EDUCATING CHILDREN PRESENTING WITH AUTISTIC SPECTRUM DISORDER: EXPLORING PARENTS' EXPERIENCES

By

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DECLARATION

I hereby declare that “Educating children presenting with autistic spectrum disorder: exploring parents' experiences” is my own original work. All sources used or quoted have been indicated and acknowledged by means of complete references using the APA 5th style of referencing, and that I did not previously submit this dissertation for a degree at another university.

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SIGNED

DATE:

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“Cherish the children marching to the beat of their own music. They play the most beautiful heart songs.” Fiona Goldsworthy

ABSTRACT

According to Pienaar and Raymond (2013, p.10) learners with disabilities have historically experienced the most serious exclusion from learning. The worldwide call for inclusive education prompted South Africa to develop the White Paper 6 (WP6) (2001, p.18) which clearly states that for Inclusive Education to be successfully implemented in South Africa, there has to be an acknowledgement that all children and youth can learn. The implementation of WP6 therefore not only benefits learners with special educational needs, but all South African learners by implementing "a more flexible system of education that focuses on removing barriers to learning and creating learning-friendly environments" (Pienaar and Raymond, 2013, pp. 10-11). However, a great disparity exists in what is proposed in official documents such as WP6 and what parents of children with barriers to learning actually experience within schools.

This phenomenological study employed memory work, drawings and focus group discussions with four purposively selected parents to explore parents' experiences of the education of their children who are on the Autistic Spectrum. Bronfenbrenner's Eco-systemic perspective was used to make meaning of the data. The findings show that parents find the education of their autistic children as a stressful and isolating experience because of an unprepared education system. Despite the challenges, the participants also find their experiences to be a journey of personal growth and fulfilment. The study therefore recommends that schools should engage parents of autistic children more actively in order to make inclusion of such children effective. Teachers who are expected to practice inclusivity in schools should be adequately prepared to work with children presenting with ASD through a collaborative effort of the Department of Health and the Department of Education.

LIST OF ACRONYMS

ASD - Autistic Spectrum Disorder

WP6- White Paper 6

DoE - Department of Education

LSEN - Learners with Special Educational Needs

SEN - Special Educational Needs

NCSNET - National Commission on Special Needs in Education and Training

NCESS - National Committee for Education Support Services

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CHAPTER ONE

INTRODUCING THE STUDY

1.1 INTRODUCTION

As early as 1994, during the Salamanca Conference held in Spain, 29 countries including South Africa, and 25 international organisations committed themselves to inclusive education. They concluded that all children have a right to education and that schools had to include them regardless of the diversity of their educational needs. Although the Salamanca Statement states that inclusion is a right, and that inclusive education in mainstream schools is the most efficient way of achieving education for all (UNESCO, 1994); inclusive education, however, requires an investment in human resources, such as training of teachers, educational psychologists and other professionals in order to uphold an inclusive policy (Pienaar & Raymond, 2013).

The South African Constitution (South Africa, Act 108 of 1996) guarantees advancement of human rights for all citizens and this includes learners with special educational needs. In October of 1996, the National Commission on Special Needs in Education and Training and the National Committee on Education Support Services was established according to White Paper 6 (WP6) (Department of Education (DoE), 2001). These committees investigated and made recommendations on all aspects of special needs and support services in education and training in South Africa. This joint report was presented to the Minister of Education in November 1997. The report recommended that "education and training should promote education for all and foster the development of inclusive and support centres, of learning that would enable all learners to participate actively in the education process so that they could develop and extend their potential and participate as equal members of society" (Department of Education, 2001, p. 5)

According to Links (2009) children with special needs were initially regarded as being a disgrace to the family and were therefore often kept at home. This resulted in a Special Education System emerging for these learners. DoE (2001, p. 9) strongly asserts that it is within the special needs sector that the ravages of apartheid can most clearly be seen. Not only were learners segregated according to race but also according to disability. Schools which catered for learners with disabilities had extremely rigid categories which denied them access to education. Simjee (2010) states that it is estimated that 135 000 autistic children in South Africa are not getting the specialised education that they need. She explains further that there are currently only nine schools in South Africa which cater specifically for children on the autistic spectrum. According to statistics supplied by Autism Eastern Cape (2013) the prevalence of autism in children is currently at 1:88. Although this figure has been reported by the Centre for Disease Control (CDC) which is based in Atlanta, America, the NGO Autism South Africa has endorsed this figure stating that the situation is thought to be similar in South Africa.

