A dissertation submitted in the Faculty of Education in partial fulfilment of the requirements for a Master’s degree in Educational Psychology at the University of Zululand, with the title:

Experiences of parents of children with Autism Spectrum Disorder attending special schools at UMgungundlovu District

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January 2018
EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER ATTENDING SPECIAL SCHOOLS AT UMGUNGUNDLOVU DISTRICT

By

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Dissertation submitted to the Faculty of Education in partial fulfilment of the requirements for the degree of Master of Education (Educational Psychology) at the University of Zululand

Supervisor: Prof M M Hlongwane
DECLARATION

I, Lungile Clarice Mngadi, declare that this dissertation is the product of my own work and effort in both conception and execution. I have, to the best of my knowledge, acknowledged all sources of information consulted during the course of this study by complete reference.

_________________________________                                      _________________
L.C. Mngadi                                                                                                Date
ACKNOWLEDGEMENTS

My sincere gratitude is extended to all those who contributed and gave immeasurable support in assisting me when undertaking this study:

- To all the parents who took time to share their lives with me, your stories and your voices are appreciated and needed.

- My supervisor, Prof M.M. Hlongwane, for his professional guidance, patience and support in completing this study.

- My sincere thanks to my friends and colleagues, Gcina Mathenjwa, Dudu Nxumalo, Zinandi Nyasulu and Lindo Makhonza for the support they gave me.

- My two wonderful sons, Bonga and Vuyo, their enormous support can never be forgotten. They are the best, may God bless them always!

- My sister, my pillar of support, Simphiwe Mngadi, thank you for your encouragement and for believing in me.

- P.D. Khanyile, a big thank you for being there whenever needed.

- To the Late Prof. Fikile Ndaki, your words of encouragement, you were a driving force, really appreciated. Thank you

- To my Lord Almighty, whose grace saw me through it all, thank you!
DEDICATION

- This work is dedicated to my late parents, Adelaide and Fred Mngadi, I am what I am today because of them. Their teachings will forever stay with me.
- A salute to my late supervisor, Prof P.T. Sibaya, with whom this project was started. The role he played will never be forgotten. “Zolala izinsizwa kusale imisebenzi”.
ABSTRACT

The study sought to explore and examine experiences of parents with regard to the education of their autistic children in special schools. Previous studies in this area looked at the inclusion of autistic children and focused on educators’ attitudes or perceptions. Thus this study intended to get parents’ perspectives, their ideas and views about the education of their children with autism spectrum disorder in special schools. To find out if they are satisfied, and explore what seem to be the concerns and challenges, the study adopted a qualitative case study design. Data were generated from nine mothers who had children attending special schools. They were purposively sampled from three special schools for children with intellectual impairment. Semi-structured interviews were conducted with mothers regarding their views and concerns about the education of their autistic children. A thematic content analysis was used to extract common themes from the collected data. Major findings were that most parents were happy and satisfied with the education of their children, though some lacked understanding and thorough knowledge about autism and special education. Parents raised concerns about lack of therapists in special schools when their ASD children need the intervention of speech and language therapists and occupational therapists. It was also found that parents struggle to access preprimary education for their children. It is recommended that special schools create forums where parents have a platform to voice their opinions and concerns. In conclusion, the study was able to give insight into parents’ experiences, views and concerns with regard to the education of autistic children. Knowing parents’ concerns and opinions may help improve the provision of education for autistic children. With the recent release of the Draft on National Strategy for Autism (September, 2017), perhaps parents’ hope for improvement in provision of education for autistic children might be realized.

Key words: Autism, Autism Spectrum Disorder (ASD), parents’ experiences and views, autistic children / learners, special needs, special schools
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CHAPTER 1
OVERVIEW OF THE STUDY

1.1 Introduction
It is every parent’s wish and responsibility to give his or her children the gift of education. The constitution of this country and the Human Rights Commission give parents hope when declaring that every child has a right to basic education. All children, irrespective of their birth circumstances and conditions deserve provision of quality basic education. Every child is entitled to basic education. This may be true for parents with typical children, but parents who have children with special needs struggle to access quality education for their children. Parents of autistic children have painful experiences, especially when trying to secure education for their children on the autism spectrum. Unlike other parents with so called “normal” children, raising and caring for a child with special needs becomes an unending arduous journey. The parents’ initial ordeal is when realising their child is different, then comes an unfamiliar diagnosis of Autism Spectrum Disorder (ASD). Even though ASD, or autism, as it is commonly known, is so rampant, most parents seem to be hearing about it for the first time when their child is diagnosed. According to Autism Speaks (2011) globally, since 1980 there has been an alarming increase in the number of children diagnosed with ASD, and it is suggested that autism is still the number one most commonly diagnosed childhood disability. There are indications that one in eighty-eight children will be diagnosed with autism: one in fifty-four boys, and one in two hundred and fifty two girls (UNLV Centre for Autism Spectrum Disorders, 2012). Local studies show that South Africa has the prevalence ranging between 0.5% and 1% among children (Dawson, 2011). This means that in South Africa an autistic child is born daily (Autism South Africa, 2011). It is evident that the number of autistic children is growing almost every day. One wonders, however, if the educational needs of children within the spectrum are catered for by the South African education system and if the Education Department does justice to the thousands of South African children with diverse educational needs. The National Department of Education should
be providing specialized educational resources and ensuring that autistic learners are able to access appropriate educational support.

However, finding an appropriate school for autistic children still remains a huge problem for most parents. Currently, there are three educational options available for a child with autism; there are special schools, inclusive or mainstream schools and home-schooling. The child’s level of cognitive functioning usually determines which school type is appropriate for the child’s educational needs. It has been documented many times that about 75% of autistic children have an intellectual impairment as well (Autism South Africa, 2012). That is why many autistic children are found in special schools rather than in mainstream schools. However parents are entitled to exercise their democratic rights and decide on a school of choice for their child (Balfour, 2007). Parental role and involvement in the education of the child is of paramount importance. Therefore, the parents’ placement decisions and wishes normally take precedence and prevail.

The Human Rights Commission Report of 2004 showed that learners with special needs experience the worst forms of educational exclusion in South Africa. The status quo remains the same up to this very day. Ideally, all autistic learners should be accommodated in autism-specific schools. These ideal special schools are extremely limited, available only in 3 provinces and non-existent in most other provinces. Learners with ASD need specialized educational resources and approaches since the conventional special needs programmes and methods are not usually appropriate and fail to yield the required results. The number of existing special schools is very limited in the country and they (special schools) are also not easily accessible to all learners who need them. This results in too many autistic learners staying at home (White Paper 6, 2001, p.5). The commission findings were displeasing, indicating that the education system has failed to meet the diverse needs of the most vulnerable learners. Autistic learners deserve quality education like all other learners and should not be discriminated against.

Autism was first diagnosed in South Africa some 30 years ago (Autism South Africa, 2011), but there is still a lack of information and awareness of this condition in the society and even among family members.
Autism Spectrum Disorder (ASD) is one of the complex neurodevelopmental disorders. It is commonly referred to as autism. The child manifests the symptoms before the age of three years. An autistic child displays severe impairment in several areas of development. There are extreme impairments in language and communication, behaviour and the ability to relate emotionally to others (Pillay, 2015). Usually ASD is accompanied by intellectual disability which results in deficits in adaptive functioning and failure to meet acceptable standards of social development and personal independence.

It is also worth noting that ASD does not always result in intellectual impairment. A lower percentage of people with ASD can have a normal or above normal intellectual ability, with close to normal speech development. These people are referred to as having Asperger’s syndrome. A small percentage of people with autism have Asperger’s Syndrome. This condition may go undetected and undiagnosed for a long period of time. The most glaring element with Asperger’s is the lack of social etiquette. Most learners with this condition are included in mainstream schooling, though their school experience is not a good one since they suffer isolation and rejection by their peers because of their (learners with Asperger’s Syndrome) social dysfunction.

Parents of autistic children face the worst challenge in finding a suitable school for an autistic child (Dzubay, 2011). There is still an urgent need for autism-specific schools as the few existing special schools are full beyond capacity and also have long waiting lists. According to Roberts (2007) and Dawson (2011), the existing special schools are not adequately equipped to meet the unique needs of children with ASD. Thousands of school going-age children with neurological conditions are let down by the Education system. Because they struggle to get placed in schools and they end up staying at home and not attending school at all. The sad reality is that these deprived children mostly come from low socio-economic class households with dire conditions (Saloojee, Phohole, Saloojee & Jsselmuiden, 2007).

The majority of the South African population are illiterate, unemployed and poverty-stricken, consequently, they can hardly afford the option of sending their ASD children to expensive private special schools. Only the few parents who can afford it, will resort to private schools or home schooling for their children with ASD.
A number of studies conducted locally and abroad have focused mainly on the inclusion of learners with autism in a mainstream setting, other studies have examined educators’ perceptions and attitudes with regard to inclusion of autistic children. There is limited research that focus on parents’ perspectives with their autistic children in special schools. Thus, the focus of this study is to explore the educational experiences of parents with autistic learners in special schools. Getting parents’ opinions and identifying the needs concerning their children’s education would be of vital importance as it would contribute immensely to improve service delivery in Special Education.

1.2 Literature review
Parents are entitled and have a responsibility to be involved and to participate fully in the education of their children. If a child has special educational needs the parent’s role becomes more demanding and sometimes very frustrating. Firstly the parent has to deal with and gradually accept the reality that his or her child is different; all the dreams and future plans are suddenly doomed. Studies by Balfour (2007) and Dzubay (2011) suggested that parents can go through a grieving process because of the loss of the normal, healthy child they had hoped for. The psychological effects on parents have been mentioned in numerous studies (Brandon, 2007; Hadjiyiannakou, Ioannou & Tziogkouros, 2007; Hing & Olivier, 2013; Bashir et al, 2014). The emotional distress that parents experience is indirectly the result of unmet educational needs for their voiceless children (Flanagan, 2001; Hadjiyiannakou et.al. 2007; Saloojee et.al. 2007).

The implementation of White Paper 6, and further introduction of SIAS strategy which was gazetted in December 2014 have not yet been able to bring about anticipated solutions and positive developments in Special Education and Inclusive Education. SIAS is an acronym for Screening, Identification, Assessment and Support. SIAS is meant to ensure a more rigorous and consistent process in responding to learners needs and addressing barriers. Most parents with autistic children know that the intellectual ability of a learner with autism determines his or her educational placement. The three most common placement options for autistic learners will be briefly reviewed hereunder. These are mainstream schools, or a special class within a mainstream setting; home schooling,
where parents take charge of their children’s education; and the special schools which are the focus of our current study with regard to parents’ perspectives.

There is little available literature pertaining to parents’ views and opinions regarding the available education options for their children on the spectrum. It appears parents have a wide range of opinions and choices with regard to education for their autistic children. Several studies in this area confirm that parents’ preferences were not the same; they expressed varied opinions that matched their experiences and general knowledge (Russel, 2003; Hadjiyiannakou et. al., 2007; Kidd & Kaczmarek, 2010).

**Inclusion of autistic children: Parental views**

A study undertaken by Elkins, Jobling, & van Kraayenoord, (2003) showed that parents were either for or against an inclusive environment for their children. Most parents were against inclusive schooling where their children would attend mainstream schools with non-disabled learners. Their main concern was the severity of the child’s disability. They felt the needs of their children would suffer as regular classrooms followed a standard curriculum while their autistic children needed self-help skills and additional support for daily functioning. The second highly raised issue was their children’s poor socialisation skills which resulted in bullying and outright rejection. They felt autistic children find themselves socially isolated, discriminated and treated as outcasts by their fellow classmates (Leach & Duffy, 2009; McDonald, 2014). The amicable solution for these parents was to consider other available options in special schools and in home-schooling settings (McDonald, 2014).

**Home-Schooling**

Home-schooling is becoming more popular for parents who believe there is nothing stopping them from giving their child the best education possible. Leading countries in promoting and practising home-schooling are USA, UK, and more recently Australia (Russel, 2003; Arora, 2006 in Kidd 2010; Leach & Duffy, 2009; Parsons & Lewis 2010 in McDonald 2014. Parents advocating home-schooling mention schedule flexibility and the rare advantage of planning the programs that suit the child’s specific need as motivating
factors. “Mom knows her child the best” is the motto and inspiration that propels mothers who choose to home educate their child. Parental direct involvement in her child’s education has been shown to strengthen mother-child bond, as well as improve knowledge and understanding of each other (Bloch, Weinstein, Seitz, 2005). The disadvantage with this approach is the lack of socialization with other children of the same age-group and its high expense, which only a few can afford (MacDonald, 2014).

**Special Education**

There is literally very limited research on parents’ experiences with special school placement. Most learners with significant barriers to learning, including autistic children are usually placed at special schools. There has been an ongoing national outcry about the shortage of special schools in the country. Added to this complaint is the fact that these institutions are not adequately geared to meet the unique needs of autistic children; autistic learners need autistic-specific schools (Draft National Strategy for Autism, September 2017). As previously indicated, according to the recently released Draft National Strategy for Autism (2017) there are only 3 provinces, nationally, schools that are best suited for children with ASD. As a result thousands of learners with special needs are unable to access their basic educational needs; their constitutional rights are violated or infringed upon. The situation is worse in rural areas (Draft National Strategy for Autism, September 2017).

