomena as they are culture and time sensitive. Allen (1993) uses the analogy of labour rights and how depending on the context in which they occur, have been expressed in various ways, which have been primarily influenced by structural factors that will impact not only the individual but also the group they experienced a sense of membership.

2.7.3. Accessibility to education

Parents of autistic children often experience challenges within the microsystem. Within the microsytem parents often have to inform their family members, friends and different community structures which the child may interact with about the ASD diagnosis. As the child's behaviour is often viewed as abnormal, the parent and autistic child may be subjected to discrimination, rejection and prejudice (Bateman, 2013). This is further compounded by the interactions with the different community structures such as the church and school which would reinforce the perceptions and beliefs that the community may have regarding the autistic child. Although the structures found within the exosystem (such as the legal institutions i.e. the Constitutional Court and national educational structures such as the National Department of Basic Education and the different media outlets put efforts) inform community members about ASD; if there are no efforts to change the culturally sanctioned values and beliefs, which inform the communities' perceptions about ASD, parents will continuously be subjected to lack of support, discrimination and prejudice. By using Bioecological systems theory, the researcher will be able to explore the parents' experiences within the different systems. Furthermore, their experiences can be utilised to improve the different structures, which they use.

2.8. Conclusion

Current literature indicates that ASD is largely a condition that warrants continuous research as there are still areas of ASD which are largely unknown or misunderstood. This has largely resulted in a lack of consensus regarding the best treatment interventions which are best suited for artistic children. These have had an immense effect on how education for autistic

children is structured which has resulted in a multitude of learning models being developed to address their learning needs. However, these learning models do not holistically address all their learning needs and ca at times be not applicable within the South African context. Furthermore, literature indicates that autistic children are often presented with challenges in accessing education due to a lack of systemic understanding. This chapter further provided a background of the theoretical framework utilised to inform the study.

Chapter Three

Research Methodology

3.1. Introduction

The chapter provides details of the research design of this study, the sample, data collection and data analysis. It further discusses ethical considerations and a reflection of the research process from the researcher. This chapter addresses the following sections: the design of the study, rationale for systems approach, the sample, overview of the research design, data collection process, data analysis process, researcher reflexivity, ethical considerations, addressing trustworthiness of the study and limitations of the study

3.2. The research paradigm

The research has been conducted from an interpretivist paradigm. The utilisation of an interpretivist approach ensures that the research embeds the researcher and the research process into the social meaning of the group's experiences (Blaikie & Priest, 2017; David & Sutton, 2004; Samekh & Lewin, 2005). An interpretivist approach allows for an in depth understanding of phenomena through a detailed orientated analysis. This allows for an exploration of areas which previously had not been thought of. The interpretivist approach provides the opportunity for active participation and interaction from the study's participants (David & Sutton, 2004; Samekh & Lewin, 2005). Interpretivism has been criticised as being prone to researcher's bias however, the effects of the bias were minimised through the use of researcher reflexivity. The achievement of researcher reflexivity is detailed in the section establishing trustworthiness of the study. The bioecological systems theory informing the research has been explored in the previous chapter.

Interpretivism provides the researcher with an opportunity to capture data in great detail. This allows for the researcher to obtain the reasons for why the data may present with a particular pattern (Babbie, 2019; Blaikie & Priest, 2017). Obtaining the previously mentioned patterns ensures that then researcher does not gain a mere description of the data but is provided with reasons for the phenomenon's occurrence. Interpretivism utilises observations and interviews in order to obtain data (Babbie, 2019; Denzin & Lincoln; 2013). The use of these research methods is said to result in data that is qualitative, empathetic and high in validity. This research study utilised interviews in order to obtain data.

3.3. The Design of the study

The research was conducted using a qualitative research approach. Qualitative research can be defined as research which attempts to capture a phenomenon or relationship through interviewing techniques (David & Sutton, 2004; Denzin & Lincoln, 2013; Samekh & Lewin, 2005). The research is primarily explorative in nature and aims to explore concepts, schemas or beliefs through the eyes of the participants who prescribe to them (Babbie, 2019; David & Sutton, 2004; Samekh & Lewin, 2005). Qualitative research is also inductive in nature which means that the research aims to capture the experience of the participants as much as possible without being contaminated by the researcher's beliefs or ideas (Babbie, 2019; David & Sutton, 2004; Samekh & Lewin, 2005). In this regard, researchers should be aware that when adopting a qualitative approach to research, the research may take a different route from the researcher's initial expectations. It is imperative that the researcher, being aware of their research objectives and aims, allows for this process to occur and not stop the process or disregard the data that is generated which was not initially anticipated.

Qualitative research enables the researcher to capture the lived experience of the group that is under study. This provides the researcher and in turn academia a unique understanding of the human experience. This is important for the research topic as it endeavours to capture the lived experiences of the participants (David & Sutton, 2004; Samekh & Lewin, 2005). Qualitative research utilises instruments which allows for a degree of fluidity. The fluidity through the use of open ended questions encourage the emergence of data which had not been previously conceptualised by the researcher. Qualitative research encourages the researcher to further probe their personal biases in relation to the research as they are an instrument to execute the data collection (Bailey, 2018; David & Sutton, 2004; Samekh & Lewin, 2005). This rings true for the researcher as she is not a parent of a child with a disability. Throughout the research process it is imperative that the researcher remains cognisant of this difference and how it can affect the research process.

3.4. Sampling method

The sample consisted of six female participants who were selected purposively. The researcher had a specific purpose to select parents of learners who have been diagnosed with ASD. In other words, purposeful sampling method was used to ensure that the participants had the experience and knowledge that this study sought to establish. By using a purposive sampling method, the researcher was able to partly ensure that the data generated will be related to the research topic (Babbie, 2019; Bailey, 2018; David & Sutton, 2004; Denzin &

Lincoln, 2013; Samekh & Lewin, 2005; Patton, 2002; Silverman, 2011). This further ensures that participants also have prior knowledge about the research topic explored in this study.

The researcher had approached a non-profit organisation which works with autistic children and their families to inform their members of the study. An advert was placed on their website informing potential participants of the study and the contact details of the researcher were provided. The researcher's supervisors and ethics office contact details were also provided. Participants were informed that participation was strictly voluntary. The researcher met with the participants prior the interview session where she clarified the procedure and answered the participants' questions.

3.5. Sample characteristics and sampling site

The sample consisted of six mothers with children diagnosed with autism spectrum disorder. Their children were male between the ages of four and nine. All of their children were enrolled in a school. Four of the children were attending public schools whist two attended private schools. One child was in an early childhood development centre whilst the others were in grades one to four. One child was enrolled in a special needs education school, with one child attending a school specifically for autistic children. It is important to be aware that the concept of grades as used in mainstream schools is not relayed similarly in special needs education schools. In most cases the term is used loosely as there is a greater focus on skill development rather than conventional academic progression. The use of the term is to ensure that special needs pupils do not feel different from their mainstream peers.

Three of the mothers were black, two coloured and one white. All of the participants were fluent in English, with three of the participants also fluent in IsiZulu and one fluent in Afrikaans. The participants agreed that interview would be conducted in English as it was a language easily understood amongst them. The researcher herself is fluent in English and IsiZulu and did inform participants that they could express themselves in the language they preferred.

Of the six participants four resided in a suburban area whilst two resided in a township. The study was conducted in Durban, a metropolis area where there are different institutional services which can be accessed for diagnostic and therapeutic purposes. These include healthcare and educational services. None of the participants had migrated in order to access services for their child. Access to the different services was used to abate their children's

symptoms. All of the participants were employed. The interview was conducted at a venue proposed by the participants. The venue was convenient and easily accessible for the participants.

The participants were recruited from Action in Autism which is a non-profit organisation located in Durban. The organisation provides awareness regarding ASD to communities. Furthermore, the organisation provides support services to families who have children diagnosed with ASD. The organisation was approached due to the extensive work and services they provide. A request was placed to access their database which was granted on condition ethical clearance was provided by the supervising university (see Appendix A). Upon receipt of ethical clearance (Appendix C), an advertisement was placed by the organisation in their electronic newsletter which detailed the purpose and aim of the study (Appendix B). The newsletter was circulated to members of the organisation. The potential participants were provided with the contact details of the researcher. Potential participants were screened in order to ensure they met the criteria. The criteria for participation in the study was that individuals had to be a parent or a guardian of an autistic child. In addition, the child needed to be of school going age and be enrolled currently in a primary school setting.

Following the screening process they were contacted to discuss in detail their role and their rights as participants. The participants were given an opportunity to consider whether they still wanted to participate and were further informed they could withdraw their participation. The participants were provided with an informed consent form to sign as a formal agreement of their participation (Appendix D). The informed consent form entailed the purpose and aim of the study. It also provided information on the type of interview and equipment used to record the interview. The informed consent form also provided the contact details of the researcher's supervisor and the ethics committee to ensure that the participants could have a platform where concerns and queries could be raised. The participants were thus informed that signing the informed consent form did not entail their failure to withdraw from the study. It was emphasised that they could withdraw at any time. Following the signing of the informed consent form, a convenient date, time and venue for the interview were agreed upon. The interview was held within the Durban Central Business District (CBD).

3.6. Data collection tools

Data collection was collected using the focus group method. The focus group method can be defined as a data collection method whereby the interview is conducted within a group in order to explore the participants' shared experiences and opinions on the phenomenon, beliefs and behaviours (Bailey; 2018; David & Sutton, 2004; Samekh & Lewin, 2005). The interviews were held in a space which was convenient to all participants. Prior to the interview being conducted the participants were informed again of their rights as their participants and were further informed that the interviews were strictly confidential. The researcher thereafter proceeded to inform the participants why she had to conduct the study. This was done to build a rapport and have participants feel at ease. The interview followed an interview schedule (see Appendix E) and first explored the participant's experiences in accessing education of their children and teaching models available for the education of these learners.

3.7. Data analysis

Thematic analysis is an analytic method used in qualitative research. It is used to identify, analyse and report patterns contained within the data. The patterns are referred to as themes (Babbie, 2019; Braun & Clarke, 2006; Miles, Huberman & Saldana, 2014). Thematic analysis allows for the emergence of the themes through the organisation and description of the data in rich detail. Thematic analysis does not only allow for the description of data in detail but further allows for the researcher to interpret various aspects of the research topic. Braun and Clarke (2006) argue that there are six phases in thematic analysis. The six phases are becoming familiar with data, generating initial codes, searching for the themes, reviewing the themes, defining and naming the themes and finally producing the report. The six phases of thematic analysis are discussed in further detail below.

3.7.1. The transcription process

The interview was audio recorded and transcribed verbatim by the researcher. The interview was captured in its true form and no efforts were taken to change or tidy up the content, the rationale for doing so was that the researcher wanted to ensure that a true and accurate representation would occur in order to extract data that was unbiased. This was key as the topic is exploratory in nature. Throughout the transcription process the researcher consulted her colleagues for guidance and input.

3.7.2. Becoming familiar with the data

The becoming familiar with the data stage requires the researcher to submerge into the collected data. This requires a review of the data, which can be transcripts, audio and visual material and notes. The data from the interview was transcribed verbatim and there was an analysis of the data. There was continuous cross checking of the transcripts with the audio material and field notes. The field notes contained key words and behavioural observations during the interview. The field notes not only contained key words that were said throughout the interview but also the time this was said. The rationale for this motive was to enable the researcher to easily separate each of the participant from another. By utilising this method, the researcher was able to ensure that the words of the respective participant were recorded accurately.

Behavioural observations recorded included documentation of the participants' body language and behaviours. The observations were overt muscular tensions, sighs, pauses, eye and physical body movements. These observations were accompanied by the participant's name in order to ensure that the observations were attributed to the right participant. Braun and Clarke (2006) have stated that this is a crucial stage in the analysis process. During this stage the researchers have to immerse themselves completely in their data. The greater the familiarisation with the data the greater the chances of generating codes which are an accurate representation of the data. For this study, the researcher repeatedly read the transcripts of the interview. Furthermore, reading of the field notes and listening to the audio recording increased her acquaintance with the data.

3.7.3. Generating initial codes

After the transcription process the data was read to in order to generate codes. According to Braun and Clarke (2006) a code is a word that emerges repeatedly in the transcription text. This is not to be confused with themes which are argued to be a secondary product of the code generation process. During the code generation process it was important that the researcher makes continuous and earnest effort not to interpret the data. The data at this time needs was utilised solely for the generation of codes. This ensured that the data is not influenced by any bias. The codes generated were solely generated from the transcripts and reviewed to ensure their validity.

3.7.4. Searching for the themes

Once the process of generating codes were completed, the researcher was required to develop the initial themes. At this time, the researcher was required to check for themes, which are emerging from the data. The themes that are developed have to solely emanate from the data and not be products from previous studies. During the theme generation process, the researcher needed to continuously analyse and search for themes until there is saturation of the data. Saturation of the data occured once there were no new themes that emerged from the data. Once saturation occurred, the themes were reviewed.

3.7.5. Reviewing the themes

Following the generation of themes the researcher was required to review their themes. The reviewing of the themes enabled the researcher to verify whether there are themes which overlap. If an overlap of themes occurred, two or more themes were merged into one. During the review process the researcher was still required to check if the data is still saturated. At this time Braun and Clarke (2006) argue that the researcher consults a colleague to ensure that the data remains independent of any bias. Thus the data is presented in an accurate manner. Following the review of themes, Braun and Clarke (2006) argue that the themes need to be defined and named. The naming and defining steps was undertaken in the results and discussion chapters respectively.

3.8. Ethical considerations

Ethical clearance or this study was provided by the University of KwaZulu-Natal (UKZN) (see Appendix C). Prior to the commencement of the study a consent was procured from the organisation as part of the ethics application. Once ethical clearance had been obtained each participant was contacted to confirm their participation. Upon confirmation, all of the participants were required to sign an informed consent form prior to the commencement of interviews (Appendix D). The informed consent form contained the details such as the nature, aims and purpose of the study. It also included the type of interview that would be administered, equipment which would be used to record the interview and their role within the study. The form also detailed that participation was voluntary and the withdrawal from the process could occur at any time in the study. Each form provided the contact details of the researcher, her research supervisor and the UKZN ethics committee whom they were encouraged to contact with any queries they might have had. The participants received clarification regarding issues of confidentiality and preservation of the data. Participants

were informed that the data would be securely stored at the School of Education, Edgewood Campus for a minimum of five years.

3.9. Establishing trustworthiness of the study

Shenton (2004) has argued that qualitative research has been often criticized for its lack trustworthiness, unlike its quantitative counterpart. He notes that qualitative research is known for not providing a model which allows for the replication of studies within the approach in other contexts or locations. Furthermore, Shenton declares that qualitative research studies often do not describe in rich detail the context in which they are conducted and at times can be conducted strictly from the researcher's predisposed view. The researcher is aware of Shenton's argument and thus is utilising data collection and data analysis models, which were found in similar studies particularly in Low and Middle Income (LMICs) countries such as South Africa.

3.9.1. Transferability

Transferability in qualitative research refers to the degree of consistency which instances are assigned by different or the same observer at different times. The concept refers to the degree that the findings are independent and have not be influenced (\Marshall & Rossman, 2016; Shenton, 2004). Thus, the question being asked of qualitative researchers is can this study be replicated by other researchers with a similar outcome. Within quantitative research this can often be easily achieved as there are instruments designed to elucidate the necessary data required. Due to a lack of a standardised instrument, qualitative researchers are encouraged to achieve transferability by providing a thick, detailed description of the research process. For the purposes of this study, a detailed description of the research process in their entirety by the researcher has been described by the researcher. This includes description of literature, methodology and theoretical framework employed in the study. The researcher also provided an account of the societal context of this study. This is of critical importance as often qualitative researchers will provide the background, methodology and the results. In most instances by acknowledging the societal factors, future researchers can critically analyse the transferability if the study.

3.9.2. Credibility

Credibility is the qualitative equivalent to objectivity in quantitative research. This refers to the researcher not contaminating their research process and the findings due to their preconceived findings. In quantitative approaches, credibility is easy to achieve due to the

use of instruments such as a survey, questionnaire or psychometric assessments to obtain the data. Thus, qualitative researchers need to ensure impartiality particularly when utilising data collection methods such as interviews and participant observation (Marshall & Rossman, 2016; Mauthner, Birch, Jessop & Miller, 2002; Shenton, 2004; Silverman, 2011). Thus, it has been argued that the researcher needs to provide context for their data extracts. This means that researcher also has to describe the preceding events, thus ensuring that the findings reflect the researcher as presenting an objective presentation of the data free from biases due to the researcher's preconceived ideas or beliefs. As the researcher will be using two data collection methods, it is imperative that researcher ensures credibility of her research. Credibility will be achieved by her description of data extracts, the preceding events and the interpersonal interaction between the participants.

Credibility for this study was achieved by a detailed description of the data extracts and peer reviewing. A detailed description includes providing a description of what occurs before, during and after the interview process. The description includes the interaction amongst the participants, their physical and verbal responses. The description of the data is not only for the participants but also includes the researcher. The rationale for this approach is to provide those interested in replicating the study can be provided with an accurate context of these responses. This also enables readers to observe how dynamics between interviewer and interviewee can inform their responses.

Often in qualitative research, the power dynamics in the interviewer and interviewee relationship are not explored and this can influence their interviewees' responses. Peer reviewing consists of the researcher critically engaging with their peers and discussing all the steps being undertaken in the research process. Peer reviewing would allow for the provision of objectivity that would ensure that the research is an accurate depiction of the topic under study. During this study the researcher consulted with two of her peers who have conducted a qualitative research. In this study peer reviewing included steps undertaken in the methodological process and a reflection of the research.

3.9.3. Dependability

Dependability refers to the extent an account or phenomenon is accurately captured. Qualitative research argues itself as an approach that captures the experiences of the participants in their most naturalistic state (Marshall & Rossman, 2016; Shenton, 2004). Through this description it enables other researchers to attempt to replicate the study.

Furthermore, the accurate recording and description of the research process ensures that the data is not influenced by the researcher's bias. An inaccurate recording of the research process can result in two errors as per Kirk and Muller's argument (Silverman, 2011). The first error is Type 1 error which is believing a statement to be true when it is not, i.e. rejecting the null hypothesis. The Type 2 error is rejecting a statement when in fact it is true, i.e. incorrectly supporting the null hypothesis. It has been proposed that qualitative researchers can ensure that validity is obtained through the researcher being aware of the impact that they as the 'experts' have on the setting, their values and validating the truthfulness of the participants accounts.

To counter making these errors it is suggested that qualitative researchers have an audit trail. An audit trail consisted of the researcher having documents which entailed their decision making process throughout the study. The researcher for this study engaged in continuous consultation with her supervisor. Her supervisor provided inputs with regard to the methodology and theoretical framework informing this study. The researcher also acquired the services of her research peers who supplemented the inputs from her supervisor and thus aided in researcher reflexivity. Researcher reflexivity included the researcher reflecting on the manner they interacted with the study. This included how they engaged with the literature, choice of theoretical framework and the research design of the study. The reflection process allows the researcher to critically analyse their position in relation to the data.

The processes previously stated are a continuous process throughout the research process. However, there are steps that can only be undertaken during the interview process such as respondent validation. Respondent validation takes place during the interview as the researcher asks the participants whether they have accurately captured their responses. The researcher achieved this by asking the participants clarifying questions while ensuring that all responses were recorded accurately.

3.10. Journey of the researcher

The research process has been a learning experience throughout. The learning firstly occurred during literature review where I had to grapple with current realities facing parents of autistic children. The gap between policy and the current reality was concerning. Despite the number of steps taken by the civic organisations, community members and policy makers there have been limited progress for autistic children in KZN. As an educator, this

concerned me deeply as I am aware of the importance a school plays in the development of a child. This development is not limited to cognition but extends to social and life skills. Hearing the parents describing the challenges they had encountered, reminded me of the disparities between mainstream and special needs schools which require urgent reform. As a teachers in a mainstream school with limited resources, however I am aware that these seemed minor compared to those of my participants.

As a mother, I empathised deeply with the participants' experiences. One of the greatest joys one can experience as a parent, is to see their child thriving and developing to the best version of themselves. However, this becomes very difficult when there are impermeable institutional barriers that prohibit this from occurring. Interacting with the parents highlighted my privileged position as I had received far greater resources and institutional support. During the transcription process I often found myself feeling emotional, it was difficult to divorce myself from the palpable emotions from the audio due to participants' frustration, anger and acute sadness stemming from the challenges they experienced. These emotions often arrested the listener and required one to do an introspection. As I continued transcribing the intensity of these emotions, a discussion with a colleague brought to my awareness that these emotions were unsettling as they were directed to two of my identities. The discussion centred around the helplessness I had experienced with the inability to assist the participants with their current situation.

3.11. Conclusion

The utilisation of qualitative research design enabled for the researcher to undertake an exploratory approach in order to answer the research questions. Purposeful sampling ensured that the participants chosen would provide the required inputs. Data collection was achieved using the focus group method with a semi-structured interview schedule guiding the interview process. Thematic analysis was used to analyse the data with the researcher detailing how she established the trustworthiness of the study. Finally, the chapter also detailed a reflection by the researcher regarding the research process.

Chapter Four

Presentation of Findings

4.1. Introduction

The following chapter will present the findings of the study. The themes presented are reimagining parenthood, resources as a developmental requirement and policy and autism. Each theme has subthemes, which are explored in further detail. The chapter contains extracts from the data, which are identified by being indented and italicised. To maintain confidentiality pseudonyms have been provided.

4.2. Reimagining parenthood

Parenthood is a time where many individuals enter another stage of their development. Parenting is a multifaceted experience with different areas of the person's life being influenced by their new role (Chua, 2011). However, when parenting those who are different from what is considered the norm, parents are tasked with having to reimagine what parenting entails. The following section explores the different facets of parenting influenced by raising an autistic child.

4.2.1. Becoming a parent to an autistic child

Parenting is a framework that is influenced by different institutions within a society. In this respect, individuals are socialised into a specific parenting style. The parenting style is designed to accommodate those without disabilities. Following the results of the diagnosis, the participants reported experiencing concerns regarding the manner in which they will parent their child. These concerns were further heightened by a lack of visible accessible parenting styles which they can model themselves after. The participants described having to reconceptualise parenting and parenthood within a special needs framework.