DoE (2001, p. 18) clearly states that in order for inclusive education to be successful, educators have to improve their skills and knowledge. It goes on to state further that staff development is be critical and that this should include ongoing assessment of educators' needs through developmental appraisal. The document points out that those teachers should be given assistance in meeting the varied needs of the individual learners in their classes.

Links (2009) states that inclusive education is a system that treats all learners as equal and believes that should be accessible to all learners irrespective of their specific barriers to learning. Therefore, Collins (2008, p. 3) asserts that any discussion in schools regarding inclusion should address several important questions:

- Do we value all children equally?
- What do we mean by "inclusion"?
- How do we get children to value inclusion and accept as equals, those children who are not as able physically or mentally as they themselves are?

Bearing this in mind, it is evident that inclusion in the mainstream classroom has many different aspects to be considered. According to Collins (2008, p. 3), a teacher who is to be successful within the inclusive classroom, needs to consider the fact that she will be working with children who display a wide range of "ability, gender, ethnicity, attainment or background" differences. All of these learners need to be given an equal opportunity to realise their full potential. However, as a parent of a child with special needs, I have not found a prevalence of these teachers who are willing to accept children with such a wide range of needs.

According to Friend and Bursuck (2009, p. 199) autism has been viewed both as an "emotional disability" as well as an "intellectual disability". More recently however, they state that autism has been viewed as a "unique disorder that occurs in many forms". These are referred to as *autism spectrum disorders* (ASD), which in turn clearly confers the diversity of its nature. This definition in itself explains that since ASD is a spectrum disorder there will always be great diversity in the abilities of persons falling within this diagnosis.

Currently there are varying opinions regarding the prevalence of individuals with ASD. According to Autism Speaks (2013) and TACA (2012), current statistics in the United States of America indicate that the ratio of children diagnosed with autism may be as many as 1:88. Quest School for Autistic Learners is currently the only state funded school in the Eastern Cape which deals specifically with learners on the Autism spectrum and can only accommodate 66 learners annually. The immediate problem presenting is, finding the correct schooling environment for learners who have been diagnosed with ASD but who could not be accommodated at Quest.

Engelbrecht and Green (2007) are of the opinion that the approach to the provision of education for learners with diverse educational needs has been undergoing significant change. They further point out that it was assumed at the time that anyone with any obvious disability would not benefit from the existing mainstream education. In fact it was felt their presence would be a distraction to learning taking place in the classroom. They further contend that this was due to the perception that people with disabilities were deserving of "pity, lacked independence and needed assistance". Their education was therefore based on the charity and kindness of others. It was due to this thinking that learners with special needs were excluded from mainstream education.

Teachers need to have guidelines which could assist in helping to make the ASD child’s inclusion into a mainstream class a less traumatic and ultimately more beneficial one. According to Links (2009) the teacher in every classroom, will encounter learners who experience barriers to learning and therefore needs to be adequately trained to deal with this diversity. Herbert (2011) maintains that it is easier to change a teacher's opinion about inclusion by giving them assistance in doing it, rather than trying to convince them to believe in the concept. In doing so, Herbert further contends that once the teacher experiences success in the inclusion of special needs children, through being shown how to do it, there will be a greater number of teachers who will be willing to believe in inclusion.

As a parent of an eleven year old child, who has been diagnosed as being on the Autistic spectrum, the lack of appropriate schooling for my child is a cause for great concern. For the first four years of formal schooling (Grade 0, R, 1 and 2), my son was in a private mainstream school and coped reasonably well. He did however have a tutor shadow him during his school day, whom we employed privately. The condition for his being at the school was that he had to have a tutor. This unfortunately became problematic for my son as he realised that he was different to his peers, due to the constant presence of his tutor. It was for this reason that we selected to place him in a private Montessori school where everybody works at their own pace. He no longer has a tutor and is making steady progress, although the possibility of a tutor can be revisited if recommended by the school. Of interest to me at this stage, is what other parents facing a similar situation, are having to do to meet the educational needs of their children who are on the autistic spectrum.

There is a definite need for research based on the unique circumstances in South Africa, particularly with regard to Special Needs Education.