As stated previously the national strategy on SIAS is a tool designed to process, manage and support learners with diverse needs as per the nature and severity of the disability (SIAS, 2014). SIAS stands for Screening, Identification, Assessment and Support (Department of Education, 2001). Thus far the implementation of the national strategy is still at its teething stage, no fruits in sight yet. Parents have to stay positive that the Department of Education will eventually deliver. It should provide appropriate, quality education for their children with special needs.
Parents who are realistic and who have come to terms with their child’s condition seek special school placement where their child can realize his or her educational potential. Children in special schools are trained to master basic life skills and to achieve personal independence. As indicated earlier that parents do not hold the same views and aspirations for their children’s education. South African studies by Balfour (2007), Dawson (2011) and van Biljon (2015) concur that parents whose autistic children attended special schools were not entirely happy about their education. They attended these schools because there was nowhere else for them to go. Thus this study has sought to get parents’ perspectives, about their concerns and expectations for their autistic children’s education.

1.3 Statement of the problem
Currently in South Africa there are only 9 autism-specific schools for learners with autism, and an alarming number of learners with autism are not getting the quality specialized education they require (Bateman, 2013). This indicates a huge shortfall and disservice in the delivery of special needs services in formal education. There is also inadequate tailor-made adaptive material and resources in schools, which negatively impact on learners learning and education process (van Biljon et. Al., 2015). Parents of school going age autistic children are struggling to access appropriate education for their children. Most educators in these schools are not trained, and have no experience in dealing with autistic children. Literature (Dawson, 2011; Balfour, 2007; van Biljon, 2015) indicates that some parents are not satisfied with the special school education for their autistic children. The Human Rights Commission Report of 2004 in Ngara (2014) indicate that learners with special needs experience the worst forms of education exclusion. Not only are there few special schools in the country, they are also not easily accessible. The few existing special schools are full beyond capacity and have long waiting lists.

Parents of autistic children face the worst challenge in finding a suitable school for their child (Dzubay, 2011).

In response to this problem, this study was designed to explore parents’ views, expectations, needs and experiences with regard to special education for their autistic
children. Furthermore, the study sought to advance proposals on how special schools can better meet expressed parental expectations and needs in relation to their autistic children’s education.

This study also attempted to provide answers to the following questions:

- How do parents view and experience the education of their autistic children in special schools?
- What concerns and challenges do parents encounter with regard to placement of their autistic children in special schools?
- How can the Department of Education and special schools meet the educational needs of autistic children?

1.4 Objectives of the study

- To investigate and enhance understanding of parents’ educational experiences, views and expectations with regard to their autistic child in special schools.
- To find out some of the concerns and challenges parents have associated with the placement of autistic children in special schools.
- To determine how the Department of Education can improve the educational experience and learning outcomes of autistic learners in special schools.

1.5 Significance of the study

There is limited research on the education of autistic learners in South Africa, and often parents’ perspectives and opinions are neglected. Much published research in this area has been done in the United States of America, the United Kingdom, New Zealand and Australia, but very little has been done locally (Enock, 2011; Dawson, 2012). This study will benefit the South African Department of Education by making recommendations for
improving educational outcomes for learners with ASD as informed by parents’ perspectives.

The National Department of Education has produced a draft on National Strategy for Autism (DBE, 2017), which aims to address backlogs and strengthen the education of autistic children. Thus this study will inform and guide this national strategy, and assist in delivering high quality educational programmes for learners with ASD. It will also provide research-based information regarding parents’ experiences, ideas, concerns and expectations in relation to the education of their autistic children.

1.6 Research design and methodology
The researcher decided to do a case study to explore the educational experiences of parents with autistic children in special schools. A case study approach was the most suitable to examine and understand the unique experiences of individual parents. “A case study provides a unique example of real people in real situations enabling readers to understand the ideas and experiences more clearly than by simply presenting them with abstract theories or principles” (Yin 2009: 72). To gain an in-depth understanding of parents’ experiences a qualitative approach seemed more appropriate. The qualitative approach fitted the exploratory nature of this study. It further gave voices to participants, and provided the opportunity to probe issues that lay beneath the surface of presenting behaviours and actions (Cohen, Manion, & Morrison, 2011: 219).

1.6.1 Sampling and data-collecting method
A non-probability, purposive sampling was used for this study. Participants were selected for their relevance to the study and their appropriateness for providing the necessary information. The high standard research rely not only on the suitability of the methodology and instrumentation, but also on the appropriateness of the sampling approach that has been undertaken (Cohen et al., 2011). The sample comprised of nine parents of autistic school going-aged children, attending a special school. These parents were recruited through the local three special schools. The relevant data were collected through
researcher-constructed interview questions which included a short biographical questionnaire with parents. Each session took approximately one hour forty minutes. The interviews took place in a comfortable setting where the interviewees were made to feel at ease and the confidentiality of their responses assured. Tape recorder was used to capture all the information during the interview sessions.

1.6.2 Data analysis
Data analysis for this research was conducted qualitatively. The researcher consolidated all the gathered data, crib-notes from interview sessions, and transcripts made from audio tapes. Data were thoroughly reviewed and scrutinized, then grouped into categories, assigned names and coded. This was done by identifying main and subthemes, then selecting and rating themes according to their significance level, and then grouping them accordingly. Data were coded according to different themes and categories. Meaningful themes were organized according to frequency of appearance. It was noted that the tools that were used were relevant and appropriate because the end-results were valid.

1.7 Validity and trustworthiness
The researcher worked skilfully to maintain the trustworthiness of this study, with a special focus on data analysis, findings and conclusions. The procedures were kept in mind throughout the research process, and the researcher kept assessing the trustworthiness of the data analysis. According to Guba and Lincoln (1994), cited in Kumar (2011), authenticity and validity in qualitative research depend on four critical requirements: credibility, transferability or applicability, dependability and conformability. These are four core elements that prove quality and trustworthiness in qualitative research.

In this study the researcher employed a series of procedures and techniques to maintain and enhance the trustworthiness and authenticity of the research. Validity was enhanced by using a variety of information gathering techniques, such as interviews, data transcripts, researcher’s notes and observations. The researcher also extensively and thoroughly described the process adopted. This was done to allow others to replicate the process to ascertain the level of dependability. Another strategy used entailed involving other investigators to help with the analysing of complex data.
1.8 Ethical considerations
The researcher ensured compliance with the laws and ethical standards of research where research is planned and carried out in a manner that is in line with the law and internationally required standards governing research with human respondents. This study commenced after the ethical clearance was granted.

The researcher sought authorization to conduct research from the KZN Department of Education, Heads of Special Schools were contacted, and permission was granted. Correct details about the nature of the study was provided. The study was conducted in accordance with the research protocol approved by the institution.

The researcher communicated in a language that was understandable to participants in obtaining Informed consent for the use of a tape recorder. The specific details of the research and its objectives were clearly explained. Signed informed consent forms were obtained from the participants before the interviews. The participants were informed of their right to decline to participate, or to withdraw at any time without fear of any negative consequences or punishment. Confidentiality was maintained and the audio-tapes were stored in a safe, locked cabinet.

The researcher made sure to adhere to all the above to maintain ethical considerations.

1.9 Knowledge dissemination
The researcher commits to disseminate knowledge through seminar presentations, publication of peer-reviewed articles in accredited journals on special education and autism and other developmental disorders. It is also the researcher’s wish to write a journal article based on the findings of the research.

1.10 Operational definitions of terms and concepts

**Autism Spectrum Disorder (ASD):** ASD is a complex neurodevelopmental disorder that affects the brain function, and causes impairment in multiple areas of development including social interaction, communication and behaviour. This complex condition
typically appears during the first three years of a child’s life. According to the DSM-V (APA, 2013), Autism spectrum disorder is a neurological disorder characterized by “impairments in reciprocal social communication and social interaction, and restricted to repetitive patterns of behaviour, interests, or activities”. In 85% of cases the condition is accompanied with intellectual impairment and or language impairment.

**NB: ASD is commonly referred to as “autism”**.

**Autism**: Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3 that adversely affects a child’s educational performance (Kansas State Department of Education, Special Education Services, 2013).

**NB**: *Autism spectrum disorder (ASD) and autism will be used interchangeably, as having the same conceptual meaning.*

**Asperger’s Syndrome (AS)**: Asperger’s syndrome is a form of autism, a disability that affects one’s ability to communicate and relate to others socially, but has high cognitive ability (Enock, 2011). It is closely related to High Functioning Autism (HFA).

**Inclusive Education**: Inclusive Education advocates that all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognize and respond to the diverse needs of their students through appropriate curricula, organizational arrangements, teaching strategies, resources and partnership with their communities (UNESCO1994: 11-12).

**Special School**: A special school is a school that caters for learners with special educational needs, especially those that require intense or high level support whose needs cannot be met in ordinary mainstream schools. Some special schools are disability-specific, like those that are for deaf/hearing impaired, intellectually impaired and blind or visually impaired.
1.11 Summary
This chapter has presented the overview of the study, briefly discussed the literature review and highlighted the problem that has led the researcher to pursue this particular research area. It has stipulated the main objectives of the study, followed by research questions which give direction to the study, as well as the research design and methodology. The next chapter reviews the literature.
CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews related literature on parents’ experiences, concerns and views on the education of their autistic children, and also highlight the current state of the South African education system. Autistic learners can be educated at either a normal mainstream school, or at a special school that caters for learners with special needs. The special school placement is guided by the severity of the learner’s special needs. It has been found that 75% of children with autism also have severe intellectual impairment. The current study focuses on children with Autism Spectrum Disorder (ASD) who are enrolled in special schools. Special schools provide high level, intense support to accommodate learners with significant learning difficulties. Education is an incredibly emotive and important issue for parents who have a child with special educational needs (Parent Carers’ Council, 2010). It is every parent’s wish to give their children the gift of a quality education, or the best education they can afford. Every child has a constitutional right to appropriate education. The Commission on Children’s Rights together with the South African Constitution guarantees children with disabilities the right to health care and education (Saloojee et al., 2007). When a child is diagnosed with ASD, accessing the right education can be difficult (Delmolino & Harris, 2012: 1197). Disability issues and rights have been at the public domain for a long time. Despite advocacy initiatives and political commitment on the part of Department of Basic Education to fight against inequities and discrimination endured by parents and children with disabilities, some children especially those that require special educational needs still have unmet educational needs. The ever growing numbers of autism diagnosis are a course for concern. Drastic measures need to be undertaken when it comes to intervention for learners with diverse educational needs. Parents with autistic children encounter dilemma while in the process of accessing suitable school for their autistic child. Finding appropriate school placements are not getting any easier, what makes things even worse are the accompanying comorbid conditions which may also present along with the autism diagnosis (McDonald, 2014).
South African education, just like other countries worldwide has embraced and implemented inclusive education with all necessary strategies in place to provide support for all learners, including those that have barriers to learning. But in spite of the increased awareness of the autism disorder, and the practice of inclusive education, most autistic children do not cope with the demands of mainstream curriculum (Frederick, Jones, & Lang, 2010; Leach and Duffy, 2009). Recent research has shown that learners with cognitive impairment including those with autism, often struggle to get admission without hurdles in mainstream inclusive setting that maximizes their academic performance (Keen, & Barret, 2008 in Kidd 2010; Humphrey & Lewis, 2008; MacDermott, 2008 cited in Ngara 2015, McDonald, 2014). The fact remains, autism numbers are multiplying at an alarming rate in South Africa. Is the South African Education system engaging rigorously with critical issues at hand?

Much research work has been done in South Africa as well as in other countries with regard to inclusive education, and how educators and learners experience the integration of learners with special needs. However, not so much research has looked from the perspective of parents with autistic children regarding the education of their children. Parents of children with autism are at the centre of this dilemma, therefore its befitting of them to have serious concerns about the educational provision made to meet their child’s needs (Lindsey, Ricketts, Peacey, Dockrell, & Charman, 2016). A number of studies have investigated the perspectives of parents of children with autism with regard to inclusion or mainstreaming of their children. This study will focus on parents’ views and experiences about the education of their autistic child in a special school setting. Once parents are officially informed of a child’s disability, parents are forced to adjust to new unexpected realities concerning the child, it’s a new route they have to follow and master (Russel 2003:144). New roles, new terminology, terrifying experiences, embarking on an unknown to discover knowledge and information to meet the unique needs of a special-needs child. The time has come for hearing more about special school, full-service school and the familiar mainstream schooling.

Inclusive education has become a worldwide phenomenon. In South African Education sphere it emerged during the rolling out of Education White Paper 6. Education White
Paper 6 advocated a strategy which has been recently gazetted in December 2014. SIAS strategy has been introduced as a tool to ensure a more rigorous and consistent process in attending to variety and diverse educational needs of all learners. Parents of children with special needs are relying on such structures and developments that the educational needs of their children are met. What is Autism Spectrum Disorder?

2.2 Definition and history of ASD

Autism spectrum disorder (ASD), more commonly referred to as autism, is a neurodevelopmental disorder. ASD is a complex and not very well understood condition. Developmental disorders such as ASD are brain-based, neurological condition that have more to do with biology than with psychology. It is characterized by gross deficits in several areas of development. The three areas that are generally affected are; communication and language, social interactions which is marked by deficits in social-emotional reciprocity and strange patterns of behaviour. Autism Spectrum Disorder (ASD) usually manifests or become noticeable before the age of three. It presents with extremely impaired social communication and nonverbal communicative behaviours (Pillay, 2015).