> *For me, it was more of how will I raise this child? I've never heard of autism before this so I didn't know how will I raise him?*- Joanne

Their concerns were not limited to the irrevocable change they had to undergo but also extended to their child's future trajectory. Trajectory in this context refers the child's prospects and development. This resulted in the participants having to undergo a rigorous research process to understand ASD and their child's specific symptom presentation. As ASD has a heterogeneous presentation the participants had to determine the best parenting approach suitable for their child's unique traits.

Table 4.1: Becoming a parent to an autistic child

Participants	Responses
Maggie	*When I heard that my son had autism my first thought was what now? Where do I go from here?* *For me I have to say that when you approach things in public with a hint of fight it can make things worse as people can become defensive and can be more troublesome.*
Samantha	*Not forgetting what does it mean for my son?* *I try to blend in as much as possible (chuckles) which requires planning and planning. So as to have as normal experience as much as possible*
Joanne	*For me, it was more of how will I raise this child? I've never heard of autism before this so I didn't know how will I raise him?* *When he has an episode and people are doing the usual disapproval stare reserved for misbehaved kids. But I know that he is different and it will take extra efforts to get him to calm down. During that time you also try to explain to strangers what is happening because they make you feel entitled to explanation*
Alison	*(pause) after the diagnosis I just started reading so I can figure out how can I be the best mother to this child.* *People are not ashamed to give their opinions or disapproving looks about your child even in public. You have to stand up for them a lot in public.*
Sonia	*You have to fight a lot. Fight for your children to get the help they deserve. Fight for them to be allowed to be part of society.*

Table 4.1. consists of the participants responses pertaining to their experience of adjusting to life as a parent of a child diagnosed with ASD.

Following the birth of a child there are multiple resources required in order for optimum development to occur. These resources include structural, financial and human. The resources required can be accessed at different levels but this sequlae of events differs for children with disabilities. Children with disabilities differ in their symptom presentation and severity. Due to the difference in symptom presentation and severity many families are required to adjust primarily at two levels. Firstly the acceptance and adjustment of living with an individual with disability. Families need to structure themselves in a way that accommodates the family member's unique needs. The second level of adjustment occurs

within the parent or caregiver has to reconceptualise their pre-existing ideas regarding parenting. For the parents of a child with autism they have to grapple with a condition that is still on the cusp of being understood by different academic disciplines. The heterogeneity of autism symptoms requires each parent to take the necessary steps in learning the best way to parent their child. The old adage states that no two people are alike and this rings most true for autistic individuals.

For parents of children living with disabilities they are required to reimagine what is normal. The participants recalled their initial thoughts after receiving their child's diagnosis. The initial reactions were laden with thoughts of how they would proceed to raise their child.

> *(pause) after the diagnosis I just started reading so I can figure out how can I be the best mother to this child.*- Alison

These initial reactions were followed by an extensive period of research where parents needed to inquire what parenting an autistic child consists of. This included how to approach development, what is required of them in this role and navigating their child's symptoms. Participants when asked to describe what motherhood meant within this context, the concept and role of motherhood furthered this. The participants explained that unlike most of their peers, as parents of an autistic child they were required to be more nurturing, patient and attuned to their child.

> *You have to fight a lot. Fight for your children to get the help they deserve. Fight for them to be allowed to be part of society.*- Sonia

> *When he has an episode and people are doing the usual disapproval stare reserved for misbehaved kids. But I know that he is different and it will take extra efforts to get him to calm down. During that time you also try to explain to strangers what is happening because they make you feel entitled to explanation.*- Joanne

Being a parent of an autistic child also entailed having to advocate for their child's right to occupy different spaces in society. Some of the participants however disagreed with having to undertake an advocacy role and rather stated that they have to undertake a more passive role.

> *For me I have to say that when you approach things in public with a hint of fight it can make things worse as people can become defensive and can be more troublesome.*- Maggie

The undertaking of a covert advocacy role should not be interpreted as parents caring less or negligent role. Rather their stance can be understood as an alternative protective measure. Within social settings overt advocacy can be misunderstood as parents being the aggressor which can result in a social backlash for both parent and the child. The choice to take on an advocacy role is seemingly unfair as some parents may not want the responsibility that comes with this role. Whilst some parents decided whether to take an advocacy role others chose to take the assimilation route. Assimilation within this context was a conscious attempt to have their autistic child follow accepted social and cultural behaviours. Participants described that assimilation was a means to seem 'normal' even though this raised challenges.

> *I try to blend in as much as possible (chuckles) which requires planning and planning. So as to have as normal experience as much as possible.*- Samantha

For the participants they however stated that they were more likely to attempt to assimilate into the preordained accepted social behaviours. The assimilation process was described as having to be supplemented by a quasi-teaching role. The attempts to assimilate did not often yield the expected results. Participants described that their assimilation attempts were unsuccessful at times as they were still subjected to discrimination from other social revellers. This placed constraints on which spaces they could occupy comfortably.

4.2.2. Gendered parenting in autistic families

Parenting is process that is said to be underpinned by a partnership between two individuals that is a mother and a father. Within this partnership there are preordained roles and responsibilities for a mother and a father. However, this differs slightly when parenting a child with disabilities. The participants described how both parents were required to engage in an active nurturing role. For the participants, parenting roles no longer consisted of mothers as nurturers and fathers in a less active nurturing role.

> *In an average normal family, the mom and the father both nurture the family in different ways. Mom will be nurturing and the father will be stern and playful. In our families, things are different. You have to relearn how to do things so that they fit with your child.*- Samantha

Less nurturing role was described as fathers would often engage in more play activities. The participants described how fathers struggled to make this adjustment. The participants described how the inability to perform the nurturing role by fathers provided distress and

conflict within the family. The participants described that those who utilised a co-parenting model experienced the same difficulties as their counterparts in households with two parents. Some of the participants reported receiving no support from their child's father. These participants reported having to rely on family and friends in raising their child.

Table 4.2: Gendered parenting in autistic families

Participants	Responses
Maggie	*That is true because society is not welcoming, so that is something many moms do not have to think about even if they do have disabilities. You are granted the opportunity to be you. With fathers, if they are around they play a nurturing role, which supplements the therapeutic interventions.*
Samantha	*In an average normal family, the mom and the father both nurture the family in different ways. Mom will be nurturing and the father will be stern and playful. In our families, things are different. You have to relearn how to do things so that they fit with your child.*
Joanne	*We did try to do the co-parenting but it did not work especially if there is no emotional investment. With an autistic child, you need to be committed. It can be an on and off thing. I am fortunate to have extended family that is willing to co-parent which shoulders a lot of the burden.*
Alison	*That is true especially if your child has sensory difficulties like mine. With most children, you can tickle them but it is excruciatingly painful. Even loud noises, so that narrows down the activities we can do. Even how you as a mother, there is a bit different extra care taken in everything that you do but also trying to make the whole experience as normal as possible.*
Sonia	*In autistic families, the father pays less of the fun parent role but that changes a bit. You both need to be focused a bit more serious because firstly you are learning about this condition. Mothers are still tasked with nurturing but you need to fight more.*
Tania	*My child's father and I separated shortly after he was born. I am the primary caregiver and take care of my son. His father attempts to be involved but its visit now and again. No real involvement, he is just a*

	financial parent. Therefore, I have to be the mother and father which is tiring.

Table 4.2. consists of participants experience of gendered roles within families that have autistic children.

A family can be described as an organisation with each member playing a role to make the organisation work. The lack of participation by fathers to participate in nurturing of their child placed a significant strain on mothers and their extended support structures.

> *In an average normal family, the mom and the father both nurture the family in different ways. Mom will be nurturing and the father will be stern and playful. In our families, things are different. You have to relearn how to do things so that they fit with your child.*- Samantha

Most of the participants acknowledged that there were differences in parenting approaches with regard to gender but these differences were not clearly articulated. It was established that there were minimal differences in parenting in autistic and non-autistic families. As with all families parents need to take into account the needs of their children's health and more. In non-autistic families, traditional roles are still often upheld but where parents of autistic children's roles differed was not clear.

For a number of the participants, traditional parental roles of adult males became inversed whereby a more active caretaking role had to be undertaken. The shift in roles particularly for men is argued as being necessary in order to meet the needs of an autistic family. The shift is therefore necessary in ensuring the development of an autistic child. However, some of the participants argued that in families with separated parents the situation is a bit different.

> *My child's father and I separated shortly after he was born. I am the primary caregiver and take care of my son. His father attempts to be involved but its visit now and again. No real involvement, he is just a financial parent. Therefore, I have to be the mother and father which is tiring.*-Tania

Some of the participants identified single parents who expressed that they encountered further difficulties within a single parenting home. A single parent in this context was described as an individual who was not romantically involved with their child's biological father. Furthermore the 'single parent' was argued as the primary caregiver and involved in

day to day nurturing of the child. It was interesting to observe that some participants who identified as single parents further described themselves as utilising a co-parenting model. Co-parenting as an alternative parenting model was argued to be a feasible alternative whilst for some participants deemed it unsuccessful. Most of the participants who were single parents agreed that co-parenting which extended to immediate and extended families was the best structure to raise their child.

> *We did try to do the co-parenting but it did not work especially if there is no emotional investment. With an autistic child, you need to be committed. It can be an on and off thing. I am fortunate to have extended family that is willing to co-parent which shoulders a lot of the burden.-* Joanne

The shared responsibility allowed child rearing duties to be shouldered by different parties. This ensured that the effects of burnout were mitigated. Co-parenting interestingly was not limited to biological parents but also included parenting provided by extended family members. Inclusion of extended family members as co-parents is not uncommon within collectivist cultures. For the purposes of this study participants had not been asked to state whether they identified with collectivist or individualistic cultures.

A communal approach to parenting was common practice for participants who subscribed to collectivist cultures. However, within these cultures there were deeply held traditional beliefs, which were discriminatory. This then required participants to carefully select who they can safely and comfortably engage with. This is common to all families but is more inherent in families with unique medical conditions, mental illness and physical disabilities. Families with autistic individuals are no exception as the unique qualities their child presents will require a parenting approach which would meet the needs of the child but not at the expense of other family members. In the following section the following sub-sections are explored reimagining parenting, gendered parenting, balancing family needs.

 Co-parenting, as a parenting approach was not only limited to single parents but also included dual parent homes. The inclusion of extended families also provided the opportunity for the family members to intimately engage with the autistic child. These actions enabled participants to feel that their child was experiencing a semblance of normal family. Therefore, by alternatively acknowledging this as the norm then we do not have to conceptualise autistic families as being different from the norm. In the following section the

following sub-sections are explored reimagining parenting, gendered parenting, balancing family needs.

4.2.3. Balancing the needs of all family members

Adjusting to living with an autistic person is one that not only affects the parents but all the family members of the community. The participants detailed during the initial weeks and months following diagnosis that most of the family's resources   are invested in the autistic child. This can lead to other members of the family such as children not receiving the necessary attention unintentionally. This, participants detailed, affected children no matter their position within the family genealogy. The participants stated that their autistic child was the eldest child within the family but was usually treated as the youngest child in the family.

> *In each family, depending if the autistic child is the first, middle or last-born, it can really affect the family in different ways. If it is the eldest, many of the responsibilities then have to fall on the younger ones because they may not be able to do certain things. They become like the baby, which can be a bit hard to adjust to a switch.*-Sonia

This resulted in the younger children having to take upon the role and responsibilities of older child. The participants also described how they had to ensure that the needs of the other children were being met. Some of the participants stated that due to the wax and wane nature of autism symptoms, they still experiencing difficulty balancing their family's needs. The participants expressed the process of having to educate their other children continuously about their sibling's symptoms in order to encourage their acceptance of their sibling. Many participants reported that their romantic relationships were not exempt from neglect. The participants described having to make a concerted effort to ensure their romantic relationship is nurtured.

> *In all families, you need to find a balance of everything. In your daily interactions, you come to know the little things, which make a person special. Our families are a bit different; autism becomes the centre of everything especially in the early days.*- Alison

Table 4.3: Balancing the needs of all family members

Participants	Responses
Maggie	*That is true your life revolves around autism. I think for many of us we don't know anything about autism so at first it's a bit of a crash course then accelerated learning.*
	Telling the rest of the family about his diagnosis was hard. They had questions, which I tried to answer to the best of my ability. However, the biggest concern was so what does it mean for the family? So I tried let them

	know that how our life is going to change and what we need to do in order to make the best of everything and make my son comfortable.
Samantha	*We did something similar and letting them know what we can expect. Just trying to assure everyone that this is a normal situation. I know it was not the normal they were used to but assuring them this was our normal. Also, calming their fears about the future.* *I have two children and my eldest is autistic. They get along well and are supportive of each other. The youngest understands that his brother is different and helps. Now the problem is with the rest of the family. Since he is the youngest, they treat him as such and when he gets home, he starts to act out because he expects the same treatment. It feels wrong to deprive or punishing him for exactly what should be happening.*
Joanne	*That is true in the mix of finding treatments, school and other day-to-day stuff, it is very easy to lose each other. It is an experience of many couples but when you have a child with special needs, it becomes a bit more difficult.* *I think the only other time our boat was rocked a bit was when our son started attending school. So, at that time you are trying to find out how to make this transition as smooth as possible, planning and all of that stuff. I guess it is the big events that need you to check again, if you are still on the same page.*
Alison	*In all families, you need to find a balance of everything. In your daily interactions, you come to know the little things, which make a person special. Our families are a bit different; autism becomes the centre of everything especially in the early days.* *I would say in my experience that it usually happens during the first few months because you are learning to function with this condition, so it does take a bit of strain on the relationship but you learn how to deal with it.*
Sonia	*In each family, depending if the autistic child is the first, middle or last-born, it can really affect the family in different ways. If it is the eldest, many of the responsibilities then have to fall on the younger ones because they may not be able to do certain things. They become like the baby, which can be a bit hard to adjust to a switch.*

Tania	*Sometimes you feel you are on a train the autism train (laughs); you are just chugging along. While you are in this train, you sometimes forget others especially your partner, you both become focused and even forget that you have your own relationship you must nurture.*

Table 4.3. details the participants experience of balancing the needs of all their family members.

Families are a nexus, which maintain the core societal values, traditions and beliefs. In all families the parental structures are the rudders which steer the family into the right direction. There needs to be an acknowledgement and awareness of each member's needs in order to have balance within the family and this should prevail in all families. The initial post diagnosis period is one where participants rallied themselves and families in learning about autism. A period where they had to teach immediate and extended family members followed. Prior to this teaching period, the participants described how they had to prepare their family members for the adjustment to living with a person with   autism. All of the participants agreed that this period was a tough transitional period for their family members.

In all families, you need to find a balance of everything. In your daily interactions, you come to know the little things, which make a person special. Our families are a bit different; autism becomes the centre of everything especially in the early days.
I would say in my experience that it usually happens during the first few months because you are learning to function with this condition, so it does take a bit of strain on the relationship but you learn how to deal with it.- Alison

Telling the rest of the family about his diagnosis was hard. They had questions, which I tried to answer to the best of my ability. However, the biggest concern was so what does it mean for the family? So I tried let them know that how our life is going to change and what we need to do in order to make the best of everything and make my son comfortable.- Maggie

This period was described as having to re-establish family member's roles in order to accommodate the needs of the autistic family member. By undertaking this approach this ensured that everyone understood how they could contribute to the family's cohesion. The role reversal as proposed by the participants seemed a common thread for participants who had more than one child.

Management of autism often became a key concern of the participants which in turn affected their relationships with their partners and other children if present. Albeit some participants agreed that this, a common occurrence with the parents' relationship, other participants disagreed.

> *That is true in the mix of finding treatments, school and other day-to-day stuff, it is very easy to lose each other. It is an experience of many couples but when you have a child with special needs, it becomes a bit more difficult.-* Joanne
>
> *I would say in my experience that it usually happens during the first few months because you are learning to function with this condition, so it does take a bit of strain on the relationship but you learn how to deal with it.-* Alison

They described that establishing a balance within their romantic relationships occurs during a transitional period. During this period, there is greater effort in terms of resources required. The transitional periods were described by the participants as being unavoidable and thus needed an injection of resources. Each of the participants however agreed that a balance or semblance of it was achieved through pooling support structures, consistent communication and awareness of the needs of all family members.

4.2.4. The costs related to autism

Children require multiple resources in order to develop optimally. Children with disabilities are not exempt and require more resources than their able bodied peers. The participants stated that providing their child with the therapeutic interventions from different professionals requires a considerable amount of money.

> *My child attends OT and speech weekly at school and at private. He used than often to see a psychologist but he is quite better now so he does not go anymore. Each of these sessions cost R700 and medical aid does not always cover them. As much as I am grateful for the school, sessions, but they really are not enough.-* Maggie
>
> *I am a single parent and I do not earn that much so everything falls on my shoulders. I am also the breadwinner at home so medical costs can really be a headache. My friends really have helped by paying for doctors and therapists' fees. This community of friends are indispensable.-* Tania

For the participants this bode true whether they sought interventions in both public and private health sectors. However, this was not the sole cost they described. The participants described the psychological and emotional toll living with a child who is autistic. The toll included the social isolation they were initially subjected to and concerns regarding money. For the

participants, they reported experiencing continuous distress following diagnoses which were related to the lack of support they were experiencing and finances. During this time participants reported being unable to channel their resources towards themselves as they were required by their autistic child. The participants agreed that contributions from their support system enabled them to ensure their child's need were met.

> *I will say that I was overwhelmed and a bit depressed. I was tired, sad and a bit anxious.*-Samantha

Table 4.4: Costs related to autism

Participants	Responses
Maggie	*My child attends OT and speech weekly at school and at private. He used than often to see a psychologist but he is quite better now so he does not go anymore. Each of these sessions cost R700 and medical aid does not always cover them. As much as I am grateful for the school, sessions, but they really are not enough.*
Samantha	*The community they are the ones who keep an eye on your child and share their parental experience on raising a child. That changes tremendously with a special needs child. People do not know what to do so they just back off and that deprives of a huge resource. You feel like an island.* *I will say that I was overwhelmed and a bit depressed. I was tired, sad and a bit anxious.*
Joanne	*When he was younger, nobody wanted us near them. They felt my child was bad and did not want to listen. I do not know how many times I was told to learn how discipline him. When people saw it was, more complex than merely disciplining him, they started distancing themselves. After that no one wants to invite you to things and it can become very lonely.* *The online groups have been god sent because there is no set time you can just go on whenever and talk to someone. Sometimes the usual meeting format can feel a bit detached sometimes.*
Alison	*Mmm yes during that time you have grief a little bit for all the dreams that you had for your child while being an attentive parent to your child. It is so hard and you feel as if you are in a storm of emotions.*

	I would say I experienced a boat of depression. Sometimes it would be so hard to sleep and I would be irritable and was not a pleasant person to be around, I was also crying a lot but I tried to not do it in front others.
Sonia	*My son also needs to see a dietician because certain foods do not agree with him, so on top of all the therapists we have doctor's fees that we must consider. More than often medical aid funds run out and you have to pay from your own pocket.* *No one tells you of the emotional drain of this journey. In the beginning after the shock, sadness and anger, you need people to rally around you, support you, all the things that people should do. Common decency you know, but for many of us you are on your own sadly.* *I try to give myself as much time to myself and it helps a lot. That hour to focus on me and I would say it makes me a better parent. I also use online forums, WhatsApp group and joining organisations that have groups. It feels good to talk to people who know exactly what I am talking about and I have made many good friends.*
Tania	*I am a single parent and I do not earn that much so everything falls on my shoulders. I am also the breadwinner at home so medical costs can really be a headache. My friends really have helped by paying for doctors and therapists' fees. This community of friends are indispensable.* *It is not even with neighbours and friends, it happens with family. You and your child become the black sheep of the family and no one wants to hang out with the black sheep. That rejection is the hardest because you grow up being told that family sticks together, helps each other, so when that expectation is not met it really hurts.* *Mmm yes, during that time you have grief a little bit, for all the dreams that you had, for your child while being an attentive parent to your child. It is so hard and you feel as if you are in a storm of emotions.*

Table 4.4 consists of participants responses regarding the different costs associated with raising an autistic child.

Individuals with special needs often need different services to ensure they are enabled, that can navigate the different spaces which they occupy. The services are a myriad and are dependent on their symptoms. For autistic children each of their needs are a valid requirement in order to

obtain the necessary skills needed for their daily tasks. Resources have always been a requirement in order to meet basic human needs. The resources described as integral for autistic children and their families were medical and assistive devices amongst others. Participants agreed that multiple medical costs were a significant part of parenting an autistic child.

> *My son also needs to see a dietician because certain foods do not agree with him, so on top of all the therapists we have doctor's fees that we must consider. More than often medical aid funds run out and you have to pay from your own pocket.* - Sonia

These medical costs were considered an essential need despite placing a financial strain on the participants at times. Some of the participants described how their family and friends' assistance mitigated these medical costs. These allowed the participants to feel less burdened and stressed.

For a majority of the participants, they vocalised how they were unprepared during the initial stages regarding the costs associated with an autistic child. This also extended to the social isolation that they were subjected to post diagnosis. The social isolation encounters were experienced within their immediate and extended social spaces and this was attributed to a lack of understanding regarding autism. With most of the participants there was an expectation that they would experience discrimination within their communities. Their communities were seen as a secondary support mechanism for caregiving and their support was argued as important in rendering support. In participants who subscribed to a collectivist approach, the community was a major component of child rearing.

> *It is not even with neighbours and friends, it happens with family. You and your child become the black sheep of the family and no one wants to hang out with the black sheep. That rejection is the hardest because you grow up being told that family sticks together, helps each other, so when that expectation is not met it really hurts.* -Tania

A collectivist culture is one where a person is not solely defined by their individual desires, goal or values but rather centred on being part of a greater whole. The whole in this regard refers to the individual's family and the culture which they identify with.

The withdrawal of the support from immediate community members was an isolatory experience which when coupled with rejection from their family members often left the participants at risk of mental illness. The limited social support often equated to the participants not receiving emotional support that many of their peers would normally

receive. The participants acknowledged that limited or no social support left them emotionally vulnerable.

> *No one tells you of the emotional drain of this journey. In the beginning after the shock, sadness and anger, you need people to rally around you, support you, all the things that people should do. Common decency you know, but for many of us you are on your own sadly.*-Sonia

For many of the participants they had to undergo a grieving process to enable an acceptance of their child's diagnosis. All the participants agreed that this process had to be done simultaneously with learning how to parent an autistic child. During this time, there is a higher need for social support to mitigate to negate the emotional and psychological difficulties they are experiencing.