1.2 PROBLEM STATEMENT

The White Paper on Special Needs Education (Department of Education, 2001), also referred to as WP6, clearly states that in order to build a fully Inclusive Education and Training System, there are a number of key issues needing to be addressed. Amongst these key issues is the need to address inadequate and inappropriate support services. However, within the WP6 there is no mention of ASD or the specific support needed by foundation phase teachers to ensure the successful inclusion of learners into the inclusive classroom. This significant gap in the information structure causes a major dilemma for educational institutions, with the result being parents of children with ASD not knowing where to turn for assistance. This leads me to the formulation of the problem statement for this research study which is as follows:

> *In spite of the publishing of WP6 in 2001, parents of children presenting with ASD experience difficulties in the placement and education of their children within the existing education system of South Africa.*

The key question of this study can thus be stated as follows:

What are the experiences of parents regarding the education of their children presenting with autistic spectrum disorders?

1.3 AIM OF THE STUDY

The main aim of this study is to explore the experiences of parents, regarding the education of their children presenting with autistic spectrum disorders in order to gain a clearer understanding of the possible inclusion of these children into the mainstream classroom.

1.4 RESEARCH DESIGN AND METHODOLOGY

This study plans to elicit information-rich data from its participants, explaining behaviour, beliefs and understanding of the context of people's experiences (Hennink et al., 2011), and therefore a qualitative approach is more appropriate and has thus been followed. This empirical study is expected to build on existing knowledge regarding the inclusion of learners on the autistic spectrum. Mertens (2010) further explains that this existing knowledge can be derived from written resources, as well as interaction with the community. The community in this case refers to parents of children with ASD and their experiences regarding the schooling of their children. Boeije (2010) in a similar manner states that participants play an active role in the construction of their social reality and the individual meanings they ascribe to it. In order to answer the research question posed for this study, phenomenology was employed as the methodology for this study, using memory work, drawings and focus group discussions as the methods of generating data with four purposively selected participants. All ethical protocol was followed during the study and the data generated was analysed thematically (see Chapter 3).

1.5 THEORETICAL FRAMEWORK

The ecosystemic perspective, pioneered by Professor Urie Bronfonbrenner, states that all humans are social beings, and this impacts on our "developing selves" (Knowles and Lander, 2011, p. 34). This is of great significance to the parent of a child with ASD and thus a suitable theory to understand how parents experience the education of their children presenting with ASD.

Bronfenbrenner's ecological environmental model explored the idea that the child does not live in isolation but rather that he is part of a family or community. This "family or community" is also referred to as a system. Within this system there exist sub-systems which all affect the child to a greater or lesser extent. According to Brendtro (2006, p. 163), one can only gain an understanding of a child once the interactions between the family, school, peer group and neighbourhood are thoroughly investigated. He further states that in order to gain an understanding of the personality of a child, one should not merely look at isolated characteristics and then label the child as a "problem" but rather that the child should be looked at holistically. By looking at the child holistically, all environmental factors are taken into consideration and evaluated. Brendtro (2006) further states that these spheres of influence impact one another and in an ideal situation should all work together to provide the child with a "positive support and instil solid values" (p. 163). Bronfonbrenner's framework therefore enables us to explore the inclusive education system as being about the development of systems e.g. parents' experiences of their children's education. This further lets us examine how inclusive education is both "constructed and constrained" by many different factors operating on different levels Singal (2006).

1.6 EXPLANATION OF CONCEPTS

The concepts used in this study can be understood from different perspectives and thus it is important for me to state how I understand and use the concepts in this exploration of parents' experiences of the education of their children presenting with ASD.

1.6.1 INCLUSIVE EDUCATION

Karten (2010) maintains that Inclusive Education refers to a situation where students who experience barriers to learning are incorporated into mainstream classrooms and every attempt is made to remove any barriers to the students' education. This sentiment is echoed by Raymond (2012) who emphasises the need for support services being integrated into the general education classroom. Breakey (2006) concurs and defines inclusion as devising or redesigning the learning environment to match the individual student's learning requirements. The student is therefore not expected to fit in but rather the environment should suit his unique needs. Inclusive education thinks beyond the needs of the learners with barriers to learning and insists that all students derive benefits from the constant presence of others, whose life challenges differ from theirs (Sylwester, 2010).

1.6.2 MAINSTREAMING

Raymond (2012) describes mainstreaming as being the temporal, physical, instructional, and/or social integration of children with disabilities with peers who are regarded as normal. In general, children with disabilities are mainstreamed into environments where their disabilities present few impediments and where the need for accommodation is minimal. When children with disabilities are mainstreamed it is generally accepted that any special education services are generally provided for outside of the mainstream classroom.