This condition is a spectrum, meaning it can present itself in different and completely varied levels and severity. Two individuals with the same diagnosis of ASD, may present with highly varied, parallel characteristics. It is also common for an individual with autism to have other secondary impairments, for instance it can co-occur with intellectual impairment or Attention-Deficit /Hyperactivity Disorder. 75% of individuals with autism has intellectual impairment as well (Autism South Africa, 2014). Autism is not curable, it is a permanent life time condition (Pierangelo & Giulliana, 2007). Autism statistics indicate that autism affects more boys than girls (ASA, 2014)

There are some major changes that were effected in the latest DSM-5 diagnostic manual-APA (2013). All forms of autism that were regarded as separate before; have been merged together as the Autism Spectrum Disorder. These are (1) Autistic Disorder, (2) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), (3) Asperger’s Syndrome. These three were previously considered as separate conditions.

2.2.1 Asperger’s Syndrome
Asperger’s syndrome was discovered a year later after Leo Kanner, an American psychiatrist had discovered autism. Asperger’s syndrome was discovered by Hans Asperger’s an Austrian psychiatrist Comer (1992) in Dzubay, 2011. An individual with Asperger’s may have average to above average cognitive ability but has poor social and interpersonal skills. ASD does not always result in intellectual impairment. People with Asperger’s can have a normal or above normal intellectual level. Most individuals with Asperger’s syndrome may have inappropriate and poor socialization skills. Most learners with this type of disorder are at mainstream schools but are subjected to extreme social exclusion. It is extremely difficult for individuals with Asperger’s syndrome to initiate and maintain relationships. Some individuals within the autism spectrum may have exceptional skills and can be highly gifted in certain aspects of life. They may excel in skills like maths, computers, music and art (ASA, 2014). There is a notion that Asperger’s disorder is a variant of high functioning autism (Dawson, 2007). It is highly possible that an individual with Asperger’s syndrome may go undetected and misunderstood because of socially inappropriate demeanours.

2.2.2 Understanding ASD and its Causes

Currently researchers have not been able to positively identify the causes of ASD. ASD is thought to have genetic components that results in atypical neurological development and functioning. There are still a number of speculations with no concrete, proven and tested evidence. Besides speculations the cause of ASD still remain unknown and a mystery. Investigations are still in progress. There is a biological theory that attributes ASD to genetic makeup and hereditary. Based on these investigations, the heritability of autistic disorder is estimated to be approximately 90%, with genetic abnormalities suspected to exist on chromosomes 7, 2, and 15. Other researchers suspect brain anomalies, but with no specific deficits in brain structure; having examined only cerebellum, frontal cortex, hippocampus and amygdala. There is some evidence that brain size is increased in some individuals with autistic disorder (Halgin & Whitbourne, 2007).

There are explanations that implicate environmental factors, whereby prenatal exposure to toxic chemicals have a significant impact (Balfour, 2007). At one point, decades ago,
a focus was on psychodynamics processes, pointing at mother’s aloof and cold personality as a cause. The term “refrigerator mother” was coined to depict the unaffectionate and detached type of parenting theorized to lead to autism (Halgin & Whitbourne, 2007). A lot of research is being done to try and find the causes of ASD, but currently there are no definitive answers.

The person with autism may have normal physical appearance, but cognitive makeup affects the way the brain functions and view the universe. They find themselves in a complex and confusing environment (Enock 2011: 30). An autistic individual is constantly bombarded by external stimuli which they are unable to process and make sense of. This is a source of great anxiety and frustration which is beyond their control and comprehension. Individuals with ASD experience perceptual difficulties (Dawson, 2007).

ASD experts assign the diagnosis of autism relying on the three cluster symptoms; impairment in social interaction; impairment in verbal and non-verbal communication; and odd behaviour patterns. Their nonverbal behaviours display an element of emotional distancing, which is further affirmed by poor eye contact, showing strange facial expressions, and using gestures to effect changes or getting what they want. Unlike most children, who effortlessly engage and play with other children. They also seem to fail to share and express thoughts, interests and feelings with others. Their universe is characterized by an uncontrollable need to be alone, others do not exist in their world (Halgin & Whitbourne, 2007).

Change in routine is a source of frustration and great anxiety. They often find comfort in a structured and predictable environment, as they do not adapt easily to change. Children with autism are susceptible to epileptic seizures, and are most likely to experience perceptual difficulties in relation to touch, pain, light, and other stimuli, which can result in a rebellious mood that can be easily taken out on anyone including family members and healthcare providers (Autism South Africa, 2014).

According to the Center for Disease Control and Prevention (2014) there is an alarming worldwide increase in the prevalence of ASD. South African statistics are not known, but it is befitting that it is also experiencing the similar fate. Currently there is no sound explanation for this increase in prevalence, but research suggests that this upscale may
be attributed to innovative diagnosis standards and heightened knowledge about the condition (van Biljon et al., 2015).

2.2.3 Autism and secondary impairments

It is a known fact that ASD can occur with any other diagnosable condition. Although clinicians have observed the comorbidity of ASD with attention deficit hyperactivity disorder (ADHD) for a long period, it has been acknowledged with the recent Diagnostic and Statistical Manual-5 (DSM-5) that this comorbid diagnosis has been formally recognized (Autism South Africa, 2014).

Landsberg (2005: 316) states that autism seldom occurs on its own. Its complexity increases when additional or secondary impairments have been identified. It happens that autism may occur with any other diagnosable physical, sensory, neurological or psychological impairment. The most common and frequent comorbidities are intellectual impairment, ADHD, myoclonic epilepsy, Tourette’s syndrome and obsessive-compulsive disorder (Autism South Africa, 2014). The presence of other conditions may create further barriers to learning for learners with ASD, as these conditions are said to interfere with social, occupational and academic functioning (ASA, 2014).

2.3 Education and placement options for autistic children

Finding an appropriate school for autistic children still remains a huge problem for most parents. Currently there are four educational options available for a child with autism. There are special schools advocated to serve as resource centres, full service schools, though many are still not fully operational; inclusive or mainstream school and home-education. Special education accessibility is incredibly an emotive and important issue for parents who have a child with special educational needs. Parents always take a prerogative role in school matters that involve their child. They form an integral part of decision-making bodies in schools where their child’s education is at stake.
Parents’ views and choices differ when considering placement of an autistic child at a learning institution. One would assume that parents’ decisions would be at the best interest of the child. (Grove & Fischer, 1999, in Elkins et al., 2003).

With the implementation of inclusive education policy, it is becoming more common that children with special needs are being admitted at mainstream inclusive settings. The implementation of inclusive education aims at enforcing quality and effective education for all. One of Inclusive education objective is to eradicate discrimination against learners with learning disabilities. Inclusive Education introduced SIAS strategy as a vital instrument in securing inclusive support for all learners despite their diverse needs. Inclusion of all learners is mandatory and gazetted, even those who have a variety of learning difficulties; cited by Mayga (2011) in Ngara, 2014). There has been no single success story of autistic children in mainstream setting. The inclusion of autistic children remains a theory and quite controversial. The majority of learners with autism do not succeed in a mainstream setting (Elkins et al., 2003).

There are three types of schools operating nationally in line with SIAS strategy. These are: (i) mainstream public schools, (ii) full-service schools and (iii) special schools. Other available options at parents’ disposal are independent (private) schools and home-education which are not the focus of the study. Parents have a key role in deciding and choosing the type of school or education for their child.

2.3.1 **Inclusion of autistic children: Parental views**

It has been a number of years since inclusive education was introduced, many countries including South Africa are practically applying inclusivity. Education White Paper 6 promoted Inclusive Education in its fight against discrimination and segregation. All learners irrespective of barriers or disabilities learning ought to learn together under the same roof. Parents have a decision-making role in the education of their children. Parents with autistic children, like any other parent, have a right to decide upon the school choice for their child. How do parents of autistic children feel about inclusion?
Many studies has shown that most parents with ASD children were against inclusive schooling where their special needs children would attend mainstream schools with non-disabled learners (Elkins et.al 2003). Parents’ main concern was the severity of the child’s disability. They felt the needs of their children would suffer as regular classrooms followed a standard curriculum while their autistic children needed self-help skills for daily functioning (Westwood, 2003). The second highly raised issue was their children’s’ poor socialisation skills which resulted in ASD learners being bullied and got outright rejection. They felt autistic children find themselves socially isolated, discriminated and treated as outcasts by their fellow classmates (Leach & Duffy, 2009; McDonald, 2014).

The results of a study by Goodall 2013: 4 cited in Ngara 2014 pointed out that inclusive education for autistic learners will never work. Inclusion of autistic learners is impossible. Many students with ASD have reported a negative experience at mainstream school; they experience loneliness, being discriminated against, being bullied and facing challenges in forming friendships (MacDonald, 2014:10). Breakey (2006) states that prejudice, stereotypes and discrimination are some of the challenges that ASD students encounter in mainstream educational settings. It is mentioned that these attitudes and practices lead to bullying; sadly, autistic learners are on the receiving end of negative attitudes and discrimination.

In the United States only about 12% of children diagnosed with autism get admitted at mainstream schools (Westwood, 2003); the majority of them attend special schools or centres.

However, many high functioning autistic learners, those with Asperger’s Syndrome can be successfully accommodated at mainstream and often they progress and get a tertiary qualification (Westwood, 2003:27). Recent South African studies by Roberts (2007) Balfour (2007) and Enock 2011 found that the South African context and education system are not yet ready for successful inclusion of autistic children.

Special schools are available to accommodate learners with significant learning challenges; high level support is provided to meet their educational needs. That is why parents are granted the right to decide which school is best their child.
2.3.2 Special school placement

A special school is a school that caters for learners with special needs, those who require high level support which is not available in mainstream schools. Some special schools are disability specific, for instance there schools for visually impaired, school for deaf learners, others for physically disabled and for intellectually impaired. Children with ASD are mostly accommodated at special schools for intellectually impaired. Special schools are now regarded as Special School as Resource Centre. As mentioned before, almost 75% of all children with autism, have intellectual impairment as well. They are referred to as Resource Centres as they are to provide support to neighbouring schools. Learners with autism should be placed at autism-specific schools, but these schools are currently extremely scarce. Fortunately almost all the special schools have autism-units within their premises. The focus of this study is to examine parents’ views with regard to special schools and their autistic children.

There is literally very limited studies on parents’ experiences with special school placement. Most learners with significant barriers to learning, including autistic children are usually placed at special schools. There has been a loud national cry about the shortage of special schools in the country. And that these institutions are not adequately geared to meet the unique needs of autistic children; autistic learners need autistic-specific schools (Draft National Strategy for Autism, September 2017). As previously indicated, according to the recently released Draft National Strategy for Autism (2017) in South Africa there are only 3 provinces with these ideal schools for children with ASD. Thousands of learners with special needs are unable to access their basic educational needs; their institutional rights are violated. The situation is worse in rural areas (Draft National Strategy for Autism, September 2017).

The national strategy on SIAS is a tool designed to process, manage and support learners with diverse needs as per the nature and severity of the disability (SIAS, 2014). SIAS stands for Screening, Identification, Assessment and Support (Department of Education, 2001).
Parents who are realistic and have come to terms with their child’s condition seek special school placement where their child can realize his or her educational potential, which means mastering and showing independence in basic life skills. South African studies by Balfour (2007), Enock (2010), Dawson (2011) and van Biljon (2015) concur that parents whose autistic children attended special schools were not entirely happy about their education. They attended these schools because there was nowhere else for them to go. Thus this study has sought to get parents’ views, about their concerns and expectations for their autistic children’s education.

According to Wing, (1996) and Sue, (2000) in Westwood 2003, as many as three-quarters of children with ASD have IQ scores below 70. This shows they can benefit from high level support which is provided in special schools. Learners with severe form of disability including ASD may have limited options when looking for school placement, as their needs are only available in special schools. Both Special schools and Full Service schools have one thing in common, they are both well-resourced because they have therapists who have the specialist knowledge and expertise which enable them to work effectively with learners on the spectrum (Breakey, 2006:42).

In other countries like America, Canada, Australia and some parts of Europe there is a belief that all children belong to a mainstream setting, irrespective of the intellectual impairment level (Westwood, 2003: 20). It is argued that the degree of disability should not discourage parents to apply to the school of their choice.

Westwood (2003) states that regardless of where they are placed, children with moderate to severe disability require very high levels of support so that their educational needs are met.

Pascoe and Norman (2011), in van Biljon et al. (2015) reiterate what other studies have raised; lamenting the poor service delivery and scarce resources in special needs services. The scarcity of special schools is further compounded by a transport problem.

A study by Gilmore, Campbell and Cuskelly (2002) in Westwood (2003) echoes other researchers that inclusive education is not meant for every learner. It is good and
humbling that disabled and non-disabled learners are together for social and emotional purpose only; but the reality is learners with autism will benefit from special classes (Elkins et al., 2003). The study by Elkins, et al. (2003) also found that parents who were against inclusion for their children with special needs; challenged the idea because mainstream classrooms were not accommodating enough for their children; their children’s needs were not met. Studying regular academic curriculum which is not suitable for learners with special needs. They maintained their children belonged to a special school where their educational needs can be met.