> *Mmm yes during that time you have grief a little bit for all the dreams that you had for your child while being an attentive parent to your child. It is so hard and you feel as if you are in a storm of emotions.-* Alison.
>
> *No one tells you of the emotional drain of this journey. In the beginning after the shock, sadness and anger, you need people to rally around you, support you, all the things that people should do. Common decency you know, but for many of us you are on your own sadly.-* Sonia

The participants agreed that they may have experienced emotional difficulties due to limited support. A detailed description was requested from the participants to establish the nature of these difficulties.

All the participants agreed to the emotional states as common experience. With their limited resources, many had to find alternative options in order to ensure they attain the necessary support. This included actively engaging self-care practices and joining support forums. The forums could be virtual or traditional. Finding alternative support forums provided the participants an opportunity to establish their own communities, which would render the emotional support they desired. Due to their easy accessibility, online forums ensured that the participants would have a wide range of their intrinsic needs met. Online forums also allowed for participants to choose the communities, which they felt, was congruent with their identity. This increased the network of resources and buffered the social isolation they experienced in their immediate contexts.

4.2.5. Social spaces and support available for parents

Social support is integral within the human experience. Parents often rely on support from their social circles to assist in child rearing duties. The participants described how difficult it was to navigate social spaces with an autistic child. This was initially attributed to many people having limited knowledge about autism. Support for the participants had different meanings within different contexts. The participants detailed the importance of continuous, consistent support and the assurance it provides for them.

> *Support means people taking the time to help me out with looking after my autistic child, it also means in helping with the household chores.*-Maggie

Table 4.5: Social spaces and support available for parents

Participants	Responses
Maggie	*Support means people taking the time to help me out with looking after my autistic child, it also means in helping with the household chores.*
Samantha	*I used to be able to take my child to private therapists but it became financially viable, as it was costly. Now I have to rely on school therapists and public hospitals. It is not the best situation but what can one do?*
Joanne	*(nods) I agree. I wouldn't be able to get by if there wasn't people behind me who I knew can depend on.*
Alison	*Support is everything. Knowing that you have someone to help you with things takes a huge weight off your shoulders.*
Sonia	*For me support is different things in different contexts. With my family and friends, support would first mean making an effort to learn about my child's autism. I feel that once you actually know what I'm dealing with then you have an idea what how you can help. So help from them means helping out with my child, this can be financial or helping with childcare duties. From his therapists you know, telling us what we can do at home or things to read. Same for school you know, letting me know how to help my child better.*
Tania	*For me a lot of the resources are far from me which creates a headache as I rely on public transport. When we are having a bad day taxis can be a nightmare.*

Table 4.5 consists of the participants responses regarding the social spaces and support available to parents.

Social interaction is an invaluable component of human existence. It allows for learning and interconnectivity with our fellow man. Our social interactions provide the mechanism to develop support structures, which assist in times of need. This was especially important for parents with autistic children. For many of the participants, the support they required depended on the institutions which they were interacting with. Regarding the family institution, parents required emotional support supplemented by child rearing assistance. This allowed the parents to not experience emotional and mental taxation. Furthermore, this also negated the effects of being burnout which allowed the participants to be able focus on their self-care.

> *(nods) I agree. I wouldn't be able to get by if there wasn't people behind me who I knew can depend on.*-Joanne

> *Support is everything. Knowing that you have someone to help you with things takes a huge weight off your shoulders.*-Alison

Within other institutions such as healthcare and education, there was an expectation that resources would be provided to assists with the relevant treatment intervention. However, not all participants experienced systemic support provision. Some of the participants described how the institutional support provision was not easily accessible. These participants described how there were different barriers, which hindered access to this support.

> *I used to be able to take my child to private therapists but it became financially viable, as it was costly. Now I have to rely on school therapists and public hospitals. It is not the best situation but what can one do?*- Samantha

> *For me a lot of the resources are far from me which creates a headache as I rely on public transport. When we are having a bad day taxis can be a nightmare.*- Tania

Proximity to support services seems to be a key indicator of accessibility. However, accessibility did not equate to quality and an important thread amongst the participants was that support is a necessity not only for their children but for themselves.

4.3. Autism and interconnectivity

Life with an autistic individual often challenges their caregivers to reconceptualise mechanisms for interconnectivity such as culture. This requires for people to have to redefine what culture constitutes and immerse themselves within that culture. This section

will explore the influence autism has on the caregivers in order to establish interpersonal connections with those within their community.

4.3.1. Reimagining culture as a parent of an autistic child

Culture is a foundation or a point of reference. Culture is a means to negotiate group membership and forms an integral part of a person's identity. Some of the participants reported identifying with individualistic cultures whilst others identified with collectivist cultures. The participants who belonged to collectivist cultures described how their culture had a framework to explain their child's symptom presentation and subsequent intervention. However, the participants described that though they were aware of the futility of these interventions they pursued them in order to achieve membership with their respective culture.

> *I know culture is there to help us but sometimes it does more harm than good. Because of these beliefs, people begin to treat you differently. Sometime it even goes as far you being isolated since no one wants to be around your omen child.*-Maggie
>
> *In my culture sometimes people, even family will say that we need to do something for him. They say that maybe we did something to anger ancestors and that kind of stuff.*-Tania

The participants reported that their assimilation attempts often resulted in distress for both a parent and a child. For the participants, they found themselves assimilating into other cultures which would provide acceptance and support their autistic child. The culture was described as that one developed by the autistic community.

Table 4.6: Reimagining culture as a parent of an autistic child

Participants	Responses
Maggie	*Alternatively, sometimes they say if you pray enough then the child will be healed of all his symptoms. That is so hurtful,* *I know culture is there to help us but sometimes it does more harm than good. Because of these beliefs, people begin to treat you differently. Sometime it even goes as far you being isolated since no one wants to be around your omen child.*
Samantha	*I think we have common experiences that can be said is your rite of passage from the diagnosis onwards. Then coming together as a group we have a way that we do things.*
Joanne	*I will say the culture of the autism is showing up for each other. Helping each other and being assertive in our pursuit for inclusion and respect.*

Alison	*It gets tiring having someone keep telling you about someone they know who can cure your child. My child does not need a cure. People need to learn how to fit in his world instead of trying to make him fit in theirs.*
Sonia	*You create culture and communities where you feel that you fit. It's mostly with other parents and those who make the efforts to learn about autism.*
Tania	*In my culture sometimes people, even family will say that we need to do something for him. They say that maybe we did something to anger ancestors and that kind of stuff.*

Tables 4.6 details how participants have reimagined culture as parents of autistic children.

Culture is a thread that connects people with each other. This thread informs how concepts and institutions are conceptualised within a system. In collectivist cultures, all parts of the system are interconnected with a problem in one part of the system resulting in negative consequences for the other parts of the system. For some of the participants their ethnic and religious cultures had their own framework of understanding their child's autism diagnosis. At times the framework was at odds with healthcare system, which they accessed for the child's treatment.

There was a consensus amongst some of the participants that the conceptualisation of autism within their cultural framework did not aid in effective treatment and support. The cultures that were described by the participants were ethnic and religious cultures.

> *It gets tiring having someone keep telling you about someone they know who can cure your child. My child does not need a cure. People need to learn how to fit in his world instead of trying to make him fit in theirs.*-Alison

These frameworks were described as harmful and further perpetuated othering of their child. This indicates the relational properties of culture for the few participants who had negative experiences within their cultures which included isolation. By further rejecting the cultural views this was seen as rebellion of sacred traditions. This in turn required the participants to explore other cultures where they attain membership that would not discriminate against their child. It was interesting to note that the participants described as parents had a culture amongst them which was for those who had experienced rejection from their own culture a renewed belonging. The participants agreed there was a culture within the autism community but they could not provide an absolute description of this culture.

I think we have common experiences that can be said is your rite of passage from the diagnosis onwards. Then coming together as a group we have a way that we do things.- Samantha

You create culture and communities where you feel that you fit. It's mostly with other parents and those who make the efforts to learn about autism.- Sonia

However, it cannot be denied that a lack of definitive culture did not hinder the participants from experiencing feelings of being part of a collective culture.

4.3.2. Life outside of autism social circles

There is an imperative need to find a balance between motherhood and the participants' own personal identity. For women, once they become mothers there is a sole expectation that their life will revolve around their children. The participants explained that they often felt as though they are under significant scrutiny in their ability to take care of a child with a disability. They perceived the scrutiny as far greater than their peers with able bodied children. The participants further described having difficulty being able to do activities specifically for themselves. This was attributed to lack of the requisite support system to provide the opportunity to take the breaks they desired. Additionally, the participants described experiencing feelings of guilt if they could not live up to the expectations imposed upon them.

Table 4.7: Life outside of autism social circles

Participants	Responses
Maggie	*Definitely and you just cannot get up and go out. You have to carefully choose someone to look after your child if you want to go out at an event. There are many times I have thought I would love to go to that or turned down an invitation because it would not work out.* *With other mothers, they are encouraged to nurture their other identities. There is an acceptance that they are multi-faceted and very importantly are women. So, they need to go out and do things to nurture that but when you have child with special needs you are just a mom.*
Samantha	*Oh I do. Being mom becomes the centre of everything, your focus is making sure your child is okay and gets a chance.* *It sounds silly doing things the way you think they want you to but you trying to prove a point. All mothers live through this but I feel that I am under a microscope.*

	Well we try to do things like a date night. So that becomes our 'us' time which helps us as a couple. So it gives us time to connect but it feels routine it lacks spontaneity. It still feels that he is the one who gets to move in and out the worlds. I still feel stuck you know.
Joanne	*In addition, many of the times there is an expectation for you to be a warrior mom for your child and many people forget that you are more than that. That is just one aspect of it; with our children there is a degree of planning when it comes to social stuff. So you need a system that no only takes care of the child but you too. For many of us we have a system in place for our child but not ourselves.*
	That is so true because mothers are the face, creators and executors, no one thinks about fathers. Even in forums, many of the people there are moms. Fathers get a free pass because society gives them a pass and secondly they are just not there
Alison	*Living with autism has become a way of life for me but sometimes you wish you could truly live without having to think about it. I wish I could get up and try new things with my child without worrying if it would distress him. When I see friends try out new things with their children and knowing that cannot be me is hard.*
	It just goes back to the expectation thing, people expect you as a mom to do everything, which you do. Then because you also feel the need to take on all this responsibility, it gives the dads the time to do all the things outside of the autistic bubble.
Sonia	*As people, we have different parts of ourselves so being a mom is one part of me but being mom sometimes seems to outweigh the different parts of me. I am not sure if you get it.*
Tania	*I think all moms who have children with disabilities feel that way. Sometimes you feel people are more judgemental towards us. Therefore, you do all in your power to make sure that no one has anything bad to say about your child. When are men ever included or thought about when it comes to raising children?*
	When I was still in a relationship that was hard. Our lives revolved around autism so much that it was all we became. Even when we were out it hung

	over us and I was always tired. I was just trying to learn a lot and teaching him. It was so unfair because he could checkout and was expected to checkout. He ended up having a life and I was left steering the boat alone.

Table 4.7 denotes how participants navigate life outside of the autism community.

All communities are connected at a certain point that forms the primary source of interconnection. Our interconnection mechanisms range from gender, class, race, ethnic and religious cultures. The interconnections also contribute to how we relate to those within and outside the group. For those who have special needs they often have to establish life outside of their initial inter-connections. The establishment of these support networks was to aid in providing much needed social interaction for the participants. However, they raised concerns that these interactions could only be achieved within these context.

For the majority of the participants, there was an acceptance of their child's diagnosis but there was an expressed desire to live a normal life. Normal was described as what society constructed acceptable manner of living life. For participants, the autism diagnosis restricted them in certain facets of normal life. The participants initially stated that they were limited in social interactivities.

> *Definitely and you just cannot get up and go out. You have to carefully choose someone to look after your child if you want to go out at an event. There are many times I have thought I would love to go to that or turned down an invitation because it would not work out.*- Maggie

> *Living with autism has become a way of life for me but sometimes you wish you could truly live without having to think about it. I wish I could get up and try new things with my child without worrying if it would distress him. When I see friends try out new things with their children and knowing that cannot be me is hard.*- Alison

There was a consensus that there was not only a limitation on their child's social lives but on theirs too. Their old normal would have enabled them to have an array of social activities for both caregiver and child. Experiences of the participants were seemingly not out of the norm for many mothers. Mothers of able-bodied children had expressed similar sentiments regarding the identity of mother usurping their other identities. They were requested to differentiate in detail how their experiences differed. Some of the participants expressed that difficulties were not merely due to a lack of support but rather was a culmination of an inadequate system and deftly managing the expectations of others.

It just goes back to the expectation thing, people expect you as a mom to do everything, which you do. Then because you also feel the need to take on all this responsibility, it gives the dads the time to do all the things outside of the autistic bubble.- Alison

In addition, many of the times there is an expectation for you to be a warrior mom for your child and many people forget that you are more than that. That is just one aspect of it; with our children there is a degree of planning when it comes to social stuff. So you need a system that no only takes care of the child but you too. For many of us we have a system in place for our child but not ourselves.- Joanne

These participants had taken great efforts to ensure that a system aimed at addressing their needs as parents of an autistic child; not their needs outside of being a mother was in place. Living up to others' expectations was argued as necessary to assert their capabilities. It was interesting to note that the participants discussed extensively on the female experience but there was little put forward regarding their male counterparts. For a number of the participants there seemingly was a distinct gendered experience with women being placed under greater scrutiny than men. Their male counterparts were described as being not included in the conceptualisation of caregiving. This in turn allowed them to have a pass in having life outside of autism. The participants agreed that the difference in gender responsibilities affected the ability to have a life outside of autism.

That is so true because mothers are the face, creators and executors, no one thinks about fathers. Even in forums, many of the people there are moms. Fathers get a free pass because society gives them a pass and secondly they are just not there.- Joanne

Their male counterparts were presented as being beneficiaries of women's labour and efforts. However, there was little provided on how participants who were in relationships developed and nurtured their relationship outside of autism. The majority of participants who had partners agreed that even within their relationships they still perceived their partners as having an opportunity to have a life outside of autism. As a unit, they expressed having to make concentrated efforts to ensure that they had a life of autism. However, despite their efforts they were unable to escape the gendered influences.

4.3.3. Life lessons learnt from living with an autistic individual

Living with a person with disabilities requires one to nurture certain traits. The participants expressed that in order to be an effective parent they had to become more patient, tolerant and attentive amongst others. These traits were not limited to the family unit but transcended to other parts of their lives. The participants described that these traits which had been specific to assist their child had also benefitted their personal growth.

> *I have used all the lessons I have learnt with my son I have used in my interactions with other people. This includes at work, which has benefited me so much. Having the ability to be patient and resilient can go a long way in the workplace (chuckles).*-Tania

> *For me, I have to say, is having less fear of the unknown. Before I had to know about everything every detail but now, I am more relaxed. Some days I do not know if we are going to have a good or a bad day. I just take it in my stride and as it comes.*- Sonia

There was a consensus amongst the participants that parenting an autistic child required for the participants to be assertive. Assertiveness enabled the participants to continuously request that their children be accommodated within the different spaces they occupied.

Table 4.8: Lessons learnt from living with an autistic individual

Participants	Responses
Maggie	*I also truly feel that if you take the lessons in your stride and do it repeatedly it ends up becoming a part of you. You know that saying that to do something often becomes habit or is it crazy. Let's go with habit (laughs).*
Samantha	*I think after experiencing rejection from different people such as your family and community members you need to take a stand. I mean at first you try to quietly take it and be nice because you do not want to alienate any more people. Then the shift starts to happen and you become fearless or assertive. That on its own is a metaphor for life and how you have to be resilient.*
Joanne	*When many people hear the word autism they have their own ideas of what the person looks like or do. Many of the times, they don't want anything to do with us because they are scared. I had to learn to stay up for us, to say that this package because we are a package must be allowed to live their life without judgement or discrimination.*
Alison	*My biggest lessons have been to learn to fight for us and be assertive. There are spaces that will overt and covert, make you feel unwanted. So I need to be assertive in order to give him the best childhood as possible.*

	I will not lie, there are bad days but there are a lot of good days. We are just parents who are learning and growing with our kids.
Sonia	*For me, I have to say, is having less fear of the unknown. Before I had to know about everything every detail but now, I am more relaxed. Some days I do not know if we are going to have a good or a bad day. I just take it in my stride and as it comes.*
Tania	*Since he was diagnosed, I have learnt to be more patient. Patient with him, life and myself. I had to be patient whilst they were trying to figure out what was happening with him. Then during the therapies learning all the different techniques to help, him out which was very trying. Repeatedly doing things and hoping there would be a breakthrough. That all needs patience which I honestly did not have much of in the beginning.* *I have used all the lessons I have learnt with my son I have used in my interactions with other people. This includes at work, which has benefited me so much. Having the ability to be patient and resilient can go a long way in the workplace (chuckles).*

Table 4.8 describes the different lessons learnt from living with an autistic person.

Living with an autistic individual is described as providing with lessons and challenges that are unique. Their experiences are said to include multiple lessons, which are described as influential for the participants. The life lessons were related to their personal characteristics. The participants agreed that a number of the lessons related to the management of their child's symptoms. Each of the lessons had enabled these participants better manage their day-to-day interactions with their child. Whilst some of the participants emphasised the importance of these lessons others relayed how their lessons emanated from their experience as a perceived minority.

> *Since he was diagnosed, I have learnt to be more patient. Patient with him, life and myself. I had to be patient whilst they were trying to figure out what was happening with him. Then during the therapies learning all the different techniques to help, him out which was very trying. Repeatedly doing things and hoping there would be a breakthrough. That all needs patience which I honestly did not have much of in the beginning.- Tania*

My biggest lessons have been to learn to fight for us and be assertive. There are spaces that will overt and covert, make you feel unwanted. So I need to be assertive in order to give him the best childhood as possible.- Alison

The participants all agreed that in whichever avenue, these lessons were invaluable to them.

I think after experiencing rejection from different people such as your family and community members you need to take a stand. I mean at first you try to quietly take it and be nice because you do not want to alienate any more people. Then the shift starts to happen and you become fearless or assertive. That on its own is a metaphor for life and how you have to be resilient.-Samantha

They further expressed that the lessons were used in other parts of their life. The transference of these lessons into other aspects of their lives was said to further the skills which they were continuously learning. This reinforcement strengthened their skills, which ensured their continuous application. The lessons were described as being one of the many positive attributes of living with autism. The majority of the participants agreed that there was often a negative perception and association with autism. This was also coupled with a romanticising of struggle that rendered most people not believing that autism can be a positive experience.

4.4. Resources as a developmental requirement

Resources are an indelible requirement for development. The resources which one has, often determine the trajectory of one's life. When discussing resources it is in reference to different tangible and intangible resources. They are located in different institutions and at times are not always easily accessible to those who require them. For those living with disabilities, provision and access to resources is tantamount.

4.4.1. Provision of resources

The provision of resources requires multiple stakeholders in order to execute and implement. For the participants they described the first point of provision of resources as themselves. In the instance they do not have the requisite resources to ensure access to interventions their child needs, the child's development would be stagnated. Resource provision also included institutions such as schools, primary health clinics and hospitals. The participants stated that having healthcare and educational institutions that were in close proximity which catered for their child's needs, would lessen the financial burden.

In terms of health, we usually go to hospitals because it is more affordable. There I am able to see different specialists who honestly would cost a lot to see privately. Therefore, the therapists, dieticians we see them all there and they try to be accommodating as much as possible. I wish we could see them more often though.-
Tania

*I am lucky in that at my son's school they do, they have OT, Psychology and Speech. The only problem is that once they see that your child is doing better they scale down on the sessions, which is not always good. So I have to add more sessions for OT and Speech that's like R700 per session. It costs a lot.-*Maggie

The participants voiced that there is a significant discrepancy in resource provision between public and private institutions. Private institutions were described by the participants as being better equipped to cater for the needs of autistic children. However, some participants disagreed and argued that in some provinces public institutions were on par with their private counterparts. The participants argued that a lack of political will and poor institutional reform resulted in limited resource provision in public institutions.

Table 4.9: Provision of resources

Participants	Responses
Maggie	*I am lucky in that at my son's school they do, they have OT, Psychology and Speech. The only problem is that once they see that your child is doing better they scale down on the sessions, which is not always good. So I have to add more sessions for OT and Speech that's like R700 per session. It costs a lot.*
Samantha	*Providing things starts with me. Some of it is through private practitioners and some of it through government. It would be too much if it was only private. It is so hard to get a school for a child or rather I should say a public school is hard to get. Autistic children are not catered for.*
Alison	*That is the case even in some private schools. The situation is a bit better but they are very expensive. So most people can't take their kids there then you have to hope for the best.* *Same as Cape Town, things are good there. You do not even have to wait to get into school. Things are so much easier and you can only wish for here.*
Sonia	*At the private schools from teachers, therapists, everything that is required for your child to develop. And that's all we want as parents for our children to be the best they can possible.*

Tania	*In terms of health, we usually go to hospitals because it is more affordable. There I am able to see different specialists who honestly would cost a lot to see privately. Therefore, the therapists, dieticians we see them all there and they try to be accommodating as much as possible. I wish we could see them more often though.*
	In addition, it is very hard to get in these schools here in Durban. There is not enough of them.
	In these schools, they think of everything. From transportation and even offer extra mural activities for the children like swimming. So your child gets to experience school like another child.

Table 4.9 details participants experience of resource provision within different institutions.

In order to utilise resources they need to be provided. The provision of resources occurs at different levels. This occurs within a nexus that is interconnected which have a symbiotic relationship. In the immediate primary level, resource provision was through the family in their interaction with primary healthcare and education. There was an agreement amongst the participants that they were the first point of contact for resource provision as they were the central figures within resource provision process. Their role was described as organising the necessary resources required from the institutions by their child. There was a generalised statement regarding resource provision from institutions such as healthcare and education.

Even though healthcare resource provision was not at an optimum level, it was regarded as being partially adequate in attempting to ensure that services are administered. Health provided a system which enabled the provision of specialist treatment and referral which they needed. However, due to the healthcare's own limited resources they were unable to render the resources required fully. For the limited achievements of the healthcare system, education was seen as lagging far behind.