1.6.3 AUTISTIC SPECTRUM DISORDER - ASD

According to Kluth and Shouse (2009), the term ASD describes conditions which include Autism, Asperger's syndrome, and pervasive development disorder, not otherwise specified childhood disintegrative disorder, Rett's syndrome and Fragile X syndrome. Because individuals with autism display very different symptoms, characteristics and abilities, but also some core commonalities; Autism has been classified as being part of the spectrum.

1.7 CONCLUSION

In this chapter, I have introduced the study and placed it in context. The research question and problem statement have been clearly discussed and motivated. I have discussed the methodology, data collection and data analysis strategies of the study. Issues relating to trustworthiness and ethics have also been highlighted. The terminology used in the study has also been defined in order to clarify how I have used them.

1.8 PROPOSED DIVISION OF CHAPTERS

CHAPTER ONE

This chapter provides an introduction to the study; including the problem statement, research question, methods of producing data and analysis methods. It provides a glimpse into the methodology employed in the study, the ethical issues and trustworthiness.

CHAPTER TWO

This chapter presents a study of literature on special education and the education policy in South Africa. The policy guidelines for the handling of barriers to learning which might include ASD is discussed further. This chapter further explains and highlights the support being offered to teachers in South Africa regarding inclusive education, as well as the expectations placed on teachers in the inclusive classroom. Bronfonbrenner's eco-systemic model is presented as the theoretical framework to understand parents’ experiences of educating children who present with ASD.

CHAPTER THREE

This chapter presents the research design and methodology, and the method employed in this study in detail, including the data production methods, data analysis methods, ethical as well as trustworthiness issues.

CHAPTER FOUR

Results of the study are presented in this chapter.

CHAPTER FIVE

This chapter presents a discussion of the findings in relation to the relevant literature and Bronfenbrenner’s theory.

CHAPTER 6

Conclusions of the study and recommendations for further research are presented in this chapter.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter presented the purpose, rationale, focus and context for this study which explores the perceptions and experiences of parents who have children that are on the Autistic Spectrum (ASD) and who find themselves in the South African education system. I have opted to view this predominantly from the perspective of the parents since their view and experiences of inclusive education could provide pertinent information that may not have been previously considered by policy-makers. This would add great value to the study of inclusive education in South Africa.

Van Wyk and Lemmer (2009) have found that a consensus exists on what parents from any ethnic, educational and socio-economic background expect of their children’s education. Generally, parents want quality education, in a caring, well-run teaching and learning environment where they receive regular, reliable and pertinent information regarding their children's progress and achievements as well as any information concerning possible problems. This remains true for parents of children with ASD.

As discussed in Chapter one, a great disparity exists between proposals in official documents such as White Paper 6 (DoE, 2001) and the way parents of children with barriers to learning actually experience within the school system. An example of this can be seen in both the long and short-term goals outlined in DoE (2001, p. 45). These goals specifically note that pupils of a "diverse range of learning needs" must be accommodated and recognized in all government-run schools. WP6 also makes mention of "addressing the weaknesses and deficiencies of our current system and on expanding access and provision to those of compulsory school-going age who are not accommodated within the education and training system" (2001, p. 45). It is important to note that even though DoE (2001, p. 45) specifically denotes a time frame of twenty years in which to implement said changes, fourteen years have passed and to date, very little has been done to ensure the inclusion of learners with special educational needs into mainstream education.

In this chapter, I discuss the terms "*inclusive education*" and "*inclusion*" as well as the policies that guide this system. This is followed by a brief history of the global development of inclusive education, as well as its development in South Africa. How inclusive education can be successfully implemented in schools has also been discussed. I also present literature on the education of children with barriers to learning in general, then to ASD, its symptoms and characteristics. Finally, I reflect on how learners and parents experience ASD within the South African educational context, from the perspective of Bronfenbrenner's ecological theory.

2.2 INCLUSIVE EDUCATION

In this section I discuss inclusive education, its origins and principles and how it can be achieved in schools. I also discuss possible barriers to inclusive education.