2.3.3 Home education

Home-schooling is becoming more popular for parents who believe there is nothing stopping them to give their child the best education possible. Leading countries in promoting and practising home-schooling are USA, UK, and more recently Australia (Russel, 2003; Arora, 2006 in Kidd 2010; Leach & Duffy, 2009; Parsons& Lewis 2010 in McDonald 2014. Parents advocating home-schooling mention schedule flexibility and the rare advantage of planning the programs that suit the child’s specific needs. “Mom knows her child the best” is the motto and inspiration that propels mothers who choose to home educate their child. Parental direct involvement in her child’s education strengthen mother-child bond, improved knowledge and understanding of each other (Bloch, Weinstein, Seitz, 2005; Mafa & Makuba, 2013).

It has been confirmed by many researchers that inclusive setting is not the best choice for a child with ASD. Many parents have been proactive when the education of autistic is concerned (Mafa & Makuba, 2013). More parents with autistic children decide to be in charge of their child’s education. If inclusive education does not provide solution to their child’s education, then it is time parents take control (McDonald, 2014).

Ngara (2014) concedes that autistic children are not likely to succeed in an inclusive environment, meaning their educational needs are likely to be compromised.
It has been noticed that taking home-education route is not an impulsive decision for parents concerned. Some parents have been turned away several times by prospective schools. Kidd & Kaczmarek (2010) study gave a profile of a likely candidate to home-educate. In most cases they are favoured by their socio-economic status, level of education and a go-getter personality.

Home education option has been widely practiced in other countries like United States, the United Kingdom and lately in Australia (Arora, 2006; Attwood, 2006; Humphrey & Lewis, 2008). Home schooled children tend to excellent academic performance when comparing with the traditionally and conservatively schooled. The above authors further indicated that the home schooled did not seem to lack in terms of socialization, emotional stability and healthy self-esteem. It was not easy to find any home education studies that were conducted locally or around the African continent. Thus home education is acknowledged as the alternative option for educating children with ASD as there are very few autism-specific schools in South Africa.

The disadvantage with this approach is the lack of socialization with group-age children; and its high expense, which only a few can afford (MacDonald, 2014).

2.4 Educational programmes and approaches

There is currently no cure for ASD, or autism, as it is commonly referred to; Autism South Africa (ASA, 2014). There are several approaches, intervention programmes that have proved to be effective when educating learners with ASD. All the approaches are equally effective if used appropriately. KSDE (2014) have had a privilege of using some of the tools and strategies, the best and most effective intervention programmes are those that focused on the individual learner’s unique needs, understanding learners weak and strong points. Sometimes it is beneficial to combine interventions to maximise outcomes (Enock, 2011: 32). To master some of the intervention programmes, it is best to first master everything about autism, the key to be effective in your programmes is more knowledge and understanding of ASD (Mesibov 2012 in Ngara 2014). The NAS (2011)
the master piece of effecting change and making a difference in autistic learners' life, work smart, not harder. Target areas that you know are a serious problem. Concentrate on learners’ problematic areas like, working on communication skills, the ability to initiate a conversation; social interaction skills, and the ability to understand other people’s feelings. Familiarize with mirror play; and finally mastering academic skills, the traditional basic literacy skills (Enock, 2011)

There are top of the game programmes that have shown to be the best and yield amazing results (Wilkinson, 2010 in Ngara, 2014). The 2 key strategies that seem to get preference in the field of autism are; TEACCH and ABA (applied behavioural analysis), more similar to the Lovaas approach (Breakey, 2006: 46). Both were constructed from the understanding that autism is a chronic and irreversible condition.

TEACCH

TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) was designed by Dr Eric Schopler in the early 1970s, while he was at the University of North Carolina, Chapel Hill. His approach was developed using basic weaknesses and strong points of autism that had an impact on learning and social interaction (Kansas State Department of Education, 2013). It is a strategy that promotes planning of the classroom setting and promoting autism-sensitive practices (Ngara, 2014). Over stimulation prevented at all costs, limit or block irrelevant distraction. Help pay attention and concentrate on the current activity.

It is one of the best researched educational approaches to address the specific barriers to learning that learners with autism experience (Landsberg, 2005: 322). This approach has been used in schools worldwide as well as in South Africa. The TEACCH approach is based on visual presentation. It is good for use at home as well as in any educational setting (Landsberg, 2005: 322).

All the approaches, activities, strategies should display pro autism. (Breakey, 2006: 49). The trick is, focus and use their strengths and downplay their weaknesses.
Autistic learners tend to be inattentive and can easily get bored and lose focus with a task, hence the visual support is essential (Ngara, 2014: 22). TEACCH is not an ordinary teaching programme, but a behavioural monitoring plan.

**ABA (Applied Behaviour Analysis) and the Lovaas approach**

Applied Behaviour Analysis is generally regarded as similar to the Lovaas approach. In the 1960s Dr Ivar at UCLA designed a programme to treat autistic children (Enock, 2011: 33). Lovaas had developed his intervention from the behaviourist work of B.F. Skinner. The key aspect of the programme is “rewarding good wanted behaviour and ignoring unwanted behaviour. The core of the programme involves one-on-one teaching. ABA is found to be effective when it begins early, from two to three years old. The therapy is intensive, can range from 15 to 40 hours per week, and continue for three to four years. It encompasses most of the child’s day and should address the child’s entire behavioural range (Balfour, 2007: 82). This programme involves language development, social behaviour and stimulation of play activity. This programme is good and effective in encouraging good acceptable behaviour and can be even better when discouraging, stopping unwanted behaviour.

**Joint action routines (JARs)**

Joint action routines (JARs) gives a chance to improve language, speech and communication skills during a group activity. This programme is developed to be used frequently and aim to improve communication skills rather than the mere participation in the activity. JARs allow for participation on many different levels. Learners with varying degrees of ability can participate at their skill level. (Kansas State Department of Education, 2013). Some may use words, others signs, or pictures. Rout (KS-DoE, 2013).

**Picture exchange communication system (PECS)**

the way they communicate and share their daily needs, thoughts, and feelings. The PECS improves learners' intuitive interactive language and feedback using a picture exchange system. It focuses and targets the child's learners' strong visual skills and apply the rules of ABA, including no-mistake exercise process to improve winning level and rate. (KS-DoE, 2013).

Learning experiences alternative program (LEAP)

LEAP is an activity for toddlers which concentrate on the social development of little ones with ASD, and is developed to be carried out in an inclusive setting. According to Strain and Cordisco (1993) in Kansas State Department of Education (2011), the aims of LEAP are founded on the rules and beliefs that:

- All young ones can enjoy, grow and learn from an encompassing child-friendly environment.
- Young children with autism benefit from early intervention when parents and professionals work together as partners or as a team.
- Young ones with ASD can benefit from early interactions when intervention attempts are organized.

Simpson (2005) cited in Kansas State Department of Education, 2013 ascertain LEAP has shown improved development in speech, communication, language, discipline, social interactions and functional skills which are kept over time.

Makaton

Makaton has become a globally recognized communication programme used in more than 40 countries worldwide (Autism South Africa, 2014). It is used for people with severe learning and communication difficulties, and is made up of universal signs and symbols to coordinate a visual and multimodal approach to communication and literacy. Makaton symbols can be used at home and in schools, therapy, hospitals, care homes and community facilities. There is a need to train more South African tutors in this structured approach (Autism South Africa, 2014).
Specialist services

Therapists’ programmes are valuable services in the education of ASD learners. Therapists utilize systems and intensive skill-oriented training sessions to assist young ones grow in all spheres of development. Ngara (2014) mentions available therapies that include:

- **Occupational therapy:** Occupational therapists help individuals with ASD improve both fine and gross motor skills, and also take care of sensory processing difficulties (Hincha Ownby, 2008: 1, in Enock, 2011). Occupational therapists can work with children through organized play, to improve their large muscles activity and improve their general health system (Hincha Ownby, 2008: 1, in Enock, 2011). He also believes occupational therapy can be beneficial for the sensory integration needs of autistic children, who experience either hyper or hypo-sensitivity to sound, sight, smell, touch and taste (Enock, 2011).

- **Speech and language therapy:** According to Green et al. (2005:1) in Ngara 2014, speech and language therapy seems to be the most popular intervention in ASD cases. The therapists rates the individuals’ language development and understanding of grammar, syntax, semantics and pragmatics, as well as their ability to make sounds and words. They are then able to develop an individual programme of therapy (Autism South Africa, 2014:38). The LST may give the cause for using language, and offer the individual the means and make chances to use language to communicate with others (ASA, 2014).

- **Music therapy**

- **Sensory integration (sensory processing disorder)**

Many autistic individuals have sensory processing difficulties, which can be mild to severe (Mace, 2008 in Kansas State Department of Education, 2011). Individuals with autism may experience significant struggle when dealing with daily sensory stimuli such as sounds, sights and smells, and may be hypersensitive or hypo reactive to these senses.
An autistic individual struggles to deal with all this messages, may easily become irritated, or moody, and may feel physical pain (ASA, 2014). One study conducted by occupational therapists indicated that 84% of children with autism had significant sensory processing delays as compared to 3% of typically developing children that were not demonstrating any signs of autism spectrum disorder (Autism South Africa, 2014).

Therapies work together harmoniously to provide support and services. They belong to the team of professionals such as teachers, parents and sometimes paediatricians. Therapists’ programmes are important for skills development for which autistic children may need special support. Among other things, these skills include fine and gross motor, sensory motor, perceptual and language skills. Intervention is most effective if it is integrated into daily routines within naturalistic contexts to increase the retention and generalization of skills (NZMOE, 2008:109, in Ngara, 2014).

2.5 Specialist skills for ASD education

It is an undeniable fact that specialist skills are needed to work with autistic children, and that these specialists should be found in any of the different types of schools that are operational in the South African education system (Breakey, 2006:119). The unique and varied presentation of ASD requires the specialized training and relevant expertise (Delmolino & Harris, 2012:1200). The entire staff should have a complete training and understanding of autism, firstly as a neurodevelopmental disorder, and secondly as a spectrum disorder which is reflected on a continuum of needs (Landsberg. 2005:318).

One of the challenges for educators in inclusive education is how to impart effective, inclusive and appropriate learning matter for autistic learners. Most teachers are not adequately trained to teach autistic learners (Ngara, 2014:32). A report by the National Autistic Society (2011) found that only 25% of special schools considered that their teachers were adequately trained in working with autistic children. Most educators who work with autistic children realize and feel that they require development in this area. A recent study/survey on Learning and Skills Development Agency (LSDA) highlighted the importance of teacher training and skills development with special focus on special needs education. The teachers would be better equipped to understand and manage autistic learners’ behaviour. From previous studies it is apparent that educators seem to want
skills development that prepares them for dealing with issues they face daily, and provides practical solutions and be empowered to deal with them (ASA, 2014).

Knowledge is a vital tool. It empowers people, and if used wisely, brings understanding and empathy that enables everyone to learn new skills and deal with diversity in a positive, constructive way. Education and training is essential. The Department of Education should seek consultation and training services specific to autism, employ experienced staff, and support their work with quality supervision (National Research Council, 2001, in Delmolino and Harris, 2012). One-time training and outdated knowledge and experience are not enough for a staff member to remain “at the top of the game”. According to Delmolino and Harris (2012), the commitment to training must be ongoing, and reflect progress in the field.

2.6 Parents’ challenges and emotional experiences

Parenting itself is a demanding responsibility, and is even more complicated when raising a child with autism. It is common for parents of autistic children to feel overwhelmed, powerless to control the situation, lacking necessary resources to cope, angry at yourself for being a failure, and angry at others for judging you mercilessly. It is indeed stressful raising a child with autism (Pottie & Ingram, 2008; Dawson, 2011; Hing, Olivier, & Everts, 2013; Dzubay, 2011; Balfour, 2007; Bashir, Bashir & Ahmad 2014). Parents’ psychological distress seem to emerge immediately after the child’s ASD diagnosis. Research shows that parents know nothing about autism until their child is diagnosed. This comes with fear, guilt, blame, anger, and asking “Why me?” “Why my child”. It is said that some parents go through a grief process, grieving for the loss of the normal child that they were expecting. When a child has ASD, studies indicate that parents manifest the same emotions as when the child dies (Dzubay, 2011). Parents dwell on the difficulties that may lie ahead; new unknown demands, new tasks, responsibilities and necessities. Parents, especially mothers as primary caregivers, are overwhelmed with a sense of hopelessness, inadequacy and helplessness. Specific preoccupations that contribute to parental distress include the permanency of their child’s condition, poor acceptance of autistic behaviour by society, the stigma associated with disabilities, and the lack of social
and professional support for parents (Bashir et al., 2014). To move forward and survive, parents are forced to accept the situation they find themselves in and start preparing themselves to learn more about this disability. Knowledge is power. Milstein et al. (2009), cited in Dzubay (2011), reported that an optimistic view by parents seemed the only hope for the future.

The main burdens experienced by parents of children with autism include fears for their children’s future, realizing the fact that this condition reduces their chances of independence Benson & Karlof, (2009). Other sources of stress are lack of knowledge and information, lack of support, and poor access to education and other professional services.

**2.6.1 Parents’ educational needs and expectations**

Parents are entitled and have a responsibility to be involved and participate fully in the education of their children. If the child has special educational needs the parent’s role is more demanding and sometimes very frustrating. Firstly the parent has to deal with and accept the reality that his or her child is different; all the dreams and future plans are suddenly doomed. Studies by Balfour (2007) and Dzubay (2011) alluded that parents can go through a grieving process because of the loss of the normal, healthy child s/he had hoped for. The psychological effects on parents has been mentioned in numerous studies. The difficulties that parents encounter are indirectly the results of unmet educational needs for their voiceless children (Saloojee et.al. 2007).