The limited number of schools was a source of frustration for a majority of the participants. This was especially the case for the public sector. Despite autistic children being legally eligible to attend special needs school many of them were unable to accommodate them. This was attributed to lack of fundamental resources required to educate them. These included infrastructure and skilled personnel. This was in stark contrast to their private school counterparts who were described as having the necessary resources required to address academic and social development.

At the private schools from teachers, therapists, everything that is required for your child to develop. And that's all we want as parents for our children to be the best they can possible.- Sonia

*In these schools, they think of everything. From transportation and even offer extra mural activities for the children like swimming. So your child gets to experience school like another child.-*Tania

There was an agreement amongst the participants that private schools offered necessary environment required in education for autistic children. Yet, like their public school counterparts, they were few and far in between. The challenges were attributed to the lack of provincial willingness to ensure that autistic children receive the necessary education needed. Some of the participants drew comparisons to schools in other provinces. The disparities between the provinces was evident as being key to poor provision of educational resources. Most of the participants described how within their own province they were lagging behind when compared to others.

*Same as Cape Town, things are good there. You do not even have to wait to get into school. Things are so much easier and you can only wish for here.-*Alison

*In addition, it is very hard to get in these schools here in Durban. There is not enough of them.-*Tania

This became a source of frustration for them as these provinces were an example that the public system can work. The difficulties noted were attributed to lack of provincial will. This was also argued to be stifling the trajectory of their educational growth.

4.4.2. Accessibility to resources

The provision of resources can only occur if individuals are able to access resources. Access to resources often determines the efficacy of treatment interventions. The participants discussed that accessing the requisite resources for their child can be difficult despite living in urban areas. Even though primary health clinics are the health institutions in close proximity to participants, they were not equipped with the resources required by the participants. The health institutions with the resources were situated in places that were far from the participants' place of residence. This was not the only qualm raised by the participants who reported that the referral process was arduous and determined which services they received. Healthcare institutions were described by participants as far more accessible than educational institutions.

The participants expressed their frustration at the limited schools which catered for autistic children.

> *That is not even half of it. There are not even schools for the children to go to. It's also worrying because most people still don't know much about autism here in the city now imagine in a rural area.*-Tania
>
> *I desperately needed a school of my son and the one I wanted him to go to kept saying no. I was losing hope then a friend put me in contact with someone from the school and that changed everything. Through that connection, he was able to get in. I don't know what I would have done without it.*-Maggie

Participants described accessing education for their children as a challenging and stressful process.

Table 4.10: Accessibility to resources

Participants	Response
Maggie	*The local clinic does not have the things we need for our children. That is a problem because for many people since it is the easiest place to go. Transport to hospitals even for us in cities can be very f expensive.. Now imagine if you live in a rural area, that must be a nightmare.* *Well here, you go to a clinic or a doctor first then they will refer you to the hospital. At the hospital, you get to see different specialists and if someone is not available, they said you to a more specialised hospital. In the rural areas, there is none of that. There is usually a clinic and maybe a hospital in the hospital there is hardly any specialists who would be needed by an autistic person. Not so, all those children never get the help they need.* *I desperately needed a school of my son and the one I wanted him to go to kept saying no. I was losing hope then a friend put me in contact with someone from the school and that changed everything. Through that connection, he was able to get in. I don't know what I would have done without it.*
Joanne	*Yes and the symptom severity fluctuates so it is not always the same. From the first assessment to the things that they need now. It costs money and needs you knowing the right people to do the best for your child.*
Alison	*Yes and many of the specialists are so far that they cannot even travel to them because I am sure it costs too much. Therefore, a parent is sitting at home with a child they do not know what to do with. I would be a mess;*

	I am fortunate to have a good paying job and so is my husband. We were able to do assessments privately and that cost R3500, which included seeing a neurologist. It helped us because we did not have to wait a long time in order to be seen by doctors and other specialists in a public hospital.
Sonia	*I mean that it is a good example of how belonging or maybe I should know certain people opens up so many doors. From professionals to even information and techniques that you can use with your child. Now if you are from a poorer background it will be much harder*
Tania	*I would say the main resources we need are health and finance related. Both are an absolute must with an autistic child. You need different specialists to help with their symptoms.* *That is not even half of it. There are not even schools for the children to go to. It's also worrying because most people still don't know much about autism here in the city now imagine in a rural area.*

Table 4.10 pertains to participants experience with accessing resources for their autistic child.

Resources are an invaluable requisite of the human experience. They are needed in the various forms to aid in development. Within different societies, there is an institutional decree on the manner in which the population can access resources. Accessibility to resources is constitutionally mandated with institutional policy detailing the path to undergo. There are a number of factors which contribute to how they can access resources. These are mainly finance, geographical location and available institutions. These institutions are necessary in the management of symptoms. The process of accessing these services can be often tedious as they follow a three-tier referral system.

Access to the first level is often the easiest as there are many primary healthcare institutions available. Primary healthcare institutions are often in close geographical proximity but unable to address the participants' needs. A majority of healthcare users in urban, peri-urban experience difficulties in accessing mental healthcare services. In rural areas this scarcity of resources is felt more profoundly. However, a key factor that also contributes to the accessibility was socioeconomic class which directly translates to financial resources.

Geographical location and finances were seemingly dependant on each other. For many of the participants they determine the quality of care that they could access.

The local clinic does not have the things we need for our children. That is a problem because for many people since it is the easiest place to go. Transport to hospitals even for us in cities can be very f expensive… Now imagine if you live in a rural area, that must be a nightmare.-Maggie

Yes and many of the specialists are so far that they cannot even travel to them because I am sure it costs too much. Therefore, a parent is sitting at home with a child they do not know what to do with. I would be a mess.-Alison

It is interesting to observe that the institutions that would be most easily accessible were not structured to meet the needs of autistic individuals. However, despite the difficulties expressed by the participants they agreed that they were in a better position than their rural counterparts. For many of the participants, the differences were largely structural and human resources. The identified geographical constraints were argued to be easily countered through the implementation of the required resources in order to meet the needs of the population. In this regard, financial resources would only minutely mitigate the difficulties experienced by those who live in rural areas. Yet the inaccessibility due to limited financial resources was not limited to rural residents but extended to socioeconomic class groups within urban areas.

Even though the participants had not been asked to identify the socioeconomic class they identified with, they stated that it was an undeniable factor in accessing resources. Those who occupied higher socioeconomic classes were able to access resources that their lower socioeconomic class counterparts were unable to.

I am fortunate to have a good paying job and so is my husband. We were able to do assessments privately and that cost R3500, which included seeing a neurologist. It helped us because we did not have to wait a long time in order to be seen by doctors and other specialists in a public hospital.-Alison

I mean that it is a good example of how belonging or maybe I should know certain people opens up so many doors. From professionals to even information and techniques that you can use with your child. Now if you are from a poorer background it will be much harder.-Sonia

This was not because of their personal wealth but also attributed to the networks which they interacted with and formed. The networks provided human resources that can be tapped to assist with various needs of the participants. Majority of the participants agreed that

socioeconomic class played a pivotal role in resource accessibility. They further posited that this often influenced the trajectory of the child's development. The higher the higher socioeconomic class occupation, the greater the resource available. This was sadly in stark contrast with institutional policy that stated that socioeconomic class should not be determinant of resource accessibility.

4.5. Policy and autism

The policy frameworks of a country inform different facets of a society. Policies directly influence how a system is structured and their respective institutions. All the institutions are explicitly influenced by policies thus, their importance is paramount. Within these institutions, there are mechanisms that need to be in place in order for the mandate of these policies to be fulfilled. However, in many cases policies remain a theoretical framework as the implementation become disconnected. The following sub themes will be explored in this section.

4.5.1. Disconnect between policy and implementation

Policy provides a framework and a blueprint for the manner in which systems and their institutions need to function. In order for institutions to function at their optimum, policy needs to be implemented in the requisite manner. The participants stated an awareness of the different policies which pertained to the institutions which they accessed for their children. For the participants there was a persistent frustration with the lack of policy implementation.

> *I agree we have to know all the policies and laws so that when we ask for change we know exactly what we are talking about. For me the frustration I see in other provinces taking the initiatives to make sure that they do things according to the policy and then you get here. We are honestly going at a snail's pace.*-Maggie
>
> *We all know we have rights and we are told how government should work but actually, that is not happening. I mean you go to any government office there are posters that tell you what should happen when you trying to get a service but the reality is very different.*-Joanne

Lack of policy implementation was described as affecting the resources available to the participants and their children. For the participants, lack of policy implementation was compounded by policy specifically pertaining to autistic individuals. However, some of the participants stated poor policy implementation prevails in some provinces and not others. This provincial discrepancy was attributed by a lack of political will by the participants.

Table 4.11: Disconnection between policy and implementation

Participants	Responses
Maggie	*I agree we have to know all the policies and laws so that when we ask for change we know exactly what we are talking about. For me the frustration I see in other provinces taking the initiatives to make sure that they do things according to the policy and then you get here. We are honestly going at a snail's pace.* *I mean, we see it all the time. People will be aware of an issue and there will debates, articles,… exposés the whole lot. But until an issue has surpassed a critical and by this I mean hanging by a thread, then and only then will they slowly make efforts to change.* *Many of the programmes here are taken from overseas and are brought here as is. Well that work for those who are from money or are a part of higher classes. This come with the resources that can be used for these imported programmes but now when you try to do that in disadvantaged communities it does not work.*
Samantha	*As much as there are problems in healthcare, I truly believe education is stagnant. In this province, there is little motivation to do right by our kids. There is a provincial framework or a memorandum, which states out a plan for ensuring that autistic children get their education. That was years ago and very little has changed. We are still struggling to find schools despite all the enthusiasm they had in the beginning.* *In South Africa, there is a trend whereby people; that is; the government focus their energies on what is pressing at the time. Remember, when HIV was rampant and people were dying because, well, firstly there were not any policies to address and even poorer implementation. I think that is the case with autism. We are not trending enough so a lot of the time people remember that there is autism during the awareness month and forget about us the rest of the year.*
Joanne	*We all know we have rights and we are told how government should work but actually, that is not happening. I mean you go to any government office there are posters that tell you what should happen when you trying to get a service but the reality is very different.*

	I mean, the national department comes up with plans to make change. So provinces need to follow but it doesn't happen. Now the problem is in this province they do not consider autism as important. If we are frustrated, imagine how people in rural areas feel. I can't imagine being told your child has autism and then not getting any help afterwards.
Alison	*I think it's all round and I am not saying this just for autism. Our health system is in tatters, honestly it is in danger. It is getting harder and harder to get things done such assessments or be seen for therapy. Waiting lists get longer because people leave and you cannot blame them, it must be tiring. Now the problem is we all cannot go to private, it is pricey. So a lot of the healthcare is poorly implemented.* *It is sad to see that we have to end up doing things ourselves but the longer we wait the more our kids fall behind. I hope that one of the days we can develop medical centres, which are affordable so that everyone can get the care for their children. Imagine an autistic friendly place where all the professionals have a knowledge and understanding of autism. This would also be available to people in small towns and rural areas. See that would really be a move forward.*
Sonia	*I know for many of us it is frustrating not getting what we should but imagine if we did not? Then we would not be able to tell people: hey! you are not doing your job this is how things should be done.* *I truly think that the best option for all of us is to continue to create things for ourselves. Many people are doing it with schools. You know developing schools for autistic children that truly feel like they are for them. It really is good to see that in play because it gives comfort that these things can be achieved.*
Tania	*That is why so many people get frustrated. It is true what they say ignorance is bliss. If we did not know then maybe, we would be better off.* *Everyone says that cities are over populated and are spread thin which is true. However, in other places they are doing what is supposed to be done. I mean, Durban is a city so we should be like Cape Town or Johannesburg. These places are taking steps to change the narrative around autism and make the needed change. Why can we not do it?*

| | *Doing things is one way of finding a solution to our current problems but it will end up with many people being excluded. It may start out with people saying that it is for everyone but soon enough it will be closed off to many. Then what would happen is that those who already can get services would continue to do so while those who need it do not. I mean then it defeats the purpose of it all if many are still excluded.* |
| | *Yes, I think it starts with things such communication; all these programmes are in English, which for many black and some white South Africans is a second language. That already is one barrier. Then you are asking them to access all these resources to help them on the internet, which is very unfair. Yes, some people may have the basic technologies to access but they may not have data so they are back at square one. It would be better if we have initiatives that we truly develop ourselves, that speak to the specific climate of South Africa. Something that accommodates everyone otherwise there will be certain groups who benefit and thrive whilst others lag very far behind.* |

Table 4.11 describes the participants perceived disconnect between policy and policy implementation.

The South African Constitution has enshrined the rights of all citizens. This is furthered by policies which are meant to provide a plan on the how to proceed with implementing policies. Through the guidance of these policies, the state can achieve their responsibility to the citizens. In many instances, this is an ideal as in reality there are multiple factors that impede on policy implementation. Poor implementation of policies often results in individuals not obtaining the services that they require.

> *I mean, the national department comes up with plans to make change. So provinces need to follow but it doesn't happen. Now the problem is in this province they do not consider autism as important. If we are frustrated, imagine how people in rural areas feel. I can't imagine being told your child has autism and then not getting any help afterwards.*-Joanne

Through policy implementation, these institutions are provided with the blueprint on how to meet the needs of the citizens. In South Africa laws such as Equal Education Act of 1996 and policy papers such White Paper 6 that advocate for accessibility of education to those living with disabilities. For many of the participants there was acute awareness of the policies that informed the different institutions that they accessed. They were further aware of the differences between the policy itself and the respective implementation. Whilst some of the

participants had formed an uncomfortable acceptance with the poor policy implementation. These participants also expressed that having a limited knowledge of policy would perhaps ease their frustrations regarding the current lack of implementation.

> *I mean, we see it all the time. People will be aware of an issue and there will debates, articles,… exposés the whole lot. But until an issue has surpassed a critical and by this I mean hanging by a thread, then and only then will they slowly make efforts to change.-* Maggie

However, some of the participants disagreed and stated that knowledge of policies enabled holding the institutions accountable. Holding institutions accountable enables that they provide the services, that they were, required to perform. The participants agreed that the discrepancies between provinces was one factor. In the same light, they expressed that in their respective province the gap in implementation was blatantly stark. The participants were asked to describe in which areas they believed there was a disjuncture between policy and implementation. There was a consensus amongst the majority of the participants that there was an apparent administrative and political urgency to address the current policy issues. They were aware of the provincial policy mandates, which were congruent with the national policies. However, where efforts are being made nationally to usher a shift in the shortfalls of the past, the lack of provincial concern often left national attempts at a loss. Some of the participants described that policy implementation difficulties were not a metropolis challenge as other areas attempted to meet them.

> *I mean, we see it all the time. People will be aware of an issue and there will debates, articles… exposés the whole lot. But until an issue has surpassed a critical and by this I mean hanging by a thread, then and only then will they slowly make efforts to change.-* Maggie

The majority of the participants agreed that the discrepancies between provinces were frustrating especially in metropolitan areas. They furthered noted that the implementation challenges were seemingly unexpected in metropolis areas. For many of the participants this rendered them feeling as vulnerable as their rural counterparts. Some of the participants however offered an alternative rationale for the lack of implementation.

Some of the participants agreed that there was a culture of reactionary politics that prevailed within the South African context. Reactionary politics was stated as limiting the

implementation of the sanctioned policies. This relegated attempts to implement policy futile.

The futility was due to the frameworks contained in the policy not being able to address a crisis. The participants did advocate however, for a self-reliant approach in order to ensure that a semblance of the policy implementation is achieved. The majority of the participants agreed that this could be a plausible solution to the current implementation challenges. By taking the initiative, they argued that they would also be acting out their responsibility as citizens in contributing to the development of society. However, some of the participants did express concerns regarding how the development of private institutions perpetuates classism; limiting the self-development to a limited number of people despite their noble efforts.

The few participants who agreed with the perpetuation of classism further argued that classism was linked to race within the South African context. These participants argued that currently the self-development programmes which are initiated in low-income areas populated by black people are often unsustainable and do not address their specific needs.

> *Many of the programmes here are taken from overseas and are brought here as is. Well that work for those who are from money or are a part of higher classes. This come with the resources that can be used for these imported programmes but now when you try to do that in disadvantaged communities it does not work*-Maggie

> *It is sad to see that we have to end up doing things ourselves but the longer we wait the more our kids fall behind. I hope that one of the days we can develop medical centres, which are affordable so that everyone can get the care for their children. Imagine an autistic friendly place where all the professionals have a knowledge and understanding of autism. This would also be available to people in small towns and rural areas. See that would really be a move forward.*-Alison

The initiatives were described as attempting to transfer programmes developed for those occupying higher social classes. Despite the participants' differences regarding classism with the autism community, they did agree that there is a need to reform policy in order for implementation to occur. This could be achieved through a reassessment of the current needs of the autism community. The reassessment would ensure that the implementation would be applicable and sustainable. The participants further agreed that the importation of

programmes was not a viable solution that may be inhibiting the optimum development of autistic children.

4.5.2. Educational policy and access

Education is an integral part of a child's development. Developing and implementing policy that allows for access to occur is essential. The participants described that currently accessing education for their children was a challenge. This challenge was said to occur despite educational policy advocating for autistic children to be catered for within mainstream and special needs schools. The participants however agreed that they noted a more concerted efforts by government to ensure that policy is implemented regarding autistic children.

Table 4.12: Educational policy and access

Participants	Responses
Maggie	*School is also where you learn how to figure things out by yourself without your parents. You do a lot of growing up in school. School is a time of discovery and so much joy. It can truly be a magical time for a child. The importance of education cannot be emphasised.* *I think all parents who have children with disabilities will tell you that it is hard to find a good school for their child. When I say a good school, I do not mean one that has state of the art facilities but rather simply a school with basics. The kids need a full bodied school experience.*
Joanne	*Most of the time you think that going to primary school will be much easier but things are not much better there. Honestly it is such a frustrating experience for people who go through the private sector route are at such an advantage.*
Alison	*I would like my child to attend a school where they are not made to feel different. In many special needs schools they are still made to feel different. I want him to learn and have fun. Most importantly, I just want him to feel welcome in school and have the full experience.* *Our problems start in finding a school. Schools for autistic children are few and far in between, you really need to search for a school and most of the time the schools are from where you stay. This is the case for both private and public schools.*
Sonia	*Education for me is everything it really is one of the greatest gifts one can receive. Going to school not only gives you the chance not only to learn*

	skills to provide for yourself in the future but you get to make great friendships. You learn how to socialise with people other than your family. Autism like many other childhood conditions falls on a spectrum so different children will present with different levels of severity. You would expect these schools to do a placement test or at least a report to determine if your child is a good candidate. That is not the case it's if autism is a bad word.
Tania	*I want my child to have a great experience of school. I want them to have friends and have as pleasant school experience as possible. I want them to look back and have positive memories when they think of school.* *I would say the situation is worse in public schools the waiting lists are so long. People wait years sometimes just for the kids to attend primary school with no hope for high school. Often when integrated special needs schools hear autism they will kindly let you know that they do not cater for you. Then it becomes a fierce competition for parents which truly want a chance for their child to be educated.* *I will say that in the past 2 to 3 years I am seeing autism much more in the media and it's not only non-government organisations. There are politicians who are talking about us especially when it comes to education that is a good step in the right direction. But when those steps mean that I still need to wait for a few years possibly to go to school then I honestly feel that we are still stuck*

Table 4.12 provides participants response to their experience of educational policy and access the policy provides.

Education provides important cognitive, emotional and social skills to children. By attending school children learn important skills that they can utilise to aid in problem solving and relating to others. This makes education an invaluable resource for those accessing it and society. Furthermore, education is a fundamental human right and is arguably a privilege passage that everyone needs to undergo. The participants offered the importance of education in the development of a child.

The participants all agreed that from their own personal experiences education had played an important role in their development into adults.

Education for me is everything it really is one of the greatest gifts one can receive. Going to school not only gives you the chance not only to learn skills to provide for yourself in the future but you get to make great friendships. You learn how to socialise with people other than your family.-Sonia

School is also where you learn how to figure things out by yourself without your parents. You do a lot of growing up in school. School is a time of discovery and so much joy. It can truly be a magical time for a child. The importance of education cannot be emphasised.-Maggie

The indelible experiences of their schooling was counted as enriching their social lives. Many of the participants expressed a desire for their children to have similar experiences. These experiences were not simply centred on primary education but rather extended to secondary and tertiary education. Individuals living with disabilities are not usually offered the opportunity to experience the transition into the three tiers of education. All the participants agreed that their children did not have similar experiences to their able bodied and some disabled individuals.

I would like my child to attend a school where they are not made to feel different. In many special needs schools they are still made to feel different. I want him to learn and have fun. Most importantly, I just want him to feel welcome in school and have the full experience.-Alison

I would say the situation is worse in public schools the waiting lists are so long. People wait years sometimes just for the kids to attend primary school with no hope for high school. Often when integrated special needs schools hear autism they will kindly let you know that they do not cater for you. Then it becomes a fierce competition for parents which truly want a chance for their child to be educated.-Tania

Autistic children were described as often feeling othered in both mainstream and special needs settings. Participants described this occurring first during the admissions process. Implementation of inclusive education would make education accessible for those living with disabilities.

Ensuring placement at a school specifically was described as arduous experience for all the participants particularly in public school setting. This was largely due to limited schools, which catered for autistic children. The limited spaces ensued an often-fraught journey of securing education. The participants agreed that difficulties in accessing education were not limited to early childhood developmental centres but also extended to primary education.

The participants described that often in these schools they expected symptom severity to be a determining factor.

> *Autism like many other childhood conditions falls on a spectrum so different children will present with different levels of severity. You would expect these schools to do a placement test or at least a report to determine if your child is a good candidate. That is not the case it's if autism is a bad word.*-Sonia

Symptom severity in autism varies with some individuals presenting with higher and lower functioning. The public versus private sector was cornerstone to the difficulties that related to accessibility. Despite a consensus of utilising private resources to cater for the needs of the autistic community, some of the participants expressed that this often absolved the public sector of responsibility. These participants expressed that although there were renewed public policy efforts to address the educational challenges regarding autism, parents did not enjoy much comfort.

4.5.3. Socialisation within schools

Socialisation is a process where individuals learn approved and disapproved behaviours within a particular group. The participants described how they felt their children were deprived of the full spectrum of socialisation. This was attributed to a lack of inclusive spaces which can accommodate autistic children. The participants further expressed their concerns regarding the limitations of their child's social group which largely consisted of other children with disabilities.