2.2.1 What is Inclusive Education?

Landsberg, Kruger and Nel (2005, p. 8) define inclusive education "as enabling schools to serve all learners, including those experiencing barriers to learning". Powell and Powell (2010, p. 96) state that "inclusion" is the term generally used to explain the placement of SEN Learners in mainstream education. The term inclusion is given further clarification in DoE (2001, p. 17) as "recognising and respecting the differences among all learners and building on the similarities". For the purpose of this study therefore, the terms, "inclusion" and "inclusive education" refer to all SEN learners capable of being placed in mainstream education and are thus used interchangeably.

The terms “inclusion” and “inclusive education” are used in place of “mainstreaming” or “integration”, which imply the need for the learner to "fit into" an existing system. This sentiment is echoed by Dyson and Forlin (2010, p. 24) who observe that inclusion has become very prominent in international education circles. They explain that inclusion has developed because of two interrelated process namely "a reconstruction of the notions of disability" as well as "wide social, economic and educational developments", which is largely due to an increase in the awareness of human rights and social justice.

The WP6 (DoE, 2001) clearly states that they undertake to assist and provide adequate support for this inclusive process. They believed that inclusive education could be achieved by focussing on teaching and learning and highlighting the need for good teaching strategies which would benefit not only learners and educators, but also the entire educational system. It was promised that sound educational strategies would be developed which would be of benefit to all learners regardless of any barriers to learning or individual educational needs.

WP6 (DoE, 2001) stresses the need to improve the skills and knowledge of classroom educators and the need to develop new skills in teachers. To accomplish this, structured programmes aimed at specifically addressing these needs were to be implemented and the on-going assessment of educators was deemed as a critical aspect in ensuring the success of inclusion in the classroom. However, in South Africa, with its nine provinces, the idea of one educational policy immediately seems problematic as each province has its own "fiscal allocation, previously disparate service provision, rural/urban disparities and infrastructure" (Landsberg et al., 2005, p. 8). The challenge therefore would be to get all nine provinces to follow the same guidelines for inclusion, which would afford all children equal opportunities to gain access to formal mainstream schools.

In order to bring about true inclusion in a school, changes need to be made in the way teachers, parents and educators view inclusion, and not only in certain sub-systems. In other words, a systemic change needs to occur. According to Engelbrecht (2010, p. 9) this refers to a "systematic way of addressing both the practical and the personal components of change". In order for a deeper understanding of inclusion, the next section will present a brief history of inclusion.

2.2.2 A Brief History of the Origin and Development of Inclusive Education

Dyson and Forlin (2010, pp. 24-40) suggest that when looking at inclusive education, it requires a look at education over the last two hundred years. In developed nations such as the United Kingdom, Scandinavia and the USA, industrialization was the catalyst and the start of educating the masses. Often, education for local communities was initiated by local charitable initiatives and was subsequently taken over by the state. The next significant step included a decision on the type of education that SEN learners needed. Local charitable organisations established a limited range of specialised education, which was then also taken over by the state. A more "comprehensive system" was established in line with the evolution of mainstream education. By the middle of the twentieth century, most industrialized countries had implemented a separate education system, providing education for many learners with SEN.

In the 1960's, the schooling system changed from separate schooling, which advocated the placement of children with special needs in schools which separated them from children without special needs, to what became known as "integration" in Scandinavian countries. This integration was the placement of learners with SEN in regular schools (Meijer, Pijl & Hegarty, 1994). According to Meijer et al (1994,) this integration was not merely to encourage social integration, which had value in itself, but the ultimate goal was that the learners with SEN would become valued, fully integrated members of these mainstream classrooms. By the 1970's, the USA, the United Kingdom and Spain had all followed this example.

A significant change came about when the integration movement was changed to the inclusion movement. Integration was viewed as being limiting in its attempts to include and support learners with SEN in mainstream schools as these learners were expected to “fit in” to the existing system. Inclusion on the other hand, meant accepting and celebrating all learners, irrespective of differences, allowing each learner to attain the highest educational standard they can. Inclusive education therefore, has the ability to change our current segregated education system into an inclusive one (Pienaar and Raymond 2013).

In the opinion of Dyson and Forlin (2010, p. 26), the more "enlightened nations", are those countries where resources are mobilised in an effort to ameliorate the effects of the barriers that learners with SEN have to learning. In doing so, an attempt was made to allow them to live as full a life as possible, with their affliction (Dyson and Forlin, 2010). However recently, the views of these countries have been called into question, since they cast people with disabilities in a disparaging light essentially labelling them as "deficit-laden dependents on the rest of the country" (Dyson and Forlin., 2010, p. 27). The feeling which then prevailed was one in which people with disabilities were not "viewed as being afflicted but rather that society needs to create social conditions in which people with disabilities could exercise full rights of citizenship" (Dyson & Forlin, p.27).