Legislation has assisted and guided our attention on what parents have the right to expect, which includes the right of all parents to be involved in the choice of the school their child will attend, be actively involved in schools’ undertakings (Russel, 2003:145). Generally, parents expect good quality teaching, happiness that their children are understood and taken good care of, fair discipline, homework and improvement in basic self-help skills (Hadjiyiannakou et al., 2007:146).

The school sometimes fails to meet the demands and wishes of every single parent. However, the parents should be seen as team members, and be included to help the teacher understand the child better. Hadjiyiannakou et al (2007) believe inclusion gives
the chance to work in cooperation with the parents in different settings or platforms where parent’s voices can be heard, as they can provide useful information about their children. According to Lake and Billingsley (2000) in Russel (2003), and Hadjiyiannakou et al. (2007), the main causes of conflict between the school and the parents was the discrepancy between their views of the child’s needs. This influence was particularly strong where the educators planned their intervention based on the child’s shortcomings instead of focusing on his or her strengths. The school thinks that the parents are expecting too much, given their child’s disabilities, while the parents accuse the school of focusing on their child’s limitations (Blok, Peetsma, & Roede, 2007:4). The above studies emphasize the importance of both educators and parents establishing a sound rapport. A new model developed by Hornby (1995) in Landsberg, 2005 was named a partnership model, which viewed educators as experts on education and parents as experts on their children. Landsberg (2005) states that learning programmes of young autistic learners should be planned in collaboration with parents or other primary caregivers. This confirms that parents’ involvement in their child’s education is of paramount importance.

Inclusive policies emphasize the importance of meeting the children’s individual needs, and of working closely with both parents and pupils, alongside teachers and schools, in the development of suitable approaches. It is right that parents are involved and have input into their child’s education, but equally they need to be able to trust the judgement and professional expertise of staff (Breakey, 2006:116).

Elkins et al. (2003) noted that parents’ views, needs and wishes for their children with special needs were (among other important needs) smaller size classes, time for consultation, the presence of a teacher-aid, in-service training for teacher development, and the availability of therapists. Lack or insufficient resources has been mentioned as one of the parental concerns in special educational settings (Elkins et al., 2003:127).

The value of parental participation in the educative process cannot be underestimated. Dawson (2011) and McDonald (2014) state that families and carers need to be recognized as having unique and specific information regarding the child’s strengths, challenges and learning styles, and need to be provided with opportunities to be ongoing collaborative partners in designing and implementing interventions and other educational
programmes (McDonald, 2014:4). Emphasizing a child’s strength can be beneficial to parents of a child with autism. Finally, the education system, together with professionals, may make things easier by educating parents, communities and educators especially in mainstream settings about autism, thus making parents’ burden a little lighter, and making this life-changing experience more bearable.

2.7 Summary

Mainstream schooling cannot effectively meet the diverse needs of all learners, especially those that require intense levels of support, including those that are on the autism spectrum disorder. The research indicates that the majority of autistic learners belong to special schools where their basic needs are catered for. Thus this study explores parents’ experiences, views and concerns with regard to the education of their autistic children at special schools. It aims to find out if parents are satisfied with the education of their children at special schools. Do they feel involved in their child’s education and decisions made for them? Finally, it seeks to find out if they feel that their expectations are being met. It also enhances the understanding of autism, giving the definition, aetiology and prevalence of ASD, and effective educational approaches / interventions for learners with autism focusing on their strengths to effect a positive impact. The success of learning and teaching of autistic learners depends on the co-involvement of relevant stakeholders, more especially trained educators, informed parents, and health-care professionals. The research design and methodology that guides the present study will be discussed in the next chapter.
CHAPTER 3
RESEARCH METHODOLOGY

3.1 Introduction

In this section the researcher presents and discusses the research design, sampling method, method of data collection, and data analysis. This chapter also describes the reason for choosing the particular methodology used, and further explain how the study was conducted. To be able to examine and explore experiences of parents with autistic children who are at special schools, an interpretive research paradigm was considered as the appropriate paradigm since the interpretive approaches rely heavily on naturalistic methods (Cohen, Manion & Morrison, 2011). The interpretive paradigm was selected because interpretivists’ approaches usually go deeper into getting meaning behind every human experience (Cohen et al., 2011). This research is a case study of educational experiences of parents of autistic children attending three special schools in and around Pietermaritzburg. Firstly, a case study was used because it can give a holistic understanding of the phenomenon, readers are able to have insight into concepts more clearly than simply by presenting them with complicated theories or principles (Yin, 2014). Secondly, a case study was used because the researcher wanted to understand parents’ educational experiences when sharing their real-life stories as individuals.

3.2 Research design

The researcher used a qualitative approach, where a case study research design was followed. The research design can be regarded as an operational plan, with relevant procedures and logistics that guides the researcher into getting answers to research questions (Kumar, 2011). It gives the complete programme concerning the current study. A qualitative approach suits the in depth investigative nature of this research project. According to Gonzales, Brown and Slate (2008:3), “qualitative research provides an in-depth, intricate and detailed understanding of meanings, actions, non-observable as well
as observable phenomena, attitudes, intentions and behaviours and these are well served by naturalistic enquiry”. It was essential to use the qualitative research approach since the study was about exploring parents’ experiences. It further gave an opportunity of self-inquiry to respondents, and dealing safely with subconscious issues before manifesting in questionable behaviour and actions (Cohen et al., 2011:219). It is meant to find answers to the researcher’s questions. It is the pathway the researcher will follow to gather and scrutinize data that are key in answering the following research questions:

- How do parents view and experience the education of their autistic children attending special schools?
- What concerns and challenges do parents encounter with regard to placement of their children in special schools?
- How can the Department of Education and Special Schools meet the educational needs of autistic children?

3.2.1 Sampling method.

As it is the case with all qualitative studies, sampling is guided by the researcher’s desire to get the suitable participants who will be able to give the best information.

The participants were selected for being more suitable, also had close connection with purpose of the study, and their convenience in giving the relevant information. Non-probability and purposive sampling are core ingredients of a qualitative study rather than probability or random sampling approaches (Maree, 2007).

The reliable research findings depend not only on the correctness of the methodology and instrumentation, but also on the appropriateness of the sampling approach that has been used (Cohen et al., 2011). Purposive sampling ensures that the researcher obtain the relevant information of the highest quality from the most reliable sources available (Maree, 2007).
The target population were 12 parents of school going-age autistic children, who were recruited through three special schools around uMgungundlovu district in Kwazulu-Natal. These special schools are for learners with intellectual impairment; they also have classrooms specifically for autistic children. The researcher had planned on using 12 parents, four from each of these three special schools, but only nine parents completed and returned the consent forms volunteering to participate. The nine respondents who agreed to participate in the study, did so completely on their own volition. Ethical considerations were strictly applied and maintained throughout the research period.

3.2.2 Method of data collection

The use of multiple methods to collect data is a valuable element of a case study, such as in-depth interviewing, obtaining information from secondary records, and gathering data through observation, discussions with focus groups and group interviews (Kumar, 2011). In this study one-to-one interviews were conducted to get relevant in-depth information.

The quality and effectiveness of any research project largely depends on the suitability of the instruments for data collection (Terre Blanche et al., 2009) The semi-structured interview is able to elicit in-depth information that will assist in giving more insight into the respondent’s viewpoint (Maree, 2007). A semi-structured interview gives a chance for follow-up questions, ensuring the interviewer is in control and able to guide against side-tracking, and allowing for the probing and clarification of answers.

The interviews were conducted to understand parents’ experiences, views and concerns about the education of their autistic children. As Kumar (2011) raise the importance of the researcher’s ability to understand the informant’s perspective. The predetermined, structured interview schedule was efficient in gathering relevant and required information from respondents, as they participated fully in sharing their experiences and ideas.

3.2.3 Recording of data

Audio or video recordings are frequently used to capture the conversation as well as all other details during the interview session. Valuable information can be observed afterwards with help of data recordings. The mood, tone, voice and facial expression of
both the researcher and informant can be extremely important when interpreting and analysing the data (Nieuwenhuis, 2007).

The researcher had made prior arrangement with the respondents, requesting permission to use an audio recorder. Recording an interview was done in a meticulous manner. The researcher was able to listen after the interview and could easily identify and close gaps with the aid of the recorded information. Verbatim transcription of the recorded information during the interviews was reviewed and done appropriately. Recording improved quality of the data collected and also enhances the credibility of the study (Nieuwenhuis in Maree, 2011).

3.3 Data analysis

As this study followed a qualitative approach, so data analysis is bound to use an interpretative strategy. The researcher had to develop meaning from the information communicated by respondents during data gathering. All the gathered data, notes from interviews and from audio-tape are carefully organized to form categories. Broad themes are developed emanating from the created meaning. The researcher had to be skilful in carefully selecting the wording of the theme that will accurately interpret the meaning (Kumar, 2011). The researcher thoroughly reviewed and scrutinized the data to identify the main themes.

The researcher formed clustered patterns and arranged the information according to certain similar or common themes. Data were coded according to different themes and categories. All significant themes were identified till saturation point was reached. Meaningful themes were organized according to frequency of appearance.

3.4 Trustworthiness and authenticity of the study

Trustworthiness and authenticity are the key elements that determine the quality and credibility of any research project. Thorough and efficient data analysis process contribute towards achieving reliable research findings and conclusion (Kumar, 2011). According to Guba and Lincoln (1994), cited in Kumar (2011) trustworthiness and
authenticity in qualitative research are almost similar to validity and reliability which are terms commonly used in quantitative research. Verbatim quote of Guba and Lincoln (1994) in Kumar 2011 “The trustworthiness criteria of credibility (parallel internal validity), transferability (parallel external validity, dependability (parallel reliability), and confirmability (parallel objectivity),” the above mentioned concepts mean more or less the same as validity and reliability.

In this study the researcher employed a series of procedures and techniques to maintain and enhance the trustworthiness and authenticity of the research. Validity was promoted by utilizing a variety of information gathering techniques, such as interviews, data transcripts, researcher’s notes and observations. The researcher also extensively and thoroughly described the process adopted. This was done to allow others to replicate the process to ascertain the level of dependability. Another strategy used was involving other external investigators to help with simplifying the coded data.

3.5 Ethical considerations

The researcher ensured to comply with the laws and ethical requirements of research where the study is formulated and carried out in a manner that is in line with the law and internationally required standards controlling research with human respondents. Permission authorizing this research project was duly granted; the clearance certificate is attached at the end of this document with other appendices, see appendix (A). This study commenced after the ethical clearance was granted.

The researcher sought authorization to conduct research from the KZN Department of Education, Heads of Special Schools were involved, and permission was granted. Creswell (2012) concedes the importance of following the correct channels when seeking permission to access particular institutions. Correct details about the nature of the study was provided. The study was conducted in accordance with the research protocol approved by the institution.

The researcher communicated in a language that was well understood by all respondents before they committed themselves into participating in the research project. Their
informed consent was requested for the use of a tape recorder. The specific details of the research and its objectives were clearly explained. Signed informed consent was obtained from the participants before the interviews. The participants were made aware of their right to participate, or decline to participation, or if they agree but change their mind later on and withdraw; no punishment or any negative consequences will be meted out to them. Furthermore participants were informed not to expect any remuneration for their participation except reimbursement for travelling expenses. Confidentiality was maintained throughout the study. The researcher made sure to comply with all ethical considerations stated above.

3.6 Planning procedures for the administration of the research project

A request for permission to conduct research in three special schools in uMgungundlovu District was sent to the Head of Department of the KZN Department of Education (Appendix F). Once permission was granted the principals of the three special schools were contacted to make an appointment. The research project and its purpose was explained to the principals, and their assistance was requested to invite interested parents with autistic children to participate in the study. Ten invitation letters for parents' participation in the study were left at each special school. Each invitation informed principals about the details of the study including its nature and purpose; and the consent form was attached to be filled in by parents who gave consent to take part in the research project. The parents who responded were contacted to arrange suitable dates for interviews. Parents were asked to decide on a convenient venue for meetings and interviews. Most parents indicated that they would be most comfortable at their child's school. Principals agreed, and interviews were conducted at the child's school.

3.7 Summary

This chapter has dealt with the research methods used in the study. A qualitative approach was used and the rationale for employing this approach has been given. The research methods and step-by-step procedures followed in conducting the study have
been briefly discussed. Data presentation and analysis will be discussed in the following chapter.
CHAPTER 4
DATA ANALYSIS AND INTERPRETATION

4.1 Introduction

The aim of this research project is to examine and understand the educational experiences of parents of autistic children in special schools. This chapter’s centre of interest is on presentation, thorough analysis and interpretation of data. There are various ways to analyse and present qualitative data; this can be accomplished by following the fundamental principles of fitness of purpose. Qualitative data analysis is usually based on interpretation, one can establish a variety of inferences from available data to be utilized (Cohen, 2007). Unlike quantitative data which deals with huge numbers, qualitative data generally uses smaller sample; however, the data retrieved is more detailed and rich. The qualitative approach used in this study was selected for its suitability and relevance in eliciting educational experiences of parents with autistic children in special schools. Before embarking on data analysis and interpretation, it is imperative that the study sample is briefly reviewed.