> *I sometimes feel that he is a bit stunted you know. What I mean by stunted is that he has very few friends. The friends are either family members or have a disability. I am grateful for that but it's so limiting socially. Other children get to explore their options but our kids have such a small pool. I mean I just think that in order to truly meet their potential it would be really nice for them to interact with able bodied children and those with disabilities.*-Alison
>
> *I understand exactly what you are saying. I think my concern is that being surrounded by autism they do not know that there is a world outside autism. I believe that if they were with other kids they would be exposed to so much more.*-Tania

Even though most of the participants believed that by interacting with able bodied children destigmatising of autism within their communities will be fostered, some participants believed

that fostering the previously mentioned relationships may provide unnecessary distress for their child.

Table 4.13: Socialisation within schools

Participants	Responses
Maggie	*I understand where a lot you are coming from but for now I don't believe that there are places where our kids can be themselves and be with other children. With autistic children, you have a lot to consider unlike kids with other needs. So already that puts us on the back burner.*
Joanne	*For me, I will say that if we were to be a part of the inclusive spaces, we will get to meet new and different people. It's a great opportunity to make friends with someone who is not fully ingrained in the autism life. It would help with our overall well being.*
Alison	*I sometimes feel that he is a bit stunted you know. What I mean by stunted is that he has very few friends. The friends are either family members or have a disability. I am grateful for that but it's so limiting socially. Other children get to explore their options but our kids have such a small pool. I mean I just think that in order to truly meet their potential it would be really nice for them to interact with able bodied children and those with disabilities.*
Sonia	*Being around and interacting with different people would benefit our children greatly and contribute to their growth. However, I agree many of the places are not autism friendly and in all fairness our first priority is to ensure our children's safety. Until I am assured without a shadow of doubt of my child's safety in these settings, I will keep him in the autism friendly settings.*
Tania	*I understand exactly what you are saying. I think my concern is that being surrounded by autism they do not know that there is a world outside autism. I believe that if they were with other kids they would be exposed to so much more.*

Table 4.13 provides participants responses regarding their experience of socialisation within schools.

Cognitive and social development are important facets of education. Children within the school setting are offered the opportunity to interact with peers of different genders, ages and racial groups. Through these interactions, children are able to be equipped with critical social skills

which can be utilised for navigation with others. These interactions allow for children to initiate and nurture relationships outside of the family with school being the cornerstone of it all. These relationships are encouraged by both families and educators. Socialisation is an important avenue of learning the acceptable behaviours within a particular society. School is an important place where the individual can explore the different facets of the self. These behaviours are taught implicitly and explicitly within various institutions in the community.

A majority of the participants agreed that the current stratification of schools into mainstream and special needs provided a limited social experience.

> *For me, I will say that if we were to be a part of the inclusive spaces, we will get to meet new and different people. It's a great opportunity to make friends with someone who is not fully ingrained in the autism life. It would help with our overall well-being.*-Joanne

By not having an inclusive approach, they argued that their children would be offered a homogenous experience of social relations whilst a heterogeneous experience would be preferred. Whilst the majority of the participants agreed with these sentiments some of the participants disagreed. Those who disagreed argued that a number of spaces did not subscribe to inclusive approach especially for those who experience sensory difficulties.

Whilst there was a disagreement amongst the participants, regarding the merits of socialising spaces that encompassed those of different abilities, the participants did however agree that these socialisations provided the opportunity to interact with parents and other caregivers which would grow their social network. The participants stated that for many of them this was one of the few opportunities outside of their current social and occupational networks to form new interpersonal relationships.

> *Being around and interacting with different people would benefit our children greatly and contribute to their growth. However, I agree many of the places are not autism friendly and in all fairness our first priority is to ensure our children's safety. Until I am assured without a shadow of doubt of my child's safety in these settings, I will keep him in the autism friendly settings.*-Sonia

Educational and social spaces were a common place for the participants in their communities as means to grow their networks. Although they described that within the autism community, there are many opportunities to network. However, the network was limited and for some participants experienced as classist. Classism for many of the participants was

intertwined with race. By accessing other networks this would allow the participants to ensure that they had autonomy and agency in the social networking engagements.

4.6. Conclusion

The findings of the study indicated that the participants had trouble in accessibility in different spheres of their lives. These difficulties were not limited to themselves but also included their children. The difficulties in accessibility transcended institutions and included their interpersonal relationships with members of their community. It was surprising to find that concepts such as gender and socioeconomic class permeated the autism community and influenced certain interactions. The participants did expectedly point out that policy and implantation were still at the cornerstone of accessibility difficulties within the autistic community. It was interesting to observe that there were perceived provincial discrepancies despite the national mandate to address the needs of autistic children and their caregivers. Taking into account the findings it has been evident that there is urgent reform required in the state institutions in order to ensure the rights of autistic children are met.

Chapter Five

Discussion of Findings

5.1. Introduction

The following chapter discusses the findings of the study in relation to the literature review and theoretical framework presented in chapters two and three respectively. In each of these chapters, the accessibility of education for autistic children and their parents' experience within this process is discussed. This chapter continues the discussion aforementioned by focussing on parenthood and autism, South African policy and autism, institutional structuring and autism within the South African context, education and autism.

5.2. There is a need for adjusting traditional parenting styles for autistic children

Parenting a child is often conceptualised within a heteronormative framework whose narrative is dominated by the development of children without disabilities. This narrative is subscribed to be within individualistic and collectivist cultures. In this framework, development follows a linear progression with each developmental stage marked by a milestone and a rite of passage in some cultures. However, for children who present with disabilities, their developmental progression is one that many individuals are not familiarised with (Bernier, Mao & Yen, 2010). The development of autistic children is often shrouded with uncertainty as developmental milestones relating to their specific development are not easily available. This is further compounded by the fact the developmental trajectory of the child is often influenced by other factors such as symptom severity, social economic class, culture and policy (Murungi, 2015).

Hetzroni, Hessler and Shalahevich (2019) describes that there is an extensive documentation of what the trajectory of development is for those living without disabilities. This includes physical, moral, cognitive and social development across various societies and cultures. Hetzroni, Hessler and Shalahevich (2019) argues that development within the realm of disability varies firstly due to the nature of the disability and secondly the severity of the symptoms. This requires redefining what development is specific to the person depending on the nature of their disability and severity. Hetzroni, Hessler and Shalahevich (2019) states that this does not mean we should not envision development for those with disabilities as not constituting the myriad of factors as per 'normal' development. It is however imperative to acknowledge the areas which may differ and how.

Taking these factors into account, parents of children living with disabilities have to shift themselves from the framework which they were socialised into. Parents of autistic children are not exempt from this experience. This was affirmed by participants who described following the diagnosis that they needed to make the necessary shifts in their approach to parenting. The shift consisted of researching extensively about their child's condition. This further extended to acknowledging the best course of parenting specific to their child's symptom presentation and severity. The process was described as challenging by the participants to shift from what they had been socialised into. A lack of accessible alternative parenting models further made the shift difficult for the participants.

The shifts were described as a necessary requirement for two reasons; development and implementation of therapeutic interventions. The realisation that the widely accepted parented approach would hinder their development depended on their symptom severity. Furthermore, therapeutic interventions were specific and required certain inputs from the parents to ensure their efficacy. For the participants, this was a difficult process which required significant adjustment. The participants described having experienced significant concerns regarding their child's future prospects. Concerns ranged from their child's prognosis, social life and quality of life. Symptom severity

Their experiences were not uncommon with Paisley and Smith (2013) finding that parents of autistic children undergo an adjustment period following receiving their child's diagnosis. The confirmation of the diagnosis for many of the participants resulted in unexpected feelings of grief. This grief like experienced expressed by the parents, was attributed to the loss of dreams and hopes they previously had for the child. Symptom severity was often a precursor to the quality of life may experience.

The feelings of grief relating to the diagnosis were argued as precipitating the process of adjustment. Paisley and Smith (2013) in her study found a similar finding where they found amongst their participants who described feeling sadness at the 'loss' of their child. Paisley and Smith (2013) argued that the loss is when the child is presumed to be unable to live up to the parents' desires and ambitions for their child's future. A number of the participants in this study stated that their feelings of grief like their counterparts in Paisley's study but added that these feelings were often compounded with feelings of guilt which deepened

their feelings of grief. Paisley argues that for parents to adjust healthily in their parental role it is essential that they must mourn for their loss.

The model which Paisley and Smith (2013) suggest for grief and mourning is the Kubler-Ross stages of grief. The Kubler- Ross stages of grief consist of five stages which are denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1997; Kubler-Ross & Kessler, 2005; Mahmood, 2016). During the denial phase, the individual will go through a period where they will deny the loss they are experiencing. Denial is often seen as a temporary defence and the person will usually pass this phase (Kubler-Ross, 1997; Kubler-Ross & Kessler, 2005). For parents of autistic children, this is usually identified during or after the diagnostic process. The participants in the study identified themselves as having undergone this stage of grief. For participants the denial was rooted in their lack of experience with autism. Whilst others attributed the denial to having reframe their idea of disability as their child did not present with physical abnormalities.

Denial often resulted in the initial rejection of diagnosis. This rejection included searching for second opinions or utilising alternate frameworks to understand the symptom presentation. The stage was said to be temporary not because they needed to undergo the other stages but rather their child's symptoms warranted them to shift their focus from grief to intervention.

The second stage in Kubler-Ross model is anger. Within this stage, the individuals following the realisation they cannot remain in denial will experience feelings of anger; of why they were in the position they were in (Kubler-Ross, 1997; Kubler-Ross & Kessler, 2005). The participants in this study expressed similar sentiments following the realisation that their child's condition did not have implications solely for the child. The participants described the implications as primarily financial and social. At this time the person may experience feelings of jealousy towards those who are in the position which they desired. For parents with autistic children, anger was experienced at the loss of normal life (Breithaupt, Thoma, Wong, Mesibov & Morrissy, 2017). Normal is described as the socially accepted way of life within the society with an emphasis on their immediate community (Kaniel & Simon-Tov, 2011). The loss of normal life was limited to autistic children but extended to themselves. However, the participants noted that this stage was short lived.

5.3 Social inclusion through bargaining

Participants indicated that bargaining was used for social inclusion when they pointed out that there are limited social spaces and social resources available to autistic children and their families. The participants described how they had experienced rejection or social disapproval when their child experienced sensory difficulties. Social interaction was further compounded by lack of knowledge by different community members about autism and the associated social communication difficulties. A number of participants stated that they had to negotiate their inclusion in the social spaces available to them.

During the bargaining stage the individual will negotiate with a higher existential being for a change in the situation that they are in, this includes asking for an extension of time or exemption from death if they are terminally ill (Kubler-Ross, 1997; Kubler-Ross & Kessler, 2005). In this case, bargaining was not undertaken with an intention to heal the child of their symptoms but rather was for social inclusion purposes. The participants described that negotiation of social spaces also required them to perform certain cultural rites. This was expressed by those who subscribed to collectivist cultures. Within their collectivist culture there was a pre-existing model of understanding illness. This model of illness also provided treatment interventions.

A collectivist culture is one where a person is not solely defined by their individual desires, goal or values but rather centred on being part of a greater whole. The whole in this regard refers to the individual's family and the culture which they identify with (Mkhize, 2014). Within collectivist cultures, responsibilities such as caregiving are understood as part of the collective group. In certain collectivist cultures, this extends to a specific framework of understanding illness. Illness is said to be the result of discord within the family, certain cultural rites not being observed or the group presenting with behaviour that would not be approved by the ancestral spirits of that family (Edwards, Thwala, Mbele, Siyaya, Ndlazi & Magwaza, 2011). Utilisation of a collectivist approach enables the parents to tap into the various resources thus decreasing the burden on the primary caregivers. However, with the permeation of western individualistic many have moved away from the collectivist approach.

The participants detailed how depending on the person's cultural belief system by performing the bargaining rite it was symbolic in two ways. Firstly, it was to disprove that their child's symptoms were the result of spiritual reasons but biological basis. Secondly,

this symbolised to the community the parents' appreciation of their cultural beliefs which enabled membership and social inclusion of their autistic child. For those individuals who are experiencing serious life adjustments, bargaining includes performing certain cultural or religious rites in order to appease the existential being and correct the abnormality they have. The participants in this study did not exact any bargaining but did report having known individuals who had performed an act of bargaining.

5.4. The risk of mental illness amongst parents of autistic children

Participants indicated that parenting an autistic child can place an emotional and psychological toll on themselves as individuals. The participants expressed that parenting a special needs child can be an isolatory experience due to the lack of social support they were subjected to. Participants further detailed that they largely invested their resources in their child with limited to none available for themselves.

The convergence of multiple stressors resulted in the participants experiencing persistent feelings of sadness. This finding concurs with Paisley and Smith's (2008) results in their study that pointed out that participants experienced the depression stage at an emotional level with minimal behavioural changes. Feelings of sadness amongst Paisley and Smith's (2008) participants were not solely contributed by the child's diagnosis but were also influenced by their prognosis, caregiving facilities and accessibility to resources required for optimum symptom intervention. Depression stage follows bargaining and the individual at this stage would usually engage with behaviours associated with grief. The behaviours can be crying, withdrawal from those near to them, feelings of hopelessness and continuous thoughts regarding their loss (Kubler-Ross, 1997; Kubler-Ross & Kessler, 2005).

5.5. Social support, a key resource for parenting autistic children

The participants described social support as an invaluable resource in their parenting of an autistic child. Social support was described by the participants as they were able to provide other resources which may be unavailable to them. These resources were described as financial and human. The participants detailed how social support had provided financial and human resources which had eased a burden for them. Furthermore, for the participants, having a well-established support system enabled the participants to invest in themselves. This would also negate their feelings experienced within the depression stage.

Social support in this context reflected interpersonal and institutional resources. Interpersonal social support was described as support from immediate and extended family

members, friends and other community members (Jeans, 2013). Institutional social support was not exclusive to the provision of interventions for autistic children but also focused on the primary caregivers' emotional and psychological needs (Paisley and Smith, 2008). According to the participants this was achieved by having support groups either by a non-government organisation or the healthcare institution which they frequented. These were described as providing a space to share their respective experiences with people who can truly understand them. Breithaupt et al. (2017) in their study, found that in addition to the support that parents receive from their loved ones it is imperative that systemically there are steps undertaken to ensure they can access support for themselves. Support in this regard is argued as continuous personal counselling or therapy for themselves (Breithaupt et al., 2017).

Human beings are a social species who biologically gravitate towards other. In this respect, humans fare best in groups where they are part of a community which tends to their needs. This then provides a network, which allows for basic needs such as food, shelter and as mentioned before social engagement to occur (Tincani, Travers & Boutot, 2009). This network also allows for the development of the self. This network's importance is experienced in the raising of children. The raising of children for many a time was not only relegated to the child's family but also included the community at large (Kang-Yi, Grinker & Mendall, 2013). The community in this respect would offer to the parents of the child their knowledge of child-rearing practices. Community members offering their services to look after the child in order to provide parents an opportunity to recuperate would also supplement this. Moreover, the participants alluded to the fact that they were raised in such communities who play an extended parental role. According to the bio ecological systems theory this would occur within the microsystem. The bio ecological systems will be explored in further detail in the upcoming section. However, for those with special needs children, social support is not always readily available. Depending on belief systems in place, the child may not be easily accepted into the community. The rejection will result in the withdrawal of the community's invaluable resource of the extended parental role.

Some of these deep held beliefs also influenced social interactions and how individuals who identify with the collectivist cultures perceive those who are different. Mizrachi (2014) documented how those with disabilities within the Asian context often experienced almost polarising positions. In some communities in South East Asia certain disabilities were revered as an indication of the individuals' special abilities or result in exclusion from the

community. The withdrawal of the support from immediate community members was an isolatory experience which when coupled with rejection from their family members often left the participants at risk of mental illness. The limited social support often equated to the participants not receiving emotional support that many of their peers would normally receive. The participants acknowledged that limited or no social support left them emotionally vulnerable.

Kang-Yi, Grinker and Mandell (2013) found that the rejection can be attributed to the child's condition being viewed as a taboo or limited knowledge of how to execute their extended parental role. The participants in this study agreed with Kang-Yi, Grinker and Mandell's (2013) findings and emphasised that in their experiences that the two reasons suggested by Paisley and Smith (2008) were interrelated. This was especially true for the participants who subscribed to collectivist cultures. For those who experienced resistance from their community members in offering their support found themselves in a position where they were physically overexerted by their parental duties. This is not an uncommon experience with the findings of Breithaupt et al. (2017) and Blaith (2016) from their respective studies that without a continuous, consisted support structure, parents placed themselves at risk of overexertion. Jeans (2013) further found that parents of autistic children are more likely to experience greater feelings of tiredness and social isolation as compared to parents of other children with special needs. Many parents have had to create their own community which would offer them the necessary social support they require to parent their child effectively (Blaith, 2016; Breithaupt et al, 2017; Glazzard & Overall, 2012).

The development of a community towards addressing the needs of the marginalised is not a new phenomenon. At a macro level this would be seen in the development of institutions such as schools and health facilities which would address the needs of this group. Within a micro level this would include the individual carefully selecting people who would be able to fill the various roles required in their community. In autistic families this may extend to the acquisition of support staff who could effectively render support services to themselves and their child (Blaith, 2016; Breithaupt et al, 2017). For the participants of the study support staff were for them an extended parental source as they provided caregiving services when they were unable to. This also included the reinforcement of therapeutic interventions that were provided by the different healthcare professionals who they consulted. It is interesting to observe that for many of the participants their support staff were often not formally trained specifically in caregiving for those with special needs. They were however described as

having some training in early childhood development for able-bodied children. The parents who employed them would have to provide a crash course on ASD. The training was largely providing the support staff with the reading material, attending support sessions of autism organisations and for a very few attendances of skills workshops. A similar approach was also undertaken by participants with their families and friends.

The limited training of the majority of support staff highlights a critical issue of access to critical skills to ensure the well-being of autistic children. This further highlights a much needed institutional reform which would easily avail the requisite skills to allow for holistic caregiving. It would seem that this necessitates for the information on autism and entry-level skills be easily available. The provision of such accessibility would ensure that the individuals who become part of the parents' community will have the requisite skills to provide social support which covers all facets of autistic life. Blaith (2016) states that support in child caregiving must not only focus on the needs of the child but also attend to the needs of the parent. This seems to be exceedingly the case for parents of autistic children as their children require attentive care for various symptoms. The current placement of social upskilling to parents is a weighted responsibility.

5.6. Mental illness permeates all facets of our society

Mental illness is defined as a condition which affects the emotional, cognitive and psychological functioning of an individual. Mental illness can be the result of biological factors, traumatic history, a medical condition, trauma, environmental factors, various life stressors and a more often than not a culmination of more than one factor (American Psychological Association, 2013). Persons with a family history of mental illness and those within environments where they are continuously exposed to stressful situations. Caregivers of those with terminal illnesses and who live with special needs also find themselves at the risk of mental illness due to the demands placed on them. Breithaupt et al (2017) have found that those who even interact with environments that place considerable stress on the individual would present symptoms of mental illness. Parenthood is often considered an ample source of joy and satisfaction. Parents are often quoted as stating that parenthood is an opportunity to play an integral part to forward the values of humanity and an opportunity to impart their knowledge to the next generation. However, parenting is often fraught with challenges which can affect the caregiver's ability to parent a child in a positive manner. These include structural factors such as poverty, socioeconomic class, gender and culture amongst others. Mental illness is a factor that is not often focussed on or explored within

parenting especially after the post neo natal stage. This is a concern as parents who are not well psychologically cannot render the effective caregiving required by a child and therefore more so children with special needs.

Jeans (2013) found that mothers of autistic children present with a greater risk of developing depressive symptoms compared to mothers of children without disabilities and those living with other disabilities. Blaith (2016) found a similar result whereby mothers of autistic children scored high on assessments which measured symptoms of depression and anxiety when compared to other groups. The participants of this study reported having experienced acute symptoms of depression and anxiety during the diagnosis process and post confirmation of diagnosis. Following these periods the participants acknowledged periods of heightened stress but none warranted concern.

Despite their protestations of experiencing mental illness symptoms these participants did describe experiences of emotional, psychological and physical symptoms which would warrant assessment by mental health practitioner. It is interesting to observe that the participants in Jeans (2013) and Blaith's (2016) respective research the participant's children were in the same age group as this study's participants.

Jeans (2013) states that mothers of autistic children have a tendency to under report symptoms of mental illness. Jeans attributes the under reporting of the symptoms to two reasons. Firstly Blaith (2016) argues that there may not be resources available for both the mother and child to utilise mental health services. In many middle and low income families resources are already thinly distributed which leaves very little available for the parents and other caregivers. Secondly Jeans and Blaith states that mothers may not seek these services as they do not want to be perceived as enacting their role as a mother of a special needs child. This role was described as one where the person presents with resilience, resourcefulness and continuous strength for their child despite any adversity. The participants of this study presented with a similar experience where they believed that they needed to have these attributes not solely to enact a perceived role but to ensure the well-being of the child. Having these attributes enabled the participants to achieve certain things for their children that their peers might not agree with.

The under reporting of mental illness amongst parents of children with autism cannot be understood as merely a difficulty within the autism community but rather representative of a greater societal problem. Mental illness is currently one of the leading costly expenditures

globally. Individuals with mental health problems are not able to contribute productively and positively to different aspects of their lives (Ismail, 2017). In South Africa, it is estimated that mental illness currently deficits the economy of R256 million but despite knowledge there is a little reform to make available affordable mental health resources. In families with mental healthcare user it, is integral that their caregivers are also provided with continuous and consistent personal counselling or therapy to assist in their caregiving duties. Blaith (2016) emphasises that denying caregivers of mental healthcare users for their own mental healthcare leaves them at risk of developing mental illness symptoms, compassion fatigue and burnout. This will in turn result in sub-par provision of caregiving.

The lack of mental health resources is not the sole reason we can attribute to the lack of under reporting of mental illness amongst parents but one has to acknowledge the role the stigma plays. The stigma surrounding mental health is still pervasive despite the knowledge of the harm one can incur if one does not attain the necessary interventions. There is seemingly a greater stigma attributed to those who experience mental illness due to life stressors they are experiencing as compared to those who have a mental illness with a biological aetiology. In Jeans' (2013) study, there was poor health seeking behaviour despite the participants knowing the benefits of receiving mental health interventions. It is interesting to observe that within this study and the other studies discussed in this section, there is a distinct gender factor. Efforts to lower the risk of mental illness were seemingly focused on maternal figures. However, this is in line with other studies as they found that gender plays an important role in determining caregiving and health seeking behaviours.