Compared to more developed countries, South Africa faces a very different set of challenges in terms of inclusion. These challenges include teachers who are without adequate training to teach in overcrowded, poorly equipped mainstream classrooms. The advent of democracy in 1994 resulted in a new Constitution, which gave all children the right to equal access to education but required a broader framework for learning. The constitution, together with the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee for Education Support Services (NCESS) report which recommended a single education system for all learners, meant that parents finally had something concrete to work with regarding the education of their children with SEN (Belknap, Roberts and Nyewe., 2010). In order for this to be correctly implemented, all concerned stakeholders needed to commit to making inclusive education viable in all mainstream South African schools.

Whilst Engelbrecht (2010, p. 22) conclude that inclusive education in South Africa is a "constitutional imperative", they concede that the actual implementation of such a policy is not an easy one, since education is generally viewed as a "conservative enterprise". They also contend that it is something worth fighting for and never to be attained without hard work. The existing ideas about teaching and learning currently being practised in South Africa were "inherited from a very conservative system of education" (Engelbrecht, 2010, p. 22). It is therefore the responsibility of every South African to take the rights discourse seriously and in so doing, create the necessary conditions for education for all. With the particularly limited educational resources available in the majority of South African schools, we have to extend and develop that which we have, to include a wider range of learners.

Pienaar and Raymond (2013) believe that a serious misconception arose from the release of WP6 that all children would be immediately enrolled in their community schools. However, WP6 makes it clear that teachers need more training and the schools need added support systems in place before this can happen. WP6 asserts that there is a need for special schools to remain as an integral part of the inclusive system but that these schools should also provide additional support for teachers in mainstream schools (DoE, 2001). In doing so as many learners as possible would receive support and continue to be educated at schools nearest to their homes. However, learners with special needs that require specialised schools should continue to receive their education within a school which can best provide for their needs.

According to Pienaar and Raymond (2013) learners with disabilities have historically experienced the most significant exclusion from learning. They state that before 1994, South African educational provision was in accordance with the medical model. The system focused only on deficits within the learner as these were seen as the only source of barriers to learning. The education of the child was therefore focused on the correction or remediation of the perceived deficit. In accordance with this medical model, two parallel education systems were created, thereby catering for the learners with so-called "normal" educational needs and the other for those with so-called "special needs”. The intention was the provision of specialised, segregated schools with specially trained teachers who could provide support to learners classified as having special needs. However, due to political policies existing at that time, support was available primarily to white learners with special educational needs. The medical model also meant that many children with SEN were immediately excluded from their local neighbourhood schools since the perception was that these schools were unable to adequately cater to their special educational needs. These children were then sent to schools, which were often far from their communities.

In 1996, the South African Constitution (1996) was adopted which included a commitment to provide basic education to all learners and was based on the principles of equality, access, equity and participation. The implementation of WP6 was therefore expected to not only benefit learners with SEN, but also all South African learners by implementing "a more flexible system of education that focuses on removing barriers to learning and creating learning-friendly environments" (Pienaar and Raymond, 2013, pp. 10-11).

The Salamanca Statement, a document used globally and introduced by UNESCO delegates at the World Conference on Special Needs Education held in Salamanca, Spain, in 1994 (UNESCO, 1994, P.7), provides a framework for action based on the guiding principle that ordinary schools should provide education for all children regardless of any barriers. This document clearly states a need for schools to work optimally in order to utilise the resources available to benefit all children. The statement further explains that the accommodation of all children should be viewed on a National level in schools as follows:

> The practice of mainstreaming children with disabilities should be an integral part of national plans for achieving education for all. Even in those exceptional cases where children are placed in special schools, their education need not be entirely segregated. Part-time attendance at regular schools should be encouraged (UNESCO, 1994, p. 18).

Stated differently, inclusion is about so much more than mere accommodation of learners with disabilities or barriers to learning. It is also about affording an opportunity for education to a wide range of marginalised learners who would otherwise have had very little chance of a mainstream education. Dyson and Forlin (2010, p. 32) point out that inclusion is not as great an issue in countries where inclusion had its roots, but rather in "less developed" countries such as South Africa, where resources are limited and inclusive practices have not been implemented in schools for an extended period of time. Inclusive education is a means of getting education to more learners, since the funds to establish special needs schools are often lacking and learners with special needs do not make up the majority of the population needing education.