The sample in this study were nine biological mothers of autistic children from three special schools around Pietermaritzburg in KwaZulu-Natal. The children’s ages ranged from seven to 17, there were 3 girls and 6 boys. The parents’ ages ranged from 26 to 48. The participants were all mothers. Two of the nine mothers were married, one widowed, one separated, and five were single parents. Of the nine mothers, two were employed, three were trying to find employment and four were stay-at-home mothers by choice. Eight participants had isiZulu as their home language, and only one participant had English. The researcher used the language that was preferred by participants without inconveniencing any participant. Language was not a limiting factor. All participants communicated comfortably and freely. The services of an interpreter were not necessarily required. The participants were confident and expressed themselves fluently in the language that was used.
Table 1: Demographic data of the participants

<table>
<thead>
<tr>
<th>Mother</th>
<th>Marital Status</th>
<th>Employment</th>
<th>Child gender</th>
<th>Learner age</th>
<th>Birth order</th>
<th>Chronic medic.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Single</td>
<td>NO</td>
<td>Female</td>
<td>7</td>
<td>1st</td>
<td>No</td>
</tr>
<tr>
<td>B</td>
<td>Single</td>
<td>NO</td>
<td>Female</td>
<td>8</td>
<td>1st</td>
<td>No</td>
</tr>
<tr>
<td>C</td>
<td>Married</td>
<td>NO</td>
<td>Male</td>
<td>17</td>
<td>2nd</td>
<td>Yes</td>
</tr>
<tr>
<td>D</td>
<td>Single</td>
<td>NO</td>
<td>Male</td>
<td>11</td>
<td>1st</td>
<td>Yes</td>
</tr>
<tr>
<td>E</td>
<td>Single</td>
<td>Student</td>
<td>Male</td>
<td>9</td>
<td>1st</td>
<td>No</td>
</tr>
<tr>
<td>F</td>
<td>Married</td>
<td>YES</td>
<td>Male</td>
<td>12</td>
<td>2nd</td>
<td>Yes</td>
</tr>
<tr>
<td>G</td>
<td>Single</td>
<td>NO</td>
<td>Female</td>
<td>8</td>
<td>1st</td>
<td>No</td>
</tr>
<tr>
<td>H</td>
<td>Widow</td>
<td>YES</td>
<td>Male</td>
<td>14</td>
<td>3rd</td>
<td>Yes</td>
</tr>
<tr>
<td>I</td>
<td>Separation</td>
<td>YES</td>
<td>Male</td>
<td>10</td>
<td>2nd</td>
<td>Yes</td>
</tr>
</tbody>
</table>

4.2 Data Analysis

In qualitative research, there is a close relationship between data gathering and data analysis. While collecting data, an experienced, seasoned researcher is able to see a need for change in data collection method or data collecting instrument (De Vos, 2005:335). The data collected from the interviews were well stored into electronic audio files, for safe keeping and easy access when necessary. The researcher transferred audio-data to paper, listening over and over on the recorder and transcribed verbatim. The researcher attempted to make sense of all the available data by repeatedly going over it. After absorbing, assimilating data, making meaning and insight of the available data in relation to research topic, research questions and research findings. The researcher took bigger strides in getting to the core of data analysing by sorting, putting together all similar ideas and concepts. The next step was to identify patterns and to categorize, do coding and be vigilant to identify emerging themes.
4.2.1 Content analysis process

There is nothing easy and forthcoming with data analysis process. It is all about being critical, very analytic and apply your mind. It is an analytic process. The researcher has to work on forming categories, developing patterns and identifying emerging themes. According to De Vos (2005) this is the most taxing and strenuous part.

The researcher has to start and generate meaning and sense into volumes of collected data. To finally derive to a solid interpretation of presented data that will answer the research questions and give valid and trustworthy research findings; it requires engaging with the fundamentals rigorously - in sorting, comparing, categorizing and coding (McMillan & Schumacher, 2014).

The definition is not just lying around to be collected, the researcher works hard to derive and decide on a definition, categories and patterns of data. McMillan and Schumacher (2014), state that qualitative data analysis is mainly an inductive process of arranging data into categories and identifying among the categories. Qualitative analysis is a systematic process of coding, categorizing and interpreting data to provide explanations of a single phenomenon of interest.

According to Nieuwenhuis (2011) the researcher should be skilled enough to be able to put together pieces of a puzzle until it makes sense, these puzzle pieces available to the researcher is the bundle of collected data. The success of the study is achieved when the researcher uncovers the truth hidden deep in the respondents’ data. Mastering data analysis depends on discovering the reality as it is understood by the participants through their experiences. The analysis of data may mean reconstruction of existing data to develop new themes and subthemes. Themes and sub-themes of this study were measured against current theories and old information as found in the relevant literature (Creswell, 2012).
Content analysis is the process that is undertaken to ensure qualitative analysis by means of data reduction. Data reduction is the main ingredient used to achieve quality data analysis. This strategy tends to minimize much worded text into much less themes. Narrowing down themes assist not to create confusion by assigning data incorrectly. The main reason for coding is to maintain confidentiality of the collected data. Coding also make a difficult task of processing data much easier for the researcher. The researcher ensured to utilize effective strategies throughout the analysing process to achieve quality and reliable research findings.

4.3 Discussion and interpretation of themes and subthemes

At this stage the researcher was extremely careful when interpreting analysed data. Making sure the available data has meaning and adds understanding to emerging patterns, associations and concepts (Nieuwenhuis, 2007). Accurate interpretation of data contributed in formulating of themes and sub-themes as they are presented hereunder.

Table 2: Outline of themes and subthemes that emerged

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental comprehension of autism spectrum disorder</td>
<td>Parental psychological and emotional effects</td>
</tr>
<tr>
<td>Special school placement</td>
<td>• Placement relief/stigma</td>
</tr>
<tr>
<td></td>
<td>• Parental expectations</td>
</tr>
<tr>
<td></td>
<td>• Lack of resources</td>
</tr>
<tr>
<td></td>
<td>• Educator suitability</td>
</tr>
<tr>
<td></td>
<td>• Transport: school bus</td>
</tr>
<tr>
<td>Parental challenges and concerns</td>
<td>• Lack of support</td>
</tr>
<tr>
<td></td>
<td>• Lack of pre-primary schools</td>
</tr>
</tbody>
</table>
| Parental Involvement and participation | • Post-special school-over age learners  
|  | • Future aspirations  
| Parents-school communication | • Check learner-progress  
|  | • Parents’ meetings  
|  | • School/functions/excursions/sports  

### 4.3.1 Parental comprehension of autism (ASD)

Parental understanding and knowledge of autism is essential for effective management and better coping.

Even though autism is so rampant, most parents seem to be hearing about it for the first time when their child is diagnosed. Autism Speaks (2011) points out that globally there has been an alarming increase in autism diagnosis, and it concedes that autism is still the number one diagnosed neurodevelopmental disorder. However, all the nine mothers who were participants in this study indicated that they knew nothing about autism before their children were diagnosed. Although it has been more than 30 years since autism was first diagnosed in South Africa (Autism Speaks, 2011), there is still a lack of information and awareness of this disorder in the society and among family members.

One may attribute parents’ lack of knowledge and information to their socio-economic background and their level of education. Eight parents were from townships around Pietermaritzburg, and from these eight, one mother indicated that she was originally from uMsinga, she relocated to Pietermaritzburg to be near the special school. Most of these mothers were young, first-time mothers, unemployed and poverty-stricken single parents. Even an experienced parent is never ready to raise a disabled child; sometimes the experience is too much to cope with.

### 4.3.1.1 Emotional and psychological effect on parents
More frequently parents with autistic children convey feelings of despair and sorrow related to their child’s ASD (Dzubay, 2011; Pottie & Ingram, 2008; Balfour, 2007). Literature in this area attribute their demanding role as a primary caregiver responsible for child’s basic needs, psychological effects take a toll on them. Parental role prove to be extremely overwhelming for some parents and they barely cope with the ever growing demands. Mothers are known to experience pronounced psychological distress which is related to raising an autistic child (Davis & Carter 2008 in Pottie & Ingrams; Dawson, 2011, Dzubay, 2011; Balfour, 2007). A mother is compelled to take a journey that is unknown to many. Most of the mothers shared feelings of fear, frustration, helplessness and inadequacy. Mother G revealed that “sometimes you are unfairly judged by others” when the child acts strangely; they think you are failing to discipline the child.” Mother D commented that “you get tired explaining your child’s condition to everyone all the time.” In order to survive this ordeal parents are forced to learn as much as they can, to be able to deal with and support their autistic child. Davis and Carter (2008) specify that parents differ in their capacity to manage and respond to problems related to their child’s autism. Lack of knowledge is not an excuse: a mother and carer should seek much needed information to deal with the needs of the autistic child. Most mothers found it difficult to communicate, and discipline and correct the unwanted behaviour. This resulted in parents viewing themselves as failures as they felt unable to meet the demands of raising the child. Their hope and sense of relief emerged when they were informed that there was a “special school” that could cater for their educational needs. These mothers mentioned that they found hospitals, health professionals and preschool teachers to be helpful sources of information with regard to appropriate schooling of their children.

4.3.2 Special school placement

All the children that were represented by their mothers are attending three public special schools for intellectually impaired learners. The three special schools have autism classes that accommodate autistic learners. Most of the mothers shared that after the application for admission was submitted, the assessment and placement process did not take long before their children were officially admitted. Five mothers related how pleasantly surprised they were when they found out that getting a proper school was easier than
they had expected. They were now eagerly waiting, not knowing what to expect in this special school journey. These five mothers shared being over-excited and relieved about special school placement, but the other four indicated some fear of being stigmatized. Mother D said: “I was really afraid of the stigma associated with that special school, but ... mm ... I had nowhere else to go.” Mother F said she did not care what neighbours would say behind her back about her child being at a special school. It was clear that half the parents were happy about the placement, and others were not so happy thinking about the stigma associated with special schools in and around black communities.

### 4.3.2.1 Parents’ expectations

A majority of parents planned their child’s education based on their own experiences and informal networks for parents (Hadjiyiannakou et al., 2007); yet according to Delmolino and Harris (2012), some parents are having unrealistic expectations from their special needs children. They go further indicating that the most important goal of teaching children with autism or children with special needs is personal independence and mastering self-help skills. Special schools for the intellectually impaired focus on providing basic life skills, the so called “self-help skills”, so that the learners are not entirely dependent on others for their daily basic functioning.

Generally parents expect good quality teaching, the happiness and satisfaction of the parents from knowing their children are understood, taken good care of, receive fair discipline and are gaining improvement in basic self-help skills (Hadjiyiannakou et al., 2007).

Seven mothers who participated in the study were so appreciative and applauding of the schools’ work in educating their children. They mentioned many improvements that they have observed in their children since being at the school. These parents commented mostly on their improved social behaviour, responding when their names are called, taking instructions, and language development. This is in contrast with two parents’ negative views on their children’s progress. They were extremely unhappy and dissatisfied with it. Mother A angrily said “My daughter has been here for almost two
years, but she is still not toilet trained; it’s like the school is doing nothing, and I’m the only one trying to train her.” Mother B indicated that her child could not even write a single word. It was apparent that parents have varied and sometimes unrealistic expectations about their children’s progress. Delmolino and Harris (2012) once stated that the level of imbalance among learners means that having an “autism” classroom in a school building may meet the needs of some learners with ASD, but it is a challenge and close to impossible to meet the needs of all. In this case, it was apparent that it was difficult to meet the expectations of all parents; because of the different and unique profiles of children with autism.

The school sometimes fail to cope and meet the expectation and wishes of every single parent; however, parents should be seen as partners and be included to assist the teacher comprehend the child better, because parents know their child best.

**4.3.2.2 Lack of resources**

Experts’ services are what every parent is hoping for, for special needs children. The learning and teaching process depends on the provision of adequate resources. Therapists’ intervention is the core programme for autistic learners (Ngara, 2014).

Almost the majority of children with autism spectrum disorder get intervention from occupational and speech and language therapists. It is only proper that a school that accommodates autistic children should also have professional experts to look after their educational needs. Six parents indicated that their children from time to time need consultation with the occupational therapists, speech and language therapists and sometimes with the physiotherapist. Parents went further, highlighting that if the school was well resourced there would be no need to join long queues at public health care centres/public hospitals for such services. These become a bitter experience for both the child and parent. Parent E explained that it is extremely hard on her finances as she is a student herself, so regularly taking a child to hospital is financially demanding. The expense was also suffered by another five mothers who are not employed, but depend on the child’s care dependency grant for survival. Among the three special schools represented in this study, there is no school with a full complement of required therapists.
4.3.2.3 Educator suitability

It is an undeniable fact that expert skills are required to work with autistic children, and that these specialist should be found in any of the three types of school that are operational in the South African education system (Breakey, 2006:119). The unique and strange presentation of autism needs skilled teachers with relevant expertise (Delmolino & Harris, 2012:1200). The staff should undergo in-service training and upgrade their qualifications to be effective in their teaching continuum. A report by the National Autistic Society discovered that only 25% of special schools considered that their teachers are not appropriately trained in working with autistic children. Ngara’s study (2014) contradicts this by stating that a majority of teachers are inefficient in working with autistic children. Ultimately both showing that there is an alarmingly high number of inadequately trained teachers.

Parents who were part of this study were not sure about the educators’ qualifications and whether they had the necessary training; but many of the parents were happy about their child’s educator. They commented that they are satisfied with the job they’re doing, and they (the educators) are so understanding, caring and loving towards their children. Mother I expressed this sentiment by saying "I don’t care and don’t know about her qualification or training, but I know she understands my son’s condition and is doing her best; she shows much love and care for my son."