5.7. Parenting within families is usually concentrated with each caregiver performing a specific role

In many cultures the role of the mother is that of a nurturer and an integral component of the child's development. Whilst fathers find themselves in the role of protector, esteemed playmate and fellow explorer. The heteronormative polarisation of caregiving amongst gendered lines has often led to romanticising of motherhood. This has often led to mothers withstanding the worst of caregiving. The appointment of a role is a process informed by the cultural and religious bodies, which the family unit subscribes to. Within each role, there are specific duties and responsibilities that the person must fulfil. The specification for each role is not limited to the parental figures of a child but extend to other parental figures such as grandparents, uncles and aunts. The key factor informs the delineation of roles and the subsequent responsibilities.

Bowen (cited in Allen & Henderson, 2017) argues that in all families each person plays a specific role. Our roles are determined by the positions we occupy such as being the mother, eldest child or youngest. Each role comes with their socially or culturally approved responsibilities (Allen & Henderson, 2017). If a person does not live up to their role it often places stress in the family unit and family members are required to find ways to cope with this change. Usually this manifests itself in relational difficulties within family including intimate partner problems. Albeit some participants agreed that this, a common occurrence with the parents' relationship, other participants disagreed.

For a number of the participants, traditional parental roles of adult males became inversed whereby a more active caretaking role had to be undertaken. The shift in roles particularly for men is argued as being necessary in order to meet the needs of an autistic family. The shift is therefore necessary in ensuring the development of an autistic child. Dosch (2019) argues that the idea of families with autistic children as being vastly different from most families is archaic and has been largely filled by unfounded myths perpetuated in communities and the media. It was established that there were minimal differences in parenting in autistic and non-autistic families. As with all families parents need to take into account the needs of their children's health and more. In non-autistic families, traditional roles are still often upheld but where parents of autistic children's roles differed was not clear.

The aforementioned role delineation is applicable and by far sustainable in child development of children without disabilities however, it poses difficulties who live with disabilities. Kaniel and Simon-Tov (2011) have stated that mothers are often the 'face' of autism. This was attributed to mothers already enacting the role of mother. Furthermore, this was also the result of having to know and play a role of autistic mother. This new found role requires as they argue assimilation into that culture. Within the autism culture they noted that caregiving is still centred along gender lines (Kaniel & Simon-Tov, 2011). They note that within autistic families the father is largely inconspicuous and their role is seemingly unknown. The participants of this study acknowledged that parenting within the autism community is also centred around mothers but offered an explanation for this. The participants stated that fathers are either minutely present or absent completely. In the case they are minutely present, participants described fathers as having minimal caregiving duties which were similar to that of mothers. In this role, the participants described that this was a far cry from what they had been socialised into and assimilation into fatherhood as per the

autistic community was difficult. In the latter role of complete absence fathers absolved responsibility themselves leaving caregiving to the mother and other parties.

Shah (2019) states that families need to be understood contextually. The image of a nuclear a heterosexual family is one that is not an accurate description of what constitutes a family. Family as Shah (2019) argues is not only limited to immediate members of biological origin but extends to extended family members and community. Therefore, by alternatively acknowledging this as the norm then we do not have to conceptualise autistic families as being different from the norm. Wilson (2016) has referred to parenting children with disabilities as being resource extensive. This constitutes a number of resources but Elliott argues that having a network or community which helps parents to ensure that their child develops in the best manner whilst also being given the opportunity to ensure they are taken care of themselves (Wilson, 2016) is crucial .

5.8. Socioeconomic class is an institutional factor that influences the various aspects of human life

Socioeconomic class can be understood as a social position that an individual occupies which is determined by financial resources an individual has. As a construct, socioeconomic class is intangible but plays a key role in determining the trajectory of an individual's life. Class determines accessibility to healthcare, education and financial resources (Bull, 2009; Gergen, 2001). Not only does access determine accessibility but the quality of service one attains at these institutions and as such, class is determinant of the quality of life and consequently life expectancy. The participants of the study described themselves as middle class and agreed that this afforded greater resources than those in the lower socioeconomic classes. However in the same regard they noted that they were still unable to access resources which the upper classes had. It was of note to observe that for the participants' education was the area which was a levelling ground. Due to limited schools available the participants had to be in fierce competition of public resources with those who occupy the same and lower classes. This was said to be a different case for those with upper classes having the ability to access private resources.

Resources have always been a requirement in order to meet basic human needs. Koller, Le Pousard and Rummens (2018) argue that due to the strides made in human development, the premise of what constitutes basic has shifted tremendously and humans require more in a society that has become competitive and technologically driven. Koller, Le Pousard and Rummens (2018) further argue that in order to perform at the expected level in our society

there needs to be a higher input of resources within the family. Koller, Le Pousard and Rummens (2018) state that in families that have individuals with a disability, be it physical or mental illness, the required resources are much greater in order to assist with meeting their basic needs. Wilson (2016) also argues that the number of resources required for the basic needs of people with disabilities can be equated as being the number for optimum development for those who are able bodied. However, Ellison argues that we have to be aware that other factors which affect the accessibility, availability and the quality of the resources are at play (Wilson, 2016). The resources described as integral for autistic children and their families were medical and assistive devices amongst others.

Those who occupy higher socioeconomic class have longer life expectancy and quality of life than their counterparts in lower socioeconomic class. Socioeconomic class also often determines the degree of power an individual has. The power refers to influence within the system and relationships. Vaandering (2010) argue that occupants in socioeconomic class often determine the structure of institutions and organisations. This renders those in lower socioeconomic classes not being given the opportunity to provide valuable inputs which would make them more applicable to a vast majority of the population. This is of particular importance within the South African context as class is intertwined with race. The participants described that a number of the interventions currently in place often exclude those within the lower socioeconomic classes. This is described as occurring in multiple ways. Firstly this occurs through the division of resources. Despite the assertion of equality there is a disparity in the nature of resources amongst economic classes.

Vaandering (2010) states that discrepancies are not a means to comfort the upper classes but enable for the narrative of certain experiences to be solely in their realm of power and thus the one who controls this narrative also determines what is required to address these issues. The autism community is not exempt from this. The current narrative surrounding the challenges of the autism community are focused on the middle class and urban dwellers. This leaves the lower socioeconomic classes and rural dwellers in a position where their concerns are not in the forefront unlike their counterparts. This is not to say there are not common experiences between these groups but there will be differences because of class differences. The participants of this study did acknowledge that their rural counterparts were perhaps in the most vulnerable position as they did not have institutional resources that they required. However, interestingly, a similar sentiment was not considered for individuals in

urban settings who also could not access certain institutional structures due to the limited resources they had as part of a lower socioeconomic class.

In addition to the dominance of the narrative, occupants of higher socioeconomic classes can also determine the language used. Language is one of the main identifiers of a particular group. Language is means to develop and concretise the identity of a group. Therefore in order to ensure that all members of the group have commonality it is important that the language used for communication is easily understood and can be used by all the members. Hodge (2017) argues that language is a connection mechanism which captures all the cognitive and emotional expressions of our experiences. Hodge (2017) further states that within a group, if the language used is not easily accessible and understood, it inadvertently creates a power dynamics with those being unable to communicate in the language feeling not acknowledged. If there is no amendment of this, it results in these members exiting the group. Hodge (2017) describes communication as not the ability express yourself but also be able to understand when the language is being used.

This highlights the importance of language which raises concerns on why the language of autism is primarily English. In the structuring of interventions, communication occurs in a language which is a secondary language for a number of South Africans. This unintentionally further perpetuates the exclusion of the underprivileged black people. In order for a truly representative experience, it is apparent that the issue of class needs to be addressed within the autism community. The current narrative does not include the needs of poor, rural and black persons living with autism. If there is a continuation of the status quo, there is a risk whereby the monopolisation of the narrative by the upper and middle classes will ensure that their needs are met. Furthermore, this renders interventions which are proposed or designed not having a critical voice to ensure that there is a shift to develop an inclusive society for those with autism and other disabilities.

5.9. Challenges in accessing education for children with disabilities

South African legislature and framework, indicates that education is a fundamental human right. The legislature further states that all children of school going age including those living with disabilities must attend school. Individuals who do not adhere can face serious legal consequences. In 2001 it was estimated that there were 25 685 children with special needs who were not attending school (Department of Basic Education, 2001). Currently the estimate of children with disabilities not attending school is 11 461 with 2 769 residing in

KwaZulu-Natal (Charles, 2017; Levy, 2017). With a total of 464 schools nationally to service children with disabilities there is a desperate need for greater accessibility (Levy, 2017).

To bridge the gap between supply and demand of special needs, it was proposed by the Department of Basic Education in 2001 that an inclusive approach be implemented in schools. Taking the cue from the UNESCO Salamanca Statement which posited that an inclusive approach to education it would be of benefit to countries who did not have the infrastructure resources to cater for a stratified school system (UNESCO, 1994). Furthermore this would also allow for a more holistic shift in socialisation and education whereby there would not be othering of those with disabilities. In South Africa the White Paper 6 on Education stated that the current school system need to shift towards an inclusive approach in order to ensure the needs of children with disabilities are met (Department of Basic Education, 2001). The participants of this study expressed an awareness of policy which advocated for their children's education but noted that the implementation process had fallen by the way side. According to the participants the poor policy implementation was the result of a systemic failure that was directly correlated to a lack of political will to ensure the development of children with disabilities.

The participants were not entirely incorrect in their analysis of systemic failure. Donahue and Berman (2014) argued that the failure in implementing inclusive education is the result of the lack of clarity contained in the White Paper 6. They argue that despite the documents assertion that there is system reform which requires an injection infrastructural resources and the upskilling of educators it does not state how this will be achieved or by whom. Their argument has validity as the Salamanca Statement states that in order for an inclusive approach requires for the educators to be efficient in inclusive approach in order to educate children with and without disabilities (Department of Basic Education, 2001; Donahue & Berman, 2014; Spies, 2013). Yet within this context there have pockets of schools who have been able to achieve a semblance of an inclusive approach which accommodated children with disabilities including autism. These schools were largely in the private sector or were former model C schools. However the criteria required for attendance in these schools allowed those who were considered as high functioning which then left a vast number of children without the opportunity to experience an inclusive approach.

The difficulties in policy implementation can be further attributed to the clash between national and provincial mandate. The national department of education has programmes which are designed to address the assessment of what is required to ensure good and quality education (Donahue & Berman, 2014). Provincial departments are roped in to achieve their goals but often provinces themselves have their own goals which are sometimes placed above those of the national department. This resulted in certain national programmes not receiving the attention they require in order to fulfil their provincial mandate. The disparity between national and provincial has also led to inter provincial disparities. There are some provinces leading in ensuring that children with disabilities include those diagnosed with ASD are educated whilst in other provinces autistic children still experience inclusion.

The discord between policy and implementation within this context can be addressed by the Salamanca Statement. Within this statement it advocates that it is possible to achieve Inclusive Education through an objective assessment to determine their resources (UNESCO, 1994). In this respect it needs to be imperative for a skills' audit to determine whether the current human resources would be able to enact and implement an inclusive approach. The audit would not be restricted to educators but extend to administrative staff as well. Bjorg and Hanssen (2016) argues that without systemic reform which includes all components of the system one cannot expect the desired change. In addition to an institutional system overhaul there would also be a shift in the organisational culture and belief. All systems have an organisational culture which informs the system as this will determine the efficacy of programmes and changes which they want to implement.

5.10. Educational resources for autistic children are not evenly distributed

The participants described how they observed the differences in provincial resources in the availability of institutions to educate for their child. The participants drew comparisons with the Western Cape and Gauteng who were perceived as making concentrated efforts to ensure that autistic children were attending school. Their perception were not unfounded as both these provinces have the lowest number of children still placed on a waiting list for admission. They further described that in these provinces there are efforts especially in Gauteng there was a plan to ensure that these schools catered for all the educational needs of autistic children throughout their schooling career and not limited to primary education. Their observations were not without merit as the Gauteng Department of Education has detailed a five-year plan to ensure that all autistic children are currently placed on a waiting list. Surprisingly the Gauteng Department of Education plan is not wholly different to the

KwaZulu-Natal's Department of Education's action plan in addressing the needs of autistic children. The difference between the two being Gauteng that is roaring ahead with implementation whilst the KZN is lagging behind at a snail's pace.

Provincial differences can be attributed to distribution of financial resources within each department. Currently within KZN provincial budget, their department of education has been allocated with 240 million to address the needs of learners. Within this R240 million budget special needs education has not been provided with a specific budget whereas in Gauteng, 120 million rand have been pledged to the continuous development of special needs education. By lumping special needs of education with mainstream education it can be easily overlooked making tracking the implementation of certain programmes specific to special needs including autism difficult. Despite the assertions of the KZN department of education, progress with special needs education implementation has not been achieved. This then begs the questions regarding the monitoring and evaluation procedures placed to assess the departmental efficacy. Monitoring and Evaluation in this respect refers to both at a national and provincial level. It is of concern that the KZN province, which has largest population of children of school going age, is excluding a number of children from attending school. This indicates that there is a systemic failure with limited efforts to ensure a change.

Donahue and Berman (2014) describe that the implementation of monitoring and evaluation tools with state departments enable good governance to occur. Monitoring and evaluation they argue is an opportunity for the state to develop the requisite objective tools to assess the efficacy government programmes. This can in turn inform which areas require specific changes and those that are performing well. Currently there is a little information regarding the efficacy and implementation of the KZN department of education autism action plan.

South Africa has different provinces which represent a microcosm of the South African government. The departments are the same as those within the national department albeit with a few who are amalgamated into a singular provincial department. Each of these departments is the engine that seeks to ensure that many national programmes are able to achieve their set goals. In the process of achieving these national goals, each province has their own goals, which are specific to their context that they attempt to achieve. Each province is provided with a similar budget from the national treasury that is managed by their provincial treasury to ensure the needs of the citizens are met (Ngcobo & Muthukrishna, 2014). Provinces can approach the national treasury in exceptional cases

where more funding is required for a special circumstances. However, despite the efforts to provide all provinces an equal footing with the appropriate funding, the difference in service delivery amongst provinces is vast. Whilst a number of the provinces are able to achieve a fair amount of service delivery, there are some provinces which are falling short of addressing the needs of their residents. According to the Auditor General of South Africa's 2017-2018 report, the best performing provinces in South Africa are the Western Cape, Gauteng and KwaZulu-Natal whilst the Eastern Cape and Mpumalanga lagged far behind (Auditor General, 2018).

The difference in the resource provision amongst provinces often affected the most vulnerable however, those within privileged positions also felt the brunt of limited provincial resources.

5.11. The legislative framework primarily determines accessibility to education

The legislative framework that informs policy on who is eligible to attend school primarily determines accessibility to education. An estimated 11 652 children with special needs are still not receiving education (Charles, 2017; Levy, 2017). This inherently influences the factors that enable the accessing of educations. These factors include infrastructure, geographical location and the availability of skilled educators to provide the requisite education. In the mainstream education arena. This process has become streamlined to ensure easier access for parents using various technological measures. However, within special needs education accessing education is still a difficult process for parents. With an estimated 464 schools available nationwide, the current infrastructure is unable to accommodate all children with disabilities (Levy, 2017). This is also complicated by the fact that many special needs schools do not have the staff with the necessary skills to teach children with conditions such as autism. In the application process, parents are often told by the schools that they do not have the necessary resources to ensure the educational development of their child. The participants affirmed this phenomenon sharing their experiences of obtaining a school that allowed children with autism to attend. This exclusion was often not related to the child's symptom presentation and severity but was specific to limited resources to ensure accessibility of education. The resources often said to be in limited numbers are infrastructure and skilled personnel.

Despite the difficulties in accessing education for autistic children in South Africa, there are some parts which are leading in ensuring autistic children access they rightfully deserve.

The Gauteng province is leading the pack in their efforts of eradicating the education waiting list for autistic children. Their development of schools for autistic children in areas, which are in close proximity to different communities, has made accessing education easier. This is of particular importance for public schools as schools that are multidimensional in their approach in their teaching of autistic children are often only seen in the private school sector. The approach being used by the Gauteng province for the participants is one they believe should become a norm within the country. However, the steps undertaken are far from the inclusive approach that is advocated for by the national department of education. Yet, it is understandable for participants to argue over the model being currently used as defective due to as there are still cases of families who have to wait for a year for the provision of education, before being able to access education.

The approach by the Gauteng province is a model that appreciates the importance of a holistic approach to education but raises concerns in certain respects. Firstly, the approach inadvertently retains the stratification of special needs and mainstream. Matvieva (2018) argue that an inclusive approach in the school environment is of particular benefit for autistic children. They cite the that inclusive education enables for the schooling system to also play a critical role in harnessing and developing their social and emotional regulation skills in an environment that challenges them in a constructive manner. Thus the learners within this school may not acquire the social and other developmental skills that they may require in adulthood. Secondly this approach does not utilise an existing resources. In a country where there are exhaustive demands placed on the fiscus it is seemingly a better option to utilise the current resources which are available to ensure that education becomes more accessible for autistic children. In certain areas there may not be enough autistic children to constitute a school. By providing, the necessary skills to educators and improving the necessary infrastructure education would become a tangible reality. In addition, the upskilling of educators would require that inclusive education training becomes a cornerstone of the teachers training. The Salamanca Statement states that it is futile in making the necessary structural changes as a shift towards inclusive education if it does not become the language in which conceptualise education.

5.12. Parents do not have knowledge of Learning model used to optimise learning of autistic children at home

Most parents expressed that they did not have personal experience with the ABA models used in schools but were aware of the efficacy in teaching children with autism. The current

learning models and the national school curriculum both require extensive resources within the school environment. However many of the learning models used to teach children with autism in private schools also require resources within the home environment. The reason for this is that the ABA teaching requires for parents to continue reinforcing the lessons learnt in the classroom at home. As their children were attending public schools, they believed that the curriculum was suitable to the abilities and needs of their children. It is important to take into consideration that the participants' children were assessed to be high functioning and could cope with the demands placed upon them by the curriculum.

The current curriculum in special needs schools is further stratified into vocational skills approach and the mainstream curriculum. Depending on the child's learning ability they will be placed accordingly. In some cases the learning is an amalgamation of both vocational skills and mainstream learning. Within the different learning models parental support is emphasised as being key in the trajectory and development of an autistic learner. Educators and therapists within the school are advised to provide parents with the supportive tools to continue the child's learning within the home environment. The participants were divided in their experiences of receiving support within the school environment. Some of the participants detailed how they received minimum to no support whilst others were provided with maximum support. The differences in support were argued to be the result of organisational culture. Organisational culture was a determinant of how the school envisioned the role of parents within the learning process and the role the school can play in ensuring they achieve their responsibilities relaying to this role.

Harvey and McFadden (2018) and states that the construction of learning models continues to require continuous resource investment with parents that are resource strapped. The reliance on different technologies to foster learning often can be counterproductive to the learning process. The counter productivity is said to occur due to the parents being unable to utilise the technology themselves which can inhibit learning. Secondly, this also occurs because of the incongruence between the learning model and the context it is being applied to. Harvey and McFadden (2018) argument is of importance in this context as there are still vast differences between the lower and upper socioeconomic classes. Those within the lower classes are more at risk to not being provided with support which can in turn have a negative outcome on their child's learning. Due to factors specific to this context it is imperative that the learning models be adapted to accommodate all those who access and utilise them within this context. This contrast resulted in a call for an inclusive education approach. Steven and

Massoni (2013) argue that by implementing an inclusive approach able bodied children are learning how to interact with those living with disabilities thus firmly entrenching a society that is inclusive as it is diverse. The argument also forwarded by Hengelaar, Wittenberg, van Haartingsveldt and Kwekkeboom (2017) is that the current understanding regarding diversity in society still largely excludes a large number of the population as they are still expected to adapt into a heteronormative society. Hengelaar, Wittenberg, van Haartingsveldt and Kwekkeboom (2017) further states that an inclusive approach within schools is the bare minimum and argues that it is rendered futile if inclusivity is not extended into other facets of society. However implementing an inclusive approach has proven a challenge.

Furthermore it is imperative that the techniques or tasks required for parents be modified so that those without certain resources are still able to engage with the program in the requisite manner. A reimagining of the learning models with the context of a developing country is required if an there is to be an attainment of an educational system which is accommodative of all in South Africa. This reimagining however will require a systemic change which can only be achieved through the efforts of the public and private institutions.

5.13. Bioecological systems theory

The theoretical framework used to inform this study was Bioecological systems theory (1974). Developed by the Urie Bronfonbrenner, a developmental psychologist conceptualised the theory following his disapproval of the behaviourist trend in psychology at the time. Bronfonbenner argued that development cannot be merely understood as a result of biological influences only but is influenced by different systemic influences. Different institutions at different levels of the system have overt and covert influences on the individual. Despite the theory's developmental psychology's foundations it has been applied to different social phenomenon. The application of the bioecological systems theory is advocated due to the systemic analysis it provides for users. Furthermore the systemic analysis occurs at a multiple tier level which adds validity in understanding the phenomenon. The different levels contained in the bioecological systems is the microsystem, mesosystem, exosystem, macrosystem and the chronosystem. The different levels within the theory are intertwined and thus leading to symbiosis to occur.

5.13.1. Microsystem

The microsystem is the first tier within the bioecological systems theory. This level comprises the interventions which the individual has with the different institutions within close proximity to them. These institutions include the family, friends, religious bodies, community members and the schools. Within this tier of the theory the institutions are described as having a direct influence on the individual. It is important that having grown from the initial foundation the bioecological systems theory does acknowledge that the individual is not a mere passive recipient of these institutional influence. The individual's biological factors such as disability influence the bidirectional relationship between the microsystem's institutions and the individual.

In the microsystem the institutions such as the family and the schools determine an autistic child's possibility to attend the school. Within the family institution the resources available at their disposal often determines the quality of education which is accessible. Collins (2014) illustrates this with the analysis of the accessibility of special needs school at the Umlazi District. This district primarily caters for areas which are low income. This places them in a position where they are dependent on government resources. Thus the availability of resources in the community indicates the intervention which the autistic individuals will access. This further plays an integral role in the trajectory of the autistic child's development.