2.2.3 How can Inclusive Education be achieved in Schools?

When considering inclusive education, the first reaction by most teachers is that it is highly challenging, unrealistic under the present circumstances, and that it does not work (Nel, Nel and Hugo, 2013). However according to Sapon-Shevin (2007), inclusion at its core begins with the right of every child to be in a mainstream classroom. Sapon-Shevin postulates that teachers should not require of learners to fulfil certain requirements in order to fit into the mainstream classroom. Rather, the classroom (thereby the teacher) should make any changes or modifications necessary which will enable learners to function as full members of the class, even if this requires the initial provision of additional and appropriate support within the classroom. Nel et al. (2013) maintain that all schools have a responsibility to make provision for all learners' needs, regardless of the diversity thereof. The sentiments of Sapon-Shevin (2007) and Nel et al (2013) are further endorsed by WP6 (DoE, 2001) in that WP6 stresses the need for schools to identify and then take steps to prevent barriers to learning which would otherwise prevent learners from reaching their full academic potential. DoE (2001) in WP6 highlights the need for "support systems" which should be adaptable to the needs of individual learners.

According to WP6 (DoE, 2001, p. 16), for Inclusive Education and training to be successfully implemented in South Africa, there has to be an acknowledgement that all children and youth can learn and need support. This has to be accepted by educators in order for inclusion to have any chance of success. Mastropieri and Scruggs (2010), suggest that teachers might well use modifications recommended for learners with severe learning disabilities when working with learners with ASD in the mainstream classroom. They also suggest the use of smaller groups or even one-on-one instruction, as this will benefit the learner with ASD as well as many other learners in the class. This form of teaching is recommended, as it can afford the teacher the opportunity to give immediate feedback and encourage learners to be attentive and responsive during lessons. The learner with ASD is also given the opportunity to practice skills such as being polite, waiting for his turn in class and sharing materials since these social skills do not always come naturally to a child experiencing ASD. This type of structured environment is beneficial to the learner with ASD, as he will be less anxious when the day is carefully planned and there are no "surprises" in store for him. The use of a visual timetable, which shows the student what the day ahead looks like, can also eliminate stress. The South African National Autistic Society also advocates the use of social stories to help the child with ASD to understand certain social behaviours or situations, which the child could find stressful or unsettling.

With this in mind, various structural adjustments and learning methodologies would need to be employed to meet the varying needs of all learners. WP6 demands the acknowledgement that learning can occur both within the home or community, as well as in the formal schooling environment. It is understood that a change in attitudes, behaviour, teaching methodologies, curricula and environment should occur before the needs of all learners can be accommodated in mainstream schools in South Africa. But, in doing so, all learners participate in the culture and curricula of educational institutions, and in this way, barriers to learning can be uncovered and minimised. The overarching ideal is to empower learners by developing individual strengths and allowing them to participate meaningfully in the process of learning. WP6 further stresses that although learners may have differences in terms of race, gender, ethnicity, language and learning needs, they are all to be equally valued within the learning environment (DoE, 2001).

In the past teachers referred to learners with Special Educational Needs (SEN) as being "uneducable" or "should not be in this school" (Evans, 2007, p. Vii). The implication of this was that for children to be included in a "mainstream" class, they had to "fit" into the mainstream class without any adjustments being made to "normal" teaching. However, as teachers gain experience, they become acutely aware that many children do not fit neatly into these prescribed boxes (Evans, 2007 p. 15). This sentiment is echoed by Rose and Howley (2007, pp. 10-11), who emphasize that although the term inclusion is used quite freely within educational circles, the "inequalities of the past often led to the exclusion and isolation of individuals who were perceived as being different". These differences could be in terms of "their needs, abilities, class, race, gender or culture". Rose and Howley (2007) further stress that whilst many teachers are aware of these potential problems, the teacher still needs to be constantly watchful to ensure that their teaching styles meet the needs of all learners within their classrooms. Rose and Howley (2007, p. 11) contend that inclusion is not merely the placement of learners with SEN in a mainstream class, but that once placed, these children must be "afforded opportunities to learn at an appropriate pace". They continue to say that these children, through socialisation with their peers, should be given the chance to become equally valued members of the school community. In this way, the teacher ensures that every learner is given the opportunity to learn in a way which is optimal for them. Evans (2007, p. 16) postulates that since mainstream schools are now expected to provide for a wide range of children with "significant learning, communication and behavioural difficulties, a school-wide awareness and understanding of diverse needs and an acceptance" is required. Evans (2007, p.16) continues to say that teachers should understand that children with barriers to learning are not "being awkward on purpose". She asserts that these children "have a need to succeed, they want to fit in, they want to please". Schools therefore have to provide a range of "strategies and resources to meet the diversity of needs". This requires schools to relook the physical resources at their disposal and provide the appropriate training for staff to adequately deal with the host of new situations which would arise.