4.3.2.4 School transport

The KwaZulu-Natal Department of Education has made a profound contribution to promote accessibility of special schools within the province by providing school buses. Almost every special school in the province has been allocated a number of buses to assist in fetching and delivery of learners. Six parents indicated that unlike other children, their children do not enjoy the privilege of commuting in a school bus. The reasons given included the long distance that the learners were required to walk to a bus stop; other parents were concerned that their child might get lost.

4.3.3 Parental challenges and concerns
Parents with autistic children has been living a life filled with misery and challenges. They were never warned or given lessons on how to raise a child with autism. Their role as parents should be fulfilling, but on the contrary, their role as parents is a source of stress and emotional turmoil. (Bashir, Bashir, Lone, & Ahmad, 2014).

Parents end up losing their self-confidence and developing poor self-image because they view themselves negatively, they think of themselves as failures as they struggle to understand their own children. Many studies documented the parents are sometimes judged by other parents and even their own family members (Dawson, 2007). Because of lack of knowledge about autism, people always regard them as being ill-disciplined, and parents are scorned for failing to discipline and control their child. Most parents agreed that they are victims of social stigma and discrimination.

Autistic children have communication problem, previous studies indicated that most mothers revealed that their child’s lack of communication is a source of great pain and frustration. The child cannot communicate her needs or share thoughts or feelings. What make the situation worse is the lack of support and understanding from the school, family and the community at large (Prince, 2007 in Bashir et.al, 2014).

Most mothers that participated in this study indicated that at times they feel overwhelmed with responsibilities, and find it difficult to cope; they feel neglected as if nobody cares. Two mothers suggested that perhaps support groups would help alleviate the stress, and would be able to support each other.

4.3.3.1 Lack of pre-primary education for autistic children

The early years of life are crucial. “Although individual children develop at their own pace, all children progress through an identifiable sequence of physical, cognitive and emotional growth and change” (World Bank, 2009:1, in Enock, 2011:9). The most important goal of early childhood development (ECD) is to improve young children’s ability to develop and learn. Sadly enough most children with autism are denied the opportunity to learn, play with friends and develop holly as a child (UNICEF, 2009:1, in Enock, 2011:9). The importance of preschool education in a child’s life cannot be overemphasized.
Most parents in this study were aggrieved by the fact that they could not find appropriate preschool education for their autistic children. Children were deprived of an early effective intervention in their educational life. Mothers reported that most pre-primary schools did not admit their autistic children. Two mothers indicated that their children were turned away from preschools after two months of admission because they were disruptive, and the staff could not manage them. Almost all their children commenced schooling between the ages of six and eight years.

4.3.3.2 Future provision for adult autistic learners

During the interviews most mothers shared their fear and concern about the future of their autistic children. Mother F said there were no options available for autistic adults. Another parent suggested that they were kept at school for longer than the official cut-off age of 18. You could tell that the post-school issue was the main concern for most parents. Mother H was so emotional when she said “At times I can hardly fall asleep when thinking about the future of my son, especially when I’m no longer around.” Talking about the unknown future of autistic children was the most sensitive and emotional topic for most parents. What made it more difficult was the fact that most autistic learners cannot be candidates for a protective workshop or any attempt at employment. In such instances parents need to accept what they cannot change; having hope and faith in the future is the only way to cope and stay sane.

4.3.4 Parental Involvement

Parents are core partners with other education stakeholders in the education of their children. Parents have a duty and a responsibility to be part of the education in the school the child attends. In some instances parents’ preferences and decisions prevail.

Parental involvement which is positive in the education process cannot be overestimated. The studies by Blok et al., (2007) and McDonald (2014) state that families and carers need to be recognized and regularly consulted regarding the child’s strengths, weaknesses and learning styles, and need to be given with chances to be recognized as partners in structuring and providing interventions and other educational programmes (McDonald, 2014:4).
The Kansas State Department of Education – Special Education Services (2013) has stated that family members are given the prestigious status as a valued member of collaborative educational team, and thus they have a voice in the evaluation of instructional strategies.

The involvement of parents in children’s education creates school-family partnerships. Epstein (1992), Mafa and Makuba (2013), define education partnership as a bond that strengthen the family-school partnership which recognize, respect and support each other in the children’s learning process. The partnership promotes equality, shared responsibility, mutual respect enhanced. There is no room for blame game for poor academic results, and doing away with us-them mentality (Mafa & Makuba, 2013).

Sharifah et al. (2001), in Mafa and Makuba (2013) Collaboration promotes unity and harmony. Where everyone is working industriously towards achieving the common goal.

A majority of parents in this study highlighted that they took part in the education of their children, but they were not sure whether their participation was enough. There were three subthemes that dominated strongly. These are presented below.

**Parents – school communication procedure**

Parents indicated that there is a standard school communication policy that is in place, and is so far very effective. Since most of their children have no speech or very limited expressive language, the school uses a communication book. This communication book is used mainly by the class educator when reporting anything to a parent, for example, a child’s lost item or the child appeared sick. The parent also reports all their queries and concerns regarding the child. Teachers that are willing to listen and take concerns seriously are highly valued by parents (Renty & Roeyes, 2006). The importance of consistent and reliable communication with teachers was highly recommended by parents, especially because their children may not be able to talk about the school day, or verbally pass on a message as requested.
**Monitoring their children’s progress:**

All mothers mentioned being invited by the school to view their child’s schoolwork. This one-to-one discussion was viewed by all participants as effective and meaningful; it also enhanced understanding of other school programmes, and sorted out any misunderstandings.

**Invitations to school functions/excursions:**

Those who took part pointed out that schools had a mechanism whereby parents are invited to school functions or celebrations. Such events give a platform for our children to showcase how much they have learned, even small achievements, like the ability to wait for your turn; to come on stage with your class to recite a poem or a song. Parents come to understand and appreciate the commitment and hard work done by educators. Most mothers also shared that they are allowed to volunteer their services to accompany the learners on school educational outings. Mother C commented that “it shows that they trust us as parents, and are confident that we know our children better than anyone.”

**Parents meeting:**

This is one area that was regularly shared by participants as a forum to share their views and concerns by being under the same roof with all other parents that understand the situation and difficulties they encounter raising their autistic children. Mothers made it clear that they enjoyed attending school meetings; even though it was not a social gathering, but most of them shared similar experiences, thoughts and concerns. They also felt they were part of the making of decisions that related to the education of children.

Family-school partnership leads to more effective intervention implementation. Working together with parents constitutes a “best practice”. Common ground found; maintained and celebrated (National Research Council, 2001).

**4.4 Summary**

This chapter provided an analysis of data in exploring and investigating parents’ views with regard to their children’s education in special schools. There was an indication that educational experiences and views of parents of autistic children in special schools has
been poorly and under researched. It appeared that the issues of lack of pre-primary education for autistic children, the stigma related to special school placement, and the transport problem have never been investigated and addressed.

The research findings indicated that parents of autistic children lack in-depth knowledge and comprehension of autism and options available to them. Compounded by the lack of support, this resulted in emotional and psychological distress.

From one of the themes, “special school placement”, it was apparent that most parents were about placement, but had to deal with the stigma associated with it. Most mothers indicated that their expectations of special needs services were met except for only a few concerns, including the lack of therapists and transport. Findings with regard to parental challenges and concerns included lack of support, lack of pre-primary education for autistic children, and the protective workshop, which was viewed as not appropriate for their children. Research findings and conclusion will be addressed in the next chapter.
CHAPTER 5
Research findings and conclusion

5.1 Introduction

This section of work deals with the discussion of the study findings and the suggestions made on the possible implications of the study results. This research carried out investigation to shed light on experiences of parents with autistic children in special schools.

5.2 Discussion of findings (summary)

This study sought to examine and elicit the journey and views of parents of autistic learners in special schools. Through data collection parents had the opportunity to voice their views and concerns regarding the schooling of their autistic children. The researcher was interested in getting parents’ perspective; their experiences, ideas, views, needs and expectations about the schooling of their autistic children. The researcher wanted to know if parents were satisfied with the current education that is available for their autistic, voiceless children.

The study sought to get the answers to the research questions below:

5.2.1 How do parents view and experience the education of their autistic children in special schools?

From the interaction with nine parents of autistic children it was apparent that their knowledge of special needs education was very limited. Most of the parents had admitted that they initially knew nothing about ASD before their children were diagnosed. This is consistent with most literature where parents indicate that they heard of autism for the first time when their child was diagnosed. Barely above half of the parents had heard about “special school”, but their knowledge and understanding of it seemed not to have improved much even after their child’s admission to such a school. This was proved when
parents were asked to suggest any school programmes/activities that they would like to be introduced as part of school curriculum, to benefit their children. Parents were not able to contribute meaningfully to enhance the current standard and quality of special education. It became apparent that parents lack understanding and sound knowledge with regard to “autism” and “special needs education”.

Of nine parents, seven parents were satisfied about the education of their children. They went further, pinpointing minor improvements and achievements they were noticing in their children. They reported improved independence in self-help skills and the ability to follow instructions. Parents were extremely pleased with educators’ dedication to their work and the way they loved and cared for their children. This is in contradiction with the results of preceding studies by Balfour (2007) and Dawson (2011), where majority of the parents were not pleased with the education of their little ones.

5.2.2 What concerns and challenges do parents encounter with regard to placement of their children in special schools?

The parents that were informants in the current research indicated that they lack support to deal with all the emotional hardships as a result of having a child with autism. They lack support as well as more relevant information from the school, professionals and community. This is consistent with findings from previous studies: Dzubay (2011), Gray (2006), Pottie and Ingram (2008), where parents experienced feeling neglected, discriminated against and being judged by other parents.

Parents’ emotional and psychological distress: Stigma and labelling

Parents, especially mothers with autistic children face many challenges. These caregivers shared that while they were happy that finally their child had found an appropriate school; they also had to bear the stigma associated with “special school placement” and labelling of the child as being “crazy”. The literature in related studies states that the parents of these autism diagnosed children tend to suffer severe strain as well as psychological distress as a result of the daily challenges they are required to cope with. In a study by Benson & Karlof (2009) they found that a third of the mums stated feeling a high level of anxiety and depression as a result of their child’s ASD, and a sixth of the dads stated
similar feelings. The discrepancy may be due to the fact that the mums are the ones who are directly involved and almost always there as a primary care-giver child. Mother’s role in child raising and caring cannot be the same as father’s role.

**Lack of resources in special schools.**

This is one of the findings that was revealed during this study. Most educational programmes for autistic learners require the intervention of occupational therapists as well as speech and language therapists; parents were specific in pointing out the lack of therapists in schools. Parents are forced to travel long distances to health care centres for services that should be provided by the school.

**Lack of pre-primary education for autistic children.**

Most parents in this study related how they struggled to find a crèche or any pre-primary institution without any success. One parent shared that her son was turned away after two weeks as teachers felt the child was disruptive and uncontrollable. Dzubay (2011) also alleges that finding a child carer for a little one diagnosed with ASD can be a strenuous quest. , almost all children with autism have strange unpredictable behaviour and no one seem to want to come closer to your child. Finding a good nanny for keeps is an unachievable mission (Stillman, 2005, cited by Dzubay, 2011). Childcare centres / private institutions are mostly independent institutions; unlike government institutions, they have no obligation to admit every child. Parents struggle to find pre-primary schooling for their young children as normal schools only consider them when they are seven years old and above.

**Lack of options for overage children with ASD.**

Mothers were deeply concerned that once their children reach a certain age, which is 18 and above; their children are not catered for. Normally special schools have protective workshops that serve as skills development centres for older students. Most parents felt these facilities were not appropriate for their autistic children. The scope of work and workshop demands might be beyond their level of cognitive functioning. This was a very sensitive issue for most parents as they shared their fears and concerns about the future of their autistic children. Balfour’s (2007) study had similar findings, where parents
expressed hopelessness and fear about the future of their ASD children, especially in South Africa. Other studies conducted internationally, in the USA, Ireland, Australia and New Zealand, show that the needs of older ASD people are well catered for. Participants in this current study suggested that their children be kept at school even longer than the cut-off standard age of 18.

Transport problem: Four of the nine mothers raised a concern about the operational manner of the school buses. In KwaZulu-Natal, the Department of Education has been able to provide schools with transport. In some areas where learners travel long distances to school, the Department made necessary resources available by purchasing buses or bicycles for such schools. Fortunately for special schools, they are all provided with school buses. However, parents feel that their children are still required to walk long distances to designated bus-stops instead of enjoying the privilege of using a school bus, they are compelled to find alternative private transport.

5.2.3 How can the Department of Education and special schools meet the educational needs of autistic children?

The last research question can be regarded as part of the recommendations for this study; it can also be viewed as the implication of the study findings. The response to this research question will be found under Recommendations.

5.3 Recommendations

- Schools are encouraged to provide appropriate support and relevant information so that parents are knowledgeable and informed about what their children are learning so that there is continuity of learning even at home by parents. Parents’ training on ASD is highly recommended so that they are able to confidently provide support to their children.

- Schools should also serve as a primary source of information for parents. This can be achieved by implementing parent-training to enhance their knowledge and
comprehension of autism and the special school curriculum. Children can also learn at home from their parents.

- Parents should participate and involve themselves with relevant organisations, like Autism South Africa, and Action in Autism, where they are positioned for empowerment and the much needed support of group membership.

- Special Schools in collaboration with School Governing Bodies can take an active role in the formation and coordination of parents’ support groups.