In this study the participants were fortunate to have schools and other institutions which were accessible in close vicinity within their community. However due these institutional resources within, the communities are often structured to meet the demands of an autistic child. The schools within the microsystem were often designed to accommodate those who presented with acceptable or normative disabilities. Acceptable or normative disabilities are described as those which do not deviate from what is prescribed as normal or is comfortable to those without disabilities. This would place those with high functioning autism as being easier to accommodate than their low functioning counterparts. This places higher functioning individuals in a more privileged position, where there are more institutions within the microsystem for them to access.

The permeation of acceptability politics within the microsystem raises concerns regarding inclusivity within the autism community. Inclusivity in this respect would consists of having the institutions which would allow for autistic children despite their functional ability to be

provided with the necessary support and resources to function and develop to their optimum level.

5.13.2. Mesosystem

The mesosystem consists of the interaction between the different institutions within the microsystem. The mesosystem has direct influence on the individual whilst the individual does not exert any influence on the mesosystem. The interactions between microsystem's institutions can be argued as having a bi-directional influence. The interactions within the mesosystem provide an opportunity for communities to develop in their own right what is acceptable and unacceptable behaviour within the community. It is important to note that within the microsystem there are micro communities which form part of the greater community. The micro communities may have interactions with each other but the community that is afforded greater prestige due to various factors will often dictate which resources are allocated to whom.

In most cases the development of accessible and reformed institutions is the result of various interactions between the different community bodies. Blaith (2016) state that communities are the vehicle which social change occurs that is later solidified through state legislature and policy. For the autism community, a key driver of change has been the organisation of families into organisations which form a collective to drive the change in their respective communities. This initial interaction between the different family institutions from various backgrounds can be argued as the first interaction within this micro community.

The organisation of this group thereafter enables the interaction with state institutions and other micro communities. Trimbur (2013) states that the organising of a group with a common cause formally legitimises their activism enabling an audience with the relevant institutions they desire. The autism community has been able to achieve this organisation through the various bodies which are representative of the community. Bateman (2013) argues that the organisation of different stakeholders within the autism community has enabled a shift towards a more autism friendly health and education system. Gentles, Nicholas, Jack, McKibbon and Szatmari (2019) found in their respective study that parents have experienced a positive shift within the healthcare interventions provided to their autistic children. In the same respect the participants of this study affirmed the findings of Wheeler and Bateman.

The interactions within the micro communities can be described as important if the communities lend themselves into ensuring the needs of all the macro community members being met. Vaandering (2010) argues that within all communities there are hierarchies which place certain groups at a disadvantage due to the position within the hierarchy. Through the communal work of all the groups this enables the faster attainment of certain goals for the micro communities which require them the most. The communal workmanship does not have to be specific to groups which have similar interests but rather need to extend to sharing of different resources. Wilson (2016) argues that the interactions between different institutions is ultimately an exchange of learning which can result in the development of social support. Social support according to Wilson (2016) does not remain solely at the intergroup level but filters down to an interpersonal level.

The mesosystem can be understood as an intergroup process. The interactions within the mesosystem do highlight the dependency between the institutions. However, it is clear that certain institutions enjoy greater privilege which results in them having greater influence. These institutions include religious and cultural bodies located within the community. These bodies influence institutions such as the family, schools and healthcare facilities. This occurs due to the membership that community members within the above mentioned institutions have in the two bodies. Thus certain narratives end up dominating regardless of whether they are accurate or not. For those who do not fit within the approved narrative, they find themselves being othered and facing possible exclusion.

5.13.3. Exosystem

The exosystem in the bioecological systems theory that consists of structures such as the media, politics and legislature. This system has an influence on the microsystem and mesosytem. The structures within the exosystem have the greatest influence on the development of the individual and these structures arguably in a symbiotic relationship with the political and legislative structures benefitting the most from the media institution. The institutions such as the media within the exosystem also enable the discourse of culture within the macrosystem.

The legislative and political institutions provide the foundations of how the system is constructed. These institutions often legally determine the responsibilities of the government towards their citizens and vice versa. Furthermore, they also determine the rights of citizens and their responsibilities towards each other. The Constitution of South

Africa explicitly states that all children of school going age whether they are living with disabilities or not, have a right to education and therefore legislatively all children should be able to access education with relative ease. However, this has not been the case with many children living with disabilities as they are struggling to access education. There have been a number of reasons for this occurrence which include limited infrastructure and skilled personnel amongst other things. The participants in this study described how they struggled to access which were accommodating of autistic children. This is despite their residence in urban areas which are often the epitome of accessibility within the South African context. Bateman (2009) described how location may mitigate the effects of inadequate service delivery in urban areas but this does not exempt them from experiencing inadequate service provision.

Education is arguably one of the hardest institutions to access with an estimated 1 in 250 autistic children currently not attending school. In order to address the challenges facing special needs education, the White Paper Six was conceptualised in 2001,to offer an alternative which would address the accessibility issues being experienced. Since the paper's inception, there has been no shift towards an inclusive approach but there has been a reported increase in the number of children with disabilities attending school. The participants stated that the current accessibility difficulties have to be understood in a context specific to autism. Autistic children were described as still being a group that was excluded in insuring that education for all is achieved.

The exclusion and inclusion practices that occur as result of the institutions within the exosystem can also be further understood from a conflict theory perspective. Conflict theory argues that education serves to perpetuate the structure of a society. This includes the nature of distribution of resources provided and addressing questions pertaining to the when and how thereof. Those who occupy the upper socioeconomic classes and living without disabilities tend to be the recipients of the best educational (Gergen, 2001). On the other hand, those who find themselves embodying the opposite of upper class and able bodied tend to receive minimal and poor quality education. Conflict theory argues that education is a direct mirror of our society and serves to maintain a prevalent social quo (Gergen, 2001; Vaandering, 2010). Within the South African context, inclusive practices to ensure that marginalised groups are able to occupy all spaces is one area that has not been successful. Even though inclusivity is advocated and mandated legislatively, implementation has received less attention and as such we cannot expect reform which would allow accessibility

for autistic children within education when accessibility is still denied at a societal level. Accessibility would have to focus on the most excluded groups which would be poor, black and disabled in all societal spaces. Conflict theory argues that unless there is a shift in societal structuring there will be a subsequent change in the different institutions within the system (Gergen, 2001; Vaandering, 2010).

Media as institution is an integral part of educating and bringing to the foreground pressing issues within the society. It is a trusted resource for those within the microsystem and influences their conceptualisation of certain issues. This often results in a bias, with public opinion being swayed by the dominant narrative in the media (McNair, 2014; Roberson, 2009). The reporting of autism in the media is one that has often been fuelled by misconception. The Wakefield theory, developed by Dr Wakefield in 1998, posited that autism was the result of vaccines being administered to children (Bearman, 2010; Gerber & Offit, 2009). This theory gained traction in many media outlets resulting in many parents forfeiting vaccinating their children as a preventative measure. Despite the debunking of this theory, the effects due to media coverage in many communities it is still held in high regard (McNair, 2014). The participants detailed that following the efforts to educate on autism media coverage often waxes and wanes. Unlike other conditions which receive continuous focus within the media, autism is described as not gaining traction and is reported on due to an impending crisis or miniscule to raise awareness.

The role of media in furthering understanding autism has become tantamount in order to debunk any inaccurate beliefs. Currently the prevalence of reporting autism in the media is estimated to be 0.25% globally. McNair (2014) undertook research using vignettes that described fictional media accounts of criminal behaviour performed by autistic individuals. The participants of McNair (2014) described how following the exposure to the fictional media reports they were of the belief that autistic individuals had an inherent criminal trait due to their condition. McNair's (2014) study findings are indicative of the immense influence media has and the critical role that it contributing to the public's knowledge of autism. The use of media outlets would also enable a shift towards developing an inclusive society. This would also provide the opportunity for members of society to understand which supportive roles they can undertake to assist those living with autism.

5.13.4. Macrosystem

The macrosytem is the tier which refers to the institution of culture. Culture as an institution has the greatest influence on the different institutions. Culture denotes the acceptable values, beliefs and acceptable behaviours within a group. Culture has a framework to understand phenomenon from health, politics and interpersonal relationships. Within the microsystem culture plays a pivotal role in how interpersonal relationships are constructed depending on the person's ability and level of privilege. Autism in the disadvantaged communities is still understood within ethnic cultures as a spiritual ailment that can be managed through the performing of certain rituals. In many communities this influences the social relationships the autistic individual and their family has with the community. Kang-Yi, Grinker and Mandoll (2008) argues that within contexts such as South Africa there is often a clash between indigenous collectivist cultures and western individualistic cultures. Tincani, Travers and Boutot (2009) states that people often gravitate towards what is sanctioned within the community.

The indelible influence of culture is often experienced during the pre and post diagnosis phase. During the pre-diagnosis where the child begins to exhibit their symptoms there is often a prevalent indigenous cultural understanding of the underlying cause including those who present with certain disabilities. In many traditional ethnic cultures the symptoms as Kang-Yi, Grinker and Mandoll (2013) describes, are related to an offence committed against the family's ancestors. This would require for a consultation with a traditional healer and the required healing process would commence. The participants who belonged to these collectivist groups described how they were often offered unwarranted advice on the traditional remedies that would 'cure' their child's autistic symptoms.

Undergoing the traditional practices would perform two functions; health provision and cementing group membership. Those who did not partake in the traditional healing practices could find themselves excluded and isolated from the group. This results in the families having to find a balance in upholding their ethnic cultures whilst pursuing western healthcare interventions. Confirmation of the western medical diagnosis does not equate to an acceptance in their community. Post the confirmation of the diagnosis, families of those living with autism may continue to experience social rejection and discrimination due to lack of understanding and obstinate retaining of traditional values and beliefs. Participants described how the post diagnosis phase had been a source of relief but did not necessarily mitigate discrimination from the community. McGregor, Nunez, Cobula and Gomez (2008)

states that following the confirmation of the autism diagnosis, two possible scenarios for their caregivers may result and these are being embraced by members of their community or face rejection due to their difference.

Stanley describes that in cases where individuals experience overt or covert rejection from their initial community of membership, they will seek out communities which have similar traits to them. In agreement with Ruble, Durlyrympie and McGrew (2008), Glazzard and Overall (2012) state that the seeking of group membership is a fulfilment of a biological human need to socialise and be around others. They argue that the social network is a means to fulfil other needs such as those of survival, sustenance and reproduction. Pezella, Pettigrew and Miller-Day (2012) have described that within the autism community negotiation and development of a culture which relates to them specifically is vital but often overlooked. This requires for parents and caregivers of those living with autism to introduce and socialise them into the culture of autism. The culture of autism was described by the participants as one which required advocacy, patience, continuous learning and teaching. The culture pf autism was described by the participants as embedded within civic organisations and movements. The mobilisation of families and caregivers provided the opportunity for a space whereby those living and affected by autism can come together and create their own definition of a normal life. By having a consensus regarding what normal constitutes in their lives, it renders socialisation into the culture of autism an easier process. Socialisation in this regard refers to newly diagnosed families and their community members.

The permeation of autism culture into already established cultures is one that has not been an easy process. As mentioned earlier, there is often conflicting points of view between indigenous ethnic and western cultures. However, this is not an experience that is limited to these specific context. In western societies, there has been evidence that parents also find themselves in the role of educator within their communities to counter the discrimination experienced within their communities. Despite the similarities, parents within the South African context lacked the systemic supplementary support which would make community socialisation regarding autism an easier process. The participants in the study noted that part of finding a convergence between the different cultures they identify themselves as part of their culture as the autism community. For the participants being part of converging cultures included having to micro educate those who they interact with including in public social

spaces, yet it is seemingly alarming that the socialisation into autism culture is not systemically filtered and sanctioned.

5.13.5. Chronoystem

The chronosystem refers to time. Time within this theory is understood as a structure that has an implicit influence on the other levels within the theory. Time in this respect does not refer to temporal changes but rather how past phenomenon and occurrences influence the current institutions within society. Globally the autism community has experienced events that have influenced the structure of different institutions. The chronosystem can be argued as an archive to which the other tiers of the bioecological systems theory access to how previous members engaged with different experiences. This indicates the importance of the chronosystem in shaping the system in which we occupy.

Within the autism community there have been various events that have influenced the institutional understanding and response to autism in modern history. As discussed previously, the Whitaker theory had a vast reaching effects in the wrongful conceptualisation of autism in both professional and community. The inaccuracy within the Whitaker theory served as an impetus for health institutions to have a robust awareness campaigning in educating the public on autism. In South Africa however the efforts to change public perception were undertaken by community organisations. This resulted in a large part of population being excluded in the learning process. The participants within this study stated that prior to their child's diagnosis they were not knowledgeable of autism. In this respect it can be argued that there has been little change within the healthcare system as there are virtually no programmes which provide awareness of autism in the communities that require education the most. Furthermore, within organisations concerned with the issues of the autism community, the space is still exclusionary and this exclusion occurs due to geographical, class and language. This results in the illusion that all the community members are receiving the requisite, which inadvertently perpetuates the mistakes of the past.

In education, the development of the declaration of the United Nation's Salamanca Statement ushered in a new framework of understanding how educational institutions can provide education to children with special needs. The systemic approval of inclusive approach by different economic, political and social institutions gave confidence to governments to shift towards an inclusive approach due to the varied benefits it had for users

and the government institutions. Within the South African context, it was the catalyst for an analysis of the feasibility of inclusive education utilising the available infrastructure and human resources. The White Paper 6 on education declared the governments should shift towards an inclusive approach but instead of moving towards an inclusive approach there is a greater move away from it. The participants stated that they were unaware of inclusive schools within the areas that they resided in. They did however present with an understanding that certain private schools utilised teaching approaches that were different to that of public schools. Even though the participants were not knowledgeable of inclusive education, there was a consensus that it would provide benefits for their child.

The failure to execute the implementation of inclusive education despite the time that has elapsed since the adoption of the White Paper 6, indicates that there is little structural change. Failure for systems to negotiate and implement the necessary structural change results in the phenomenon or social issues enjoying a continuous hold on the persons who form members of the system. Despite the department of education having a knowledge that for a large period of time children with autism struggle to access education. This means that the lessons from past institutional errors have not yielded the desired changes to the current structures. However, this seems to pertain to those in marginalised groups as structural reform is a trickle down process with those occupying more privileged positions being the first recipients of structural change. Therefore, the structural changes that the chronosystem should currently witness is firstly developing a system that the marginalised can access as the current system is inaccessible for them. Accessibility in this respect would not mean solely accessing infrastructure but how to make the decision making bodies accessible in order for the marginalised groups within the autism community be included. This would lead to applicable and sustainable systemic change which caters for all.

5.15. Conclusion

The study findings which are: limited social and institutional support, social bargaining, poor policy implementation regarding accessing education, risk of mental illness for parents and the institutional frameworks which account for the participants' experiences as parents of autistic children. The participants have indicated that a systemic failure can account for the challenges that the parents of autistic children have in accessing the education their children require. In addition, the different institutions within the system are in a symbiotic relationship which accounts for how they, across the board will experience the same difficulties. Our society due to various institutions it consists of, affects all facets of human

life from interpersonal relationships and access to fundamental institutions. These institutions include culture, legislature, family, technology, media and the economy amongst. It could be argued that the current system does not adequately address the needs of all those who constitute it. This is in stark to what the legislature and policy advocates. According to the findings, systemic reforms are required to avoid future perpetuation of the current failures and provide full access to all autistic learners

Chapter Six

Summary, Study limitations and Recommendations

6.1. Introduction

The following chapters provide the summary of the findings as per the research questions of the study. The chapter will detail the limitations specific to this study. Recommendation for further areas requiring studying are also included.

6.2. Summary of findings

The study had aimed to explore the experiences of parents with autistic children in accessing education for their children. In asking this question the study wanted to present a nuanced and detailed account of their experiences. The findings of the study indicated that the participants' experiences were often challenging with multiple factors influencing the accessibility process. The factors which influenced accessibility to education included geographical location, socioeconomic class and institutional structure. Socioeconomic class was described as an imperative determinant of which institutions can be accessed and the quality of said institutions. Those who occupied higher socioeconomic classes were afforded the choice to select from a myriad of educational institutions from public and private educational institutions. On the other hand, those within the lower socioeconomic classes had to experience intense competition as there were not many schools which catered for autistic children. This resulted in parents being placed in waiting lists and highlights an institutional challenge. Despite those within the middle class describing experiencing difficulties, one can argue that these are fewer to their counterparts within the lower socioeconomic classes who have far less resources to draw on in order to access education for their children.

The findings of the study indicated that the current educational system is not structured and concerned with addressing the needs of the autism community. The structuring of the educational system still largely focuses on the needs of those living without disabilities whilst people with special needs are not earning much needed attention. In special needs education there is no provision for early childhood development centres and this can be argued as one of the factors that highlight the limited accessibility of education for children with special needs when compared to their mainstream counterparts. The limited provision of adequate infrastructure can be argued as hindering accessibility for autistic children. Lack of physical schools which autistic children can attend is another factor that contributes

to accessibility difficulties experienced by parents. Limited infrastructure is a resource challenge that has received extensive attention but not enough emphasis has been placed on the deficit of appropriately skilled educators. The White Paper 6 on education stated at the time of its conceptualisation that there is a skill deficit within the South African education that does not enable greater accessibility to education for those with special needs. The paper argued that changing infrastructure would be a futile exercise if there were not skilled personnel to administer the approach. Donahue and Berman (2014) argue that since the inception of White Paper 6 their recommendation of upskilling educators has not been executed which contributes to the accessibility difficulties. This indicates that if an institutional reform is to occur it would be imperative to determine the feasibility of the approach that would be used to counter the accessibility difficulties being experienced by children with special needs, thus an assessment determining the available resources and the resources required would be vital.

The discrepancy between policy and implementation was acknowledged within the findings. Surprisingly the discrepancies were described to be province specific and not a generalised experience for all parents of autistic children. The participants detailed that when compared to other provinces, the province of KwaZulu-Natal trailed behind to their counterparts in ensuring children with autism are able to access education. Their counterparts were stated to be provinces which had major metropolitan cities that is Gauteng and Western Cape. When compared to these provinces KwaZulu-Natal has a higher number of children with special needs currently not attending school (Levy, 2017). In the Western Cape and Gauteng there have been dedicated efforts to ensure that autistic children are provided with education. This has been achieved in Gauteng by having schools dedicated specifically to autism and the Western Cape having a referral system that efficiently refers parents to the schools which would accommodate their children. The implementation of the policies which advocated for accessibility to education in these provinces can be argued as an example of how accessibility can be achieved if the requisite changes within education that can be achieved.

The second question which study aimed to address was the efficacy of the learning models being utilised to teach autistic children in South Africa. Currently in South Africa there are a number of models being utilised with many having their foundations in the Applied Behaviour Analysis model. These learning models in the South African context are largely and exclusively administered with the private sector. The efficacy of these learning models used in the private sector within this context has not been objectively established. All the

participants' children in this study had been enrolled in public schools and had no exposure to these learning models. However, they described that they were aware that efficiency of the learning models was dependant on the symptom severity and learning ability of the child. In the public school system, children were taught using a curriculum developed specially by the Department of Basic Education. Similarly, children in public schools were taught depending on their learning abilities and symptom severity like their peers in the private sector. Those who would be described as presenting as higher functioning would often be taught using the mainstream curriculum whilst their peers who were lower functioning would be taught stage appropriate content focusing on skills development. For the participants, this was described as effective means to educate their children as it took their abilities into account. There was an appreciation that their child would be reassessed by their teachers to ensure that their child receives education that is suitable to them.

6.3. Study limitations

The study consisted of six participants who were the biological parents of autistic children. All the participants were tertiary educated and were employed full time. The participants all resided in urban areas which provided detailed input on the experiences of those residing in metropolitan areas but this meant that there was no input for those who located in rural areas. The inputs from participants within the rural context would have been of great importance. Firstly, the experiences of autistic families in rural areas within the South African context have not been documented and little is known in how they navigate life with an autistic child. Secondly, their inputs would have enabled a comparison with their urban counterparts especially as this study focused on experiences of accessibility. Having participants from rural backgrounds would also have provided critical inputs regarding mechanisms used to ensure accessibility. It was interesting to observe that all the participants were female. The contributions of male participants would have provided the opportunity to explore whether there was a gender factor within the experiences.

The participants described themselves as middle class who resided in areas that were considered as suburban. Their socioeconomic class afforded the participants access and proximity to certain resources. In addition, their economic class contributed to further homogeneity of the group however this was countered by their differences in race and culture. The absence of participants from lower socioeconomic class rendered the study to account for the experiences of those from disadvantaged backgrounds. The lack of heterogeneity and the sample size limits the generalisability of the findings of the study.

Despite these limitations, the study has brought forth multiple areas which can be explored for further research.

6.4. Recommendations for further study

- It is recommended that future research studies explore experiences of those from the lower socioeconomic classes. This also extends to those residing in rural areas.

- Future studies should explore how individuals within the rural areas access different institutions other than only education. Currently studies including this one have centred their lens on the middle class experiences of autistic families and unintentionally excluded a large portion of the population. The capturing of their experiences would inform the desperate system change that is required in an inclusive manner.

- A study that explores measures the Gauteng and Western Cape provinces have undertaken to counter accessibility challenges specifically for autistic children. This can be used to create a model that can be used in other areas of South Africa.

- The efficacy and applicability of learning models within the South African context is an area of research which requires further exploration.

- A study can be undertaken to ascertain the efficacy of support structures available for parents living with autistic children. A study of this nature would assist in determining the measures that need to be put in place to ensure that parents and caregivers receive the necessary support.

- A final recommendation is that a study which explores the mental health of parents would be beneficial as it has been indicated parents of autistic children present with a greater risk of developing mental illness such as depression.

6.5. Conclusion

The study findings have indicated that multiple factors influence parents' experiences of accessing education for their autistic children. Findings indicate that those who occupied middle and upper socioeconomic classes were more likely to have positive experiences due to the resources made available to them. The findings however were not able to provide extensive input regarding the efficacy of learning models within the South African context. The lack of heterogeneity and sample size limits the generalisability of this study. The experiences of those within lower socioeconomic class and residing in rural areas is one that requires further exploration in order to have greater understanding of the autism community within the South African context.

References

Allen, K.R., & Henderson, A.C. (2017). Family theories: Foundations and applications. Chichester, West Sussex: Wiley Blackwell

American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (2013). Arlington, VA: American Psychiatric Association

Attia, M. (2017). Be(com)ing a reflexive researcher: a developmental approach to research methodology. Open Review of Educational Research 4(1): 33-45. Doi: 10.1080.23265507.2014.1300068

Auditor General South Africa. (2018). 2017-2018 Integrated Annual Report. Retrieved from http://www.agsa.co.za/Reporting/AnnualReport.aspx

Babbie, E.R. (2019). The practice of social research. Belmont, California: Wadsworth Cengage Learning

Bailey, C.A. (2018). A guide to qualitative field research. Thousand Oaks, California: Sage Publications

Bateman, C. (2013). Autism-mitigating a global epidemic. *South African Medical Journal 103(5)*: 64-71. Doi:10.7196/SAMJ6915

Bearman, P. (2010). Just so stories: vaccines, autism and the single bullet disorder. Social Psychology Quarterly 73(2): 112-115

Benderix, Y., Nordstrom, B & Sivberg. (2007). Parents experience of having a child with autism and a learning disabilities living in a group home. *The National Autistic Society 10(6):* 629-641. Doi: 10.1177/136236307070902

Bernier, R., Mao, A. & Yen, J. (2017). Psychopathology, families and culture: autism. *Child an Adolescent Psychiatry Clinics of North America 19(4):* 855-867

Billington, T., McNally, B & McNally, C. (2000). Autism: working with parents and discourse in experience, expertise and learning. *Educational Psychology in Practice 16(1):* 59-61

Bjørg, M. H., & Hanssen, N. B. (2016). Special needs education in light of the inclusion principle: an exploratory study of special needs education practice in Belarusian and Norwegian preschools. *European Journal of Special Needs Education 31(4):*520-534. Doi:10.1080/08856257.2016.1194576

Blaikie, W.H. & Priest, J. (2017). Social research: paradigms in action. Malden, Massachusetts: Polity Press

Blaith, L.K. (2016). Improving mental health in families with autistic children: benefits of using video feedback in parents' counselling sessions offered alongside music therapy. *Health Psychology Report 5(2):* 138-150

Braun, V & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3:* 77-101

Breithaupt, A.G., Thoma, K.C., Wong, C.S., Mesibov, G.B & Morrissey, J.P. (2017). Finding common ground: exploring undergraduate volunteers as a support for parents of children with autism. *Focus on autism and other developmental disabilities 32(3):* 229-231

Bronfenbenner, U .(1994). Ecological models of human development. International Encyclopedia of Education: Vol 3, 2nd Ed. Oxford: Elsevier

Bull, B. (2009). Policy implications of social justice in education. Ethics and Education 4(2): 1

Charles, M, (2017, 14 July). Calls for more special needs school in South Africa. Retrieved from www.iol.co.za/capeargus/news/calls-for-more-special-needs-schools-in-sa-10285985

Chua, A. (2011). Battle hymn of the tiger mother. Soho, London: Bloomsbury Publishing

Collins, C.W. (2014). Barriers to admission to mainstream schools for children with high functioning autism/ asperger's syndrome (Umlazi District). (unpublished thesis), University of KwaZulu-Natal.

David, M & Sutton, D. (2004). Social research: the basics. Thousand Oaks, CA: Sage Publishing

Denzin, N.K. & Lincoln, Y.S. (2013). The landscape of qualitative research. Los Angeles, California: Sage Publishing

Department of Education (2001). Education White Paper 6. Special needs education: building an inclusive education and training system. Pretoria, South Africa

Donohue, D., & Berman, J. (2014). The challenges of realising inclusive education in South Africa. *South African Journal of Education 34(2):* 1-15

Dosch, R. (2019). Resisting normal: Questioning media depictions of autistic youth and their families. *Scandinavian Journal of Disability Research 21(1):* 150-157

Evans, J (2016, 12 May). Gauteng rolling out schools for autistic children. News 24. Retrieved from m.news24.com/news24/South Africa/News/Gauteng-rolling-out-schools-for-autistic-children-20160512

Edwards, S.D., Thwala, J.D., Mbele, P.B., Siyaya, V., Ndlazi, N & Magwaza, N.J. (2011). Ancestral Consciousness in the Zulu Culture: A Wilberian View. *Journal of African Psychology 21(1):* 131-137

GemIIni. (2015). Autism. Retrieved from http://www.gemiini.org/solutions/autism.

Gentles, S.J., Nocholas, D.B., Jack, S.M., McKibbon, A. & Szatmari, P. (2019). *Health Psychology and Behavioural Medicine 7(1):* 1-18

Gerber, J. S. & Offit, P. (2009). Vaccines and autism: a tale of shifting hypotheses. *Clinical Infectious Disease 48(4):* 456-461

Gergen, K. J. (2001). Social construction in context. Thousand Oaks, CA: Sage Publishing

Glazzard, J. & Overall, K. (2012). Living with autistic spectrum disorder: parental experiences of a child with Autism Spectrum Disorder (ASD). *Support for Learning 27(1):* 37-45

Harvey, C & McFadden, K. (2018). Difference not disorder: understanding autism theory in practice. London: Jessica Kingsley Publishing

Hengelaar, R., Wittenberg, Y., van Haartingsveldt, M. & Kwekkeboom, R. (2017). Informal care and diversity explored in interdisciplinary research. *International Journal of Integrated Care 17(5):* 10-17

Hetzroni, O.E., Hessler, M. & Shalahevich, K. (2019). Learning new relational categories with autism spectrum disorders, children with typical development and children with intellectual disabilities: effects of comparison and familiarity on systemacity. *Journal of Intellectual Disability 63(6):* 564-575

Hodge, B. (2017). Social semiotics for a complex world: analysing language and social meaning. Malden, Massachusetts: Polity Press.

Hunt, P. F. (2011). Salamanca Statement and IDEA 2004: possibilities of practices for inclusive education. *International Journal of Inclusive Education 15(4):* 461-476

Ismail, A. (2017, 26 July). Revealed: The mental illnesses costing SA billions. Retrieved from www.fin24.com/Companies/Health/revealed-the-mental-illnesses-costing-sa-billions-20170724

Jeans, L.M. (2013) Examining ECLS-B: maternal stress and depressive symptoms when raising children with ASD. *Topics in Early Education*. Doi: 10.1177/0271121413481680

Kang-Yi. C. D., Grinker, R. R. & Mandoll, D.S. (2013). Korean culture and autism spectrum disorders. *Autism: 43(4):* 503-520

Kaniel, S. & Simon-Tov, A. (2011). Comparison between mothers and fathers with autistic children. *Journal of Autism 26(4):* 479-493

Koller, D., Le Pousard, M. & Rummens, J. A. (2018). Defining social inclusion for children with disabilities: a critical literature review. *Children and Society 32(1):* 1-13

Kubler-Ross, E. (1997). On death and dying. New York: Macmillan

Kubler-Ross & Kessler, D. (2005). On grief and grieving: finding the meaning of grief through the five stages of loss. London: Simon & Schuster

Le Fanu, G. (2014). International development disability, and education: Towards a capabilities-focused discourse and praxis. *International Journal of Educational Development 38(09):* 69-79

Levy, M. (2017, 13 July). Children with disabilities grow old waiting for schools. News 24. Retrieved from www.news24.com/SouthAfrica/News/children-with-disabilities-grow-old-waiting-for-schools-20170713

MacKenzie, H.E. (2010). Reaching and teaching the child with autism spectrum disorder: using learning preferences and strengths. Philadelphia: Jessica Kingsley Publishing

Mahmood, K. (2016). Dr. Elisabeth Kubler-Ross stages of grief of dying and phenomenology of grief. *Annals of King Edward Medical University 12(2):* 25-36

Marshall, C. & Rossman, G.B. (2016). Designing qualitative research. Thousand Oaks, California: SAGE

Matvieva, N. (2018). Inclusive education in schools: Organizational pedagogical aspects of the problem. *Journal of Vasyl Stefanyk Precarpathian National University 5(1):* 80-87

Mauthner, M., Birch, M., Jessop, J & Miller, T (2002). Ethics in qualitative research. Thousand Oaks, CA: Sage Publishing

Miles, M.B., Huberman, A.M. & Saldana, J. (2014). Qualitative data analysis: a methods handbook. Thousand Oaks, California: Sage Publications

Mizrachi, N. (2014). Translating disability in a Muslim community: a case of modular translation. *Culture, Medicine, and Psychiatry: An International Journal of Cross-Cultural Health Research 38(1):* 133-159

McGregor, E., Nunez, M., Cebula, K & Gomez, J.C. (2008). Autism an integrated view from neurocognitive, clinical and intervention research. Malden, MA: Blackwell Publishing

McNair, B. (2014, February 17). The media, MMR and autism. The Conversation. Retrieved from theconversation.com/the-media-mmr-and-autism-a-cautionary-tale-23321

Midence, K& O'Neill, M. (1999). The experience of parents in the diagnosis of autism. *The National Autistic Society 3(3):* 273-285

Mkhize, N. (2014). Ethical decision making in cultural context: Implications for professional practice. *Mediterranean Journal of Social Sciences 11(01):* 24-36

Morgan, D.L. (1993). Successful focus groups. Advancing the state of the art. Newbury Park, CA: Sage Publishing

Motala, R., Govender, S. & Nzima, D. (2015). Attitudes of Department of Education district officials towards inclusive education in South African primary schools. *African Education Review 12(4):* 515-532

Murungi, L.N. (2015). Inclusive basic education in South Africa: issues in its conceptualisation and implementation. *Potchefstroom Electronic Law Journal 18(1):* 3159-3195

Ngara, C. (2014). Autism in inclusive education: the employment of TEACCH in a secondary school in Auckland, New Zealand: a case study. (unpublished thesis), University of South Africa, South Africa

Ngcobo, J. & Muthukrishna, N. (2011). The geographies of inclusion of students with disabilities in an ordinary school. *South African Journal of Education 11(31):* 357-368

Nudzor, H. (2012). Unmasking complexities involved in operationalising UPE policy initiatives: Using the 'fCUBE' policy implementation in Ghana as an exemplar. *Journal of Educational Change 13(3):* 347-371

Paisley, K & Smith, J. (2013). One parent's experience of autism spectrum disorder. *Learning Disability Practise 16(5):* 21-28

Patton, M., Q (2002). Qualitative research and evaluation methods. Thousand Oaks, CA: Sage Publishing

Pezella, A., Pettigrew, J. & Miller-Day, M. (2012). Researching the researcher- as- instrument: an exercise in self-reflexivity. *Qualitative research 12(2):* 165-185. Doi: 10.1177/14879411111422107

Robertson, J. W. (2009). Informing the public? UK newspaper reporting of autism and aspergers syndrome. *Journal of Media 9(1):* 12-26. Doi: 10.1111/j.1471-3802.2009.01112.x

Ruble, L.A., Dulrymple, N.J & McGrew, J.H. (2013). Collaborative model for promoting competence and success for students with ASD. New York, NY: Springer

Samekh, B & Lewin, C. (2005). Research methods in the social sciences. Thousand Oaks, CA: Sage Publishing

Shah, A.M. (2019). The structure of Indian society: then and now. New York, New York: Routledge

Shenton, A.K.(2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information 22(2004):* 63-75

Silverman, D (2011). Interpretative Qualitative data. 4th ed, Thousand Oaks, CA: Sage Publishing

Statistics South Africa (2015). Millennium Development Goals Country Report 2015. Pretoria, South, Africa

Stone, W.L & DiGeronimo, T.F. (2006). Does my child have autism? A parent's guide to early detection and intervention in autism spectrum disorders. San Francisco, CA: Josey-Bass

TEACCH. (2014). Clinical Services. Retrieved from http://www.teacch.com/clinical-services/

Tincani, M., Travers, J. & Boutot, A. (2009). Race, culture, and autism spectrum disorder: understanding the role of diversity in successful educational interventions. *Research and Practice for Persons with Severe Disabilities 34(3):* 81-90

Trimbur, J. (2013). Grassroots literacy and the written record: asbestos activism in South Africa. *Journal of Sociolinguistics 17(4):* 460-487

United Nations, Education, Scientific and Cultural Organisation. (1994). The Salamanca Statement. Geneva, Switzerland

Vaandering, D. (2010). The significance of critical theory for restorative justice in education. *Review of Education, Pedagogy and Cultural Studies 32(2):* 145-176

Van Niekerk, A (2016, 20 March). Searching for belonging: Autism (Part 2). Auckland Park, South Africa: SABC TV

Wetherston, V., Gangat, S., Shange, N., Wheeler, K., Sayed Karrim, S. B., & Pahl, J. (2017). The views and knowledge of parents of children with autism spectrum disorder on a range of treatments. *South African Journal of Child Health 11(3):* 117-121. Doi:10.7196/SAJCH.2017.v11113.12.74

Wilson, A. (2016). The life we never expected: hopeful reflections on the challenges of parenting children with special needs. Wheaton, Illinois: Crossway

Woodgate, R.L., Ateah, C & Secco, L. (2008). Living in a world of our own: the experiences of persons who have a child with autism. *Qualitative Health Research 18(8):* 1075-1083

World Health Organisation (2014). Autism spectrum disorders and other developmental disorders. From bringing awareness to building capacity. Geneva, Switzerland

Spies, H.L. (2013). Teachers' readiness to support children with asperger's syndrome within mainstream schools (unpublished thesis). University of Pretoria, South Africa

Appendices

Appendix A

Letter of Request to Gatekeeper

<div align="right">

17 Shiner Place

Newlands East

Durban

4035

10 August 2016

</div>

Dear Sir/Madam

<u>Request for gatekeepers consent.</u>

My name is Letticia Nkosingiphile Khabanyane and I am currently a Masters of Education candidate at the University of KwaZulu-Natal, Edgewood Campus. I am writing this letter to request conducting my research at your organisation.

My research is focused on exploring the experiences of parents with children diagnosed with Autism Spectrum Disorder. I chose this area to study as I believe it is under researched in South Africa, and there needs to be research conducted in order to develop our structures to suit autistic children and their families. I believe that your organisation can provide me with access to parents with autistic children who are the focus of my research. Participation in my study is voluntary and those who wish to participate will not be compensated. My ethical clearance number is HSS/2122/016M and all participants will be informed of their rights if they wish to participate. Correspondence with me will be strictly confidential and all measures will be taken to ensure confidentiality.

For more information you are welcome to contact me on ngiphilekh@gmail.com or 079 564 5480. I hope my request will be granted.

I look forward to your response.

LNKhabanyane

Letticia Nkosingiphile Khabanyane (Mrs.)

Appendix B
Gatekeepers Consent

www.actioninautism.org.za
A Non-Profit Organisation (NPO)
Registration No. 047-002-NPO
Tel: 0312074858 fax: 0865568973
E-mail Address: info@actioninautism.org.za
74 Keal Road, Sydenham, Durban 4091

17 October 2016

To Whom it May Concern

Re: Mrs Nkosingiphile Khabanyane (Mrs)

Nkosingiphile Khabanyane has volunteered for Action in Autism, and recently helped out at a meeting between our constituency and a representative from the Department of Education.

Action in Autism is aware that Mrs Khabanyane wishes to pursue research into the experiences of parents of children with autism in the education system for her Masters degree. Action in Autism would be happy to help Mre Khabanyane out with her research in any way that we can, provided that she provides us with her ethical clearance, a brief outline of her research and a letter from her supervisor and/or the university. We also require students to give back in some way, either through donation or time to Action in Autism as a volunteer. We value her input and are grateful for her commitment, and we hope this relationship will continue.

Please don't hesitate to contact me if you require any further information.

Yours sincerely,

Kirsten Miller

Manager
ACTION IN AUTISM

Action in Autism is a non-profit organization created by parents of children with autism to improve the quality of life for people with Autism Spectrum Disorders and their caregivers by building partnerships between people with ASD, their families and the community to provide information, services, learning and research. Action in Autism's vision is that every child with autism in KwaZulu-Natal be enrolled in a school in 2013

Appendix C
Ethical Clearance Letter

UNIVERSITY OF ™
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

15 December 2016

Mrs LN Khabanyane 208520645
School of Education
Edgewood Campus

Dear Mrs Khabanyane

Protocol reference number: HSS/2122/016M
Project title: Parent's experiences of children diagnosed with Autism Spectrum Disorder in accessing edcuation for their children and the learning models currently available to educate their children

Full Approval – Expedited Application
In response to your application received 8 December 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

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)
Humanitities & Social Scinces Research Ethics Committee

/pm

Cc: Supervisor: Mr Patrick Mweli
Cc. Academic Leader: Dr SB Khoza
Cc. School Administrator: Ms Tyzer Khumalo

Appendix D

Informed consent letter

<div align="right">

School of Education, College of Humanities,
University of KwaZulu-Natal,
Edgewood Campus,

</div>

Dear Participant

<div align="center">

INFORMED CONSENT LETTER

</div>

My name is Nkosingiphile Letticia Khabanyane, I am a Masters in Education (Educational Psychology) candidate studying at the University of KwaZulu-Natal, Edgewood campus.

I am interested in capturing the experiences of parents who have children diagnosed with Autism Spectrum Disorder in accessing education for their children and the learning models which are currently used to teach their children. My study is focused on parents from all racial groups, socioeconomic classes and is not gender specific. I believe that as a parent, you can provide great insight and input for this research. I am interested in asking you some questions.

Please note that:
- Your confidentiality is guaranteed as your inputs will not be attributed to you in person, but reported only as a population member opinion.
- The focus group may last for about 1to 2 hours.
- Any information given by you cannot be used against you, and the collected data will be used for purposes of this research only.
- Data will be stored in secure storage and destroyed after 5 years.
- You have a choice to participate, not participate or stop participating in the research. You will not be penalized for taking such an action.
- Your involvement is purely for academic purposes only, and there are no financial benefits involved.
- If you are willing to be interviewed, please indicate (by ticking as applicable) whether or not you are willing to allow the interview to be recorded by the following equipment:

	willing	Not willing
Audio equipment		
Photographic equipment		
Video equipment		

I can be contacted at:
Email: ngiphilekh@gmail.com
Cell: 079 564 5480

My supervisor is Mr. Patrick Mweli who is located at the School of Education, Edgewood campus of the University of KwaZulu-Natal.
Contact details: email: Mwelip@ukzn.ac.za   Phone number: 031 260 3549.

Thank you for your contribution to this research.

Isicelo semvume

Obambe iqhaza

Igama lami nginguNkosingiphile Letticia Khabanyane, ngingumfundi waseNyuvesi yaKwaZulu-Natali ngenza iziqu zeMaster of Education kulesisikhungo eEdgewood campus, Pinetown. Ngenza ucwaningo ngokusebenzisana nabazali babantwana abanezingane ezineAutism Spectrum Disorder ukuthi bazizwa kanjani ngendlela ezifundiswa ngayo izingane ezineAutism Spectrum Disorder, nezinqinamba abahlangabezana nazo ukutholela abantwana babo isikole. Njengomzali ngibone ukuthi ungakwazi ukunginikeza ulwazi olufanele ngalolucwaningo.

Nakhu okudinga ukwazi ngaphambi kokuba uvume ukuba ingxenye yaloucwaningo:

1. Ukubamba kwakho iqhaza akuphoqiwe futhi ungahoxa noma ngasiphi isikhathi.

2. Imininingwane yakho izohlala iyimfihlo futhi ayikho imininingwane yakho ezosetshenziswa embhalweni wokugcina ozoveza ukuthi nguwe obubambe iqhaza kulolucwaningo.

3. Ukubamba kwakho iqhaza kuyisihle akukho nzuzo nemali ezotholakala.

4. Idata izobekwa ehhovisi lweNyuvesi iminyaka emihlanu emva kocwaningo oluphelele.

5. Ngizodinga ihora elilodwa ukuthi ngikubuze imibuzo.

6. Ukuqiniseka imvume yakho, ngicela ufake uphawu (X) esikhaleni esifanele kokuvumelana nawe nendlela engasetshenziswa ukuthola ulwazi lwakho kulolucwaningo.

	Uyavuma	Awuvumi
Ukuqoshwa		
Ukuthathwa isithombe		
Ukuqoshwa ngesithombe		

Uma udinga ukungithinta ngicela usebenzise lemininigwane:

Email: ngiphilekh@gmail.com

141

Umakhal'ekhukhwini: 079 564 5480

Umphathi wami nguMnumzane Patrick Mweli, otholakala esikoleni sezemfundo, eNyuvesi yaKwaZulu-Natali, eEdgewood campus.

Uma udinga ukumthinta ngicela usebenzise lemininigwane:

Email:Mwelip@ukzn.ac.za

Inombolo yasehhovisi lakhe: 031 260 3549.

ISIVUMELWANO

Mina _____**(igama nesibongo)**
ngiyaqondisisa imininingwane nezizathu zalolucwaningo. Ngiyavuma ukubamba
iqhaza kuloluhlelo nokuthi ngingakwazi ukuhoxa noma ngasiphi isikhathi.

Isignesha yomhlanganyeli   Usuku

_____   _____

Appendix E

Focus group interview schedule

- What has been your experience of living with an autistic child?

- Was it easy to get a diagnosis for your child?

- Is your child receiving formal education at this time?

- How was your experience when trying to access education for your child?

- How does your child cope in school?

- What has been your experience with the learning models used to educate your child?

- What are the resources provided for your child in school?

Appendix F
Letter from Language Practitioner

Inhle Skills Dynamics
(Pty) LTD

V1004 Umlazi township, Othandweni Circle, Umlazi, 4066
Reg. No. k2013136555, 7 August 2013; Cell: 064 527 2885; Fax No.: 086 542 8606

25 September 2019

TO WHOM IT MAY CONCERN

This is to record that I have carried out a language editing on the dissertation by Nkosingiphile Lettticia Khabanyane, entitled 'Parent's experiences of children diagnosed with Autism Spectrum Disorder in accessing education for their children and the learning models currently available to educate their children.'
The editing has been limited to language issues within paragraphs and has not addressed referencing and structure. Subsequent work still has to be undertaken by the student to address required changes.

Cleopatra Ntombezinhle Mabaso
Director: Inhle Skills Dynamics Pty (LTD)
Lecturer: English and Communication, Durban University of Technology
princesszinhle1@gmail.com
C: 064 527 2885

Appendix G
Turn it in Report

Turnitin Originality Report

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