- In South Africa, more especially in KwaZulu-Natal where this study was conducted, the Department of Education should equip special schools with necessary resources, especially the therapists, so that the teaching and learning of autistic children is more effective and of maximum quality.

- There is a need to increase community awareness and knowledge about autism to deal with ignorance and reduce stigma and labelling of autistic children as “crazy”. Special schools, working in partnership with NGOs and community-based organizations, should educate the society about autism and fight discrimination against autistic individuals and their families.

- The Department of Education should authorize existing special schools to open their doors to pre-primary classes for early education intervention, targeting marginalized children with the variety of special needs.

- It is recommended that special schools, together with SGBs, review the policy with regard to appropriate age for school-leaving, considering there is currently no suitable facility for overage autistic learners.
To establish an in-house body to address and manage all parents’ concerns, including the transport problem. The school community, led by the school management and SGB, should be able to reach an amicable solution.

5.4 Limitations of the study

The limitation concerns the size of the sample. The sample size was small and had limited scope since the sample was drawn only from around Pietermaritzburg, from one district. If the scope had been wider, including all the districts, especially those in deep rural areas; the findings might have been different, and of great value..

Participants were more homogeneous in the sense that they were from the same vicinity, most had a similar socio-economic background, in that most were single parents and unemployed. It is likely that their experiences were more or less the same.

All the participants were seen and had interview only once; with an average time of 1 hour 30 minutes per interview. A follow-up interview might have strengthened the gathered data.

5.5 Avenues for future research

It is critical that we continue to examine parents’ experiences, views, needs and concerns about the education of their children with special needs in special schools. A study with deep rural participants deserves to be pursued, a similar study using a larger heterogeneous sample; a wider scope and applying a mixed method approach.

This study provided insight into parents’ views and experiences; a further study is warranted into educators’ views and experiences in the education of autistic children in a special school setting.
In this study most mothers were single parents, young and unemployed. The marital status of parents together with their socio-economic background in South Africa should be included and distinctly reviewed. The young, unemployed single-parents with low education could be more vulnerable and may need additional intense support in the case the child is diagnosed with ASD. In other words, future research should investigate the impact of socio-cultural factors, such as poverty, unemployment and lack of education or illiteracy among parents with autistic children.

5.6 Conclusion

This study was able to illuminate parents’ wishes and views in respect to the schooling of their autistic children. Accessing parents’ views and concerns may help improve the provision of special needs education; the Department of Education may review some of the policies in response to parental dissatisfaction. The mothers who volunteered to be part of this study were given the chance and a platform to share their experiences, opinions, and express their needs and concerns. The study findings contradict prior studies that indicated that parents of children with autism were displeased about education provision for their child’s education. This study found that most parents are happy with the education of their autistic child, even though there are concerns that need to be addressed.

This investigation has successfully attained its goal. It has examined and documented the educational experiences of parents with autistic children in special schools. The study findings and recommendations will greatly benefit special schools when they are interacting with parents, and a valuable source of reference for Department of Education.
REFERENCES


UNESCO. (1994). *The Salamanca statement and framework for action on special needs education: world’s conference on special needs education access and quality*. Salamanca: UNESCO.


Appendix A: ETHICAL CLEARANCE CERTIFICATE

![UNIVERSITY OF ZULULAND RESEARCH ETHICS COMMITTEE](image)

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<th>Certificate Number</th>
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<tr>
<td>Principal Researcher/Investigator</td>
<td>LC Mngadi</td>
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<tr>
<td>Supervisor and Co-supervisor</td>
<td>Prof MM Hlongwane</td>
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<td>Department</td>
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The University of Zululand's Research Ethics Committee (UZREC) hereby gives ethical approval in respect of the undertakings contained in the above-mentioned project proposal and the documents listed on page 2 of this Certificate.

Special conditions:
1. This certificate is valid for 2 years from the date of issue.
2. Principal researcher must provide an annual report to the UZREC in the prescribed format [due date: 31 October 2017]
3. Principal researcher must submit a report at the end of project in respect of ethical compliance.

The Researcher may therefore commence with the research as from the date of this Certificate, using the reference number indicated above, but may not conduct any data collection using research instruments that are yet to be approved.

Please note that the UZREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the documents that were presented to the UZREC
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

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LC Mngadi - PGM 2016/337
Classification:

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Low Risk | Medium Risk | High Risk

X

The table below indicates which documents the UZREC considered in granting this Certificate and which documents, if any, still require ethical clearance. (Please note that this is not a closed list and should new instruments be developed, these would require approval.)

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The UZREC retains the right to

- Withdraw or amend this Certificate if
  - Any unethical principles or practices are revealed or suspected
  - Relevant information has been withheld or misrepresented
  - Regulatory changes of whatsoever nature so require
  - The conditions contained in this Certificate have not been adhered to

- Request access to any information or data at any time during the course or after completion of the project

The UZREC wishes the researcher well in conducting the research

[Signature]

Professor Gideon De Wet
Chairperson: University Research Ethics Committee
Deputy Vice-Chancellor: Research & Innovation
12 December 2016

LC Mingadi - PGM 2016/337

Page 2 of 2
Appendix B: PERMISSION TO CONDUCT RESEARCH

PROVINCE OF KWAZULU-NATAL

Enquiries: Prinile Duma
Tel: 033 392 1004
Ref: 24/8911

Ms LC Mgadi
PO Box 1995
Pietermaritzburg
3200

Dear Ms Mgadi

PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS

Your application to conduct research entitled: “EDUCATIONAL EXPERIENCES OF PARENTS WITH AUTISTIC CHILDREN IN SPECIAL SCHOOLS”, in the KwaZulu-Natal Department of Education institutions has been approved. The conditions of the approval are as follows:

1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 25 August 2016 to 26 March 2018.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department.
8. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
9. Should you wish to extend the period of your survey at the school(s), please contact Miss Connie Kehologile at the contact numbers below
10. Upon completion of the research, a brief summary of the findings, recommendations or a full report / dissertation / thesis must be submitted to the research office of the Department. Please address it to The Office of the HOD, Private Bag X137, Pietermaritzburg, 3200.

Please see list of Schools attached

Adv. MB Mtshuku
Acting Head of Department: Education
Date: 26 September 2016
APPENDIX C: SEMI-STRUCTURED INTERVIEW SCHEDULE

1. How much did you know about autism when your child was first diagnosed?
   - What were red flags, glaring indicators that s/he was different? What is his birth position/order? How old was he when he was diagnosed?

1. Can you tell me your experiences and challenges of finding the school for him? Did he attend any crèche or pre-primary school?
   What can you say about application, assessment, admission /placement procedure?
   What was challenging the most during this time?

2. How much did you know about special schools?
   - Who/ what was your source of information?
   - What would you consider helpful during this journey?

3. How would you describe your involvement in your child’s education? How is your interaction/relationship with the class teacher/school?
   For how long has the child been to this school? Any other school before this one?
   - How did you experience your child’s previous school? How do you think your child experiences/feels about school now?
   - What would you say about the school’s contribution to your child’s life?
   - Are his educational needs met?
   - What aspects/programmes would you like the school to provide?
   - Why would you encourage other parents to send their autistic children to special-needs school? Why not?
   - How does s/he get to and from school? What would you say about the school fees?
   - What do you like most about his school?
   - What do you like least about the school?
   - What are your worst fears about your child at the school? Any concerns?

4. What are/were your expectations of the school?
5. What changes/improvements would you like to see being implemented?
6. What makes a good teacher for autistic children?

Appendix D: DEMOGRAPHIC QUESTIONNAIRE

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Appendix E: REQUESTING PERMISSION FROM PRINCIPALS OF SCHOOLS

P.O. BOX 1995
PIETERMARITZBURG
3200

The Principal

_________________________________________ Special School

Dear Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am a Master’s student at the University of Zululand in the Department of Educational Psychology and Special Education. I am also an employee of the Education Department at UMgungundlovu District. I am doing the research project and the research focuses on parents' educational experiences with regard to special schooling of their autistic children. Valuable information can be obtained from the parents’ perspective if they share their opinions and experiences.

I therefore request the school’s permission and assistance in recruiting few parents (less than 10) by distributing participant invitation after addressing them after a parents meeting. An information sheet explaining the details of the research and their participation will be handed out to parents. Only those who volunteer to be participants will be required to fill in the consent form. The findings of this study will benefit and assist the Department of Education and add value to the existing body of knowledge on autism.

Your assistance in this regard will be highly appreciated. Should you have any queries, I can be contacted at 078 166 7189. My email address is: lungile.mngadi@kzndoe.gov.za

Yours sincerely

__________________________________

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Dear Parent,

I am Lungile Mngadi, studying towards a Master’s degree at the University of Zululand. I am working under the supervision of Prof. P.T. Sibaya on the research project that explores the educational experiences of parents with autistic children attending in special schools, and also reviewing the role of the special school. Your participation in this study would be much appreciated.

If you decide to volunteer and participate, you will take part in an individual interview where you will be asked questions in relation to your child’s schooling experience. Interviews can be conducted at your child’s school or another place of convenience. All the information shared will be kept strictly confidential. With your permission, an audio-recorder will be used to ensure accuracy and reliability of information. You will not be required to reveal any personal information and will remain completely anonymous, as pseudo-names will be used. Access to the audio recordings will be restricted only to me and the supervisor. The interview will be conducted at a time that is convenient to you; it will take approximately 45 minutes. The interview will be conducted either in English or IsiZulu; you will decide which language you prefer.

It is possible that your participation may make you feel emotional when sharing potentially sensitive and personal information. If so, you will be provided access to free counselling. Alternatively, you may also find this opportunity helpful in telling your story in a safe and conducive environment.

Your participation in this project is completely voluntary, should you wish to withdraw from the project at any stage you are free to do so without fear of any negative consequences. You may also refuse to answer any question you would prefer not to. However, your contribution in sharing your child’s schooling experience will be of great help in adding new insights to the body of knowledge and in designing intervention programmes that enhance the education of autistic children.

If you have any questions or concerns about the study, you can contact the researcher at 078 166 7189 (Lungile Mngadi) or the Supervisor- Prof. PT Sibaya at 035 902 6628.

If you decide to participate, kindly fill in the attached consent form.

Kind regards

Lungile Mngadi
APPENDIX G: PARTICIPANT INFORMED CONSENT

Project Title: Educational experiences of Parents with Autistic Children in Special Schools

Lungile Mngadi from the Department of Educational Psychology and Special Education, University of Zululand, has requested my permission to participate in the above-mentioned project.

I ______________________________, agree to participate in the research project and consent being interviewed. The research details have been explained to me in a language that I understand.

I also understand:

- The nature and purpose of the research project
- That participation is voluntary
- I understand and agree to the use of tape-recording of the interview in which I am a willing participant
- That I may refuse to answer any question I would prefer not to
- That I may withdraw from the study at any time and no negative consequence will arise from that.
- No identifying information will be included in the research report and my responses will remain confidential
- My name and that of my child will be changed to protect our identity
- The transcripts of the interview will be published in the research report
- There are no ensured, direct benefits to participating in this study
- There are no known risks associated with this study, however, if line of questioning may make me feel emotional, in which case I will be provided with access to free counselling.

Participant Signature: ______________________________
Appendix H: (IsiZulu Version of Participant Informed Consent)

Ukuzibophezela kozobamba iqhaza ocwaningweni

Isihloko Socwaningo: Imibono yabazali mayelana nemfundu yabantwana babo abane-othizimu

Umncwaningi: Lungile Mngadi

Isikhungo Semfundo: University of Zululand- Department of Educational Psychology and Special Education

Lona obhalwe ngenhla wenze isicelo sokuba mina ngihlanganyele ocwaningweni alwenzayo ngesihloko esibhalwe ngenhla. Ukubeke kwacaca ukuthi angiphoqekile. Ngichazelekile ngenhlolo yalolucwango nangayo yonke imininingwane yokuzibandakanya kwami nalo lucwango.

Mina ________________________________ngiyaqonda ukuthi:

1. Ngizingenele ngokuthanda kwami kulolucwango, angiphoqekile nhlobo.
2. Uma ngingasathandi ukuqhubeka nalo ngizoyeka ngaphandle kokujeziswa yokusolwa.
3. Ngiyavuma ukusetshenziswa kweni qo-mazwi ngesikhathi sixoxisana.
5. Kodwa ngiyobuyiselwa izindleko zami uma ngisebenzise imali yami nalo lucwango
6. Akukho mininingwane eqondene nami kumbe nomntwana wami ezodaluleka.
Appendix I: REQUESTING HoD FOR PERMISSION TO ACCESS SPECIAL SCHOOLS

P.O. Box 1995
Pietermaritzburg
3200

06 May 2016

The HoD
Department of Education (KZN)
PIETERMARITZBURG

Dear Sir

Request for Permission to Conduct Research in Special Schools

I am a registered Master’s student in the Department of Educational Psychology and Special Education at the University of Zululand. I am being supervised by Prof. P.T Sibaya. The proposed research title is: **Educational Experiences of Parents with Autistic Children in Special Schools at UMgungundlovu District.**

At present I am permanently employed by the Department of Education as an Education Specialist at UMgungundlovu District. For the success of this study, I need your permission to access parents of autistic learners through special schools.
I hope the findings of this study will contribute immensely to the existing body of knowledge in autism and improve special schools resources.

Granting me the permission to conduct this study will be greatly appreciated.

Yours faithfully

Lungile Mngadi