Ofsted (2000) advocates for schools to bring about changes in the school which would ensure that all children are adequately accommodated within the school. Ofsted (2000) describes a school which is completely inclusive as being one in which the education, goal achieved and happiness of every learner found within the school matter. Successful schools are schools which include every learner in their educational endeavours. This is evident in the manner in which the school is willing to present learning opportunities to learners who may have educational difficulties.

2.2.3.1 A model inclusive classroom

Giangreco (1997) lists the following characteristics as being present in situations where inclusion is thriving, and glaringly absent in situations where inclusion is either non-existent or not working at an optimal level:

A. Collaborative teamwork

Collaborative teamwork is vital to ensure an inclusive educational environment. Although it is generally an accepted practise for a child with barriers to learning to be assigned a group of adults to assist with his educational needs (e.g. classroom teacher, speech/language specialist, physiotherapist etc.), merely having a group of people does not make it a team. This team has to do more than simply inform members of decisions made regarding the education of the child. This team has to adhere to the most crucial characteristic of a true team. They need to have common goals. Without a shared goal, the team might meet to discuss the learner but then head off in very different directions. The result of this is a programme lacking cohesiveness and this in turn means that the student could be left without an educational programme geared to benefit him. This could lead to families feeling discouraged and class teachers feeling a lack of adequate support (Giangreco, 1997).

B. Developing a Shared Framework

Research on attitudes of school personnel and parents of children with special needs, has shown differences of opinions regarding how these members view some of the most basic issues regarding inclusive education. In the opinion of Giangreco, Edelman, MacFarland, & Luiselli (1997) it is crucial that the SEN learners be placed in the correct classroom. They emphasise the need for the educational programme content to be at the correct level for the learner, as well as determining the correct support needed for each learner. This data indicates that many teams do not possess a shared framework. According to Giangreco (1996, p. 4), this means an "ever-evolving set of beliefs, values or assumptions about education, children, families and professionals to which all team members agree and upon which they base their actions" is required. In the creation of a shared framework, the members of the team are able to create common goals even though the individuals may hold different opinions. Without this clearly defined framework, the individuals in the group will not work effectively and will therefore not be classified as a true team.

Landsberg et al*.* (2005, p. 416) also make reference to this teamwork, calling it a "trans-disciplinary team approach". They stress the need for all members of the team to view the learner in a holistic way. Landsberg et al*.* emphasise the need for the implementation of intervention strategies to be used within the classroom situation rather than being used by individual therapists in isolated sessions with the learner. In using this approach, members of the team assist each other and also assist in teacher training. This approach is particularly effective when the learner has multiple disabilities which require various therapists to work with each other in order to assist the learner (Giangreco et al., 1997). For this to work however, the teacher also needs to be involved since without the implementation of the therapists' suggestions there would be little or no improvement in the learners' academic performance.

C. Involving Families

Giangreco, Cloninger, & Iverson (1993, p. 7) state that the family forms an essential part of the "team" since their input lends a greater depth of understanding of the child in question. This sentiment is echoed by Donald, Lazarus and Lolwana (2010, p.162) who state that "family-based protective factors" are key to fostering resilience in children. Resilience is best described as the process by which a child is able to "withstand or bounce back from developmental risks or difficulties". A child with stable family bonds therefore has a chance of a greater degree of success.

Giangreco et al. (1993, p. 7) point out that the child's immediate family can provide the so-called "experts with intimate information, only gleaned from living with the child". This information gives further depth to the understanding they might never have had. They state that involving the family is vital since families have a greater stake in the education of their children, and their involvement in the child's education will continue long after the expert has moved onto another learner. The families have to live with the consequences of their actions on a daily basis, where every decision made in the education of their child is carefully considered and no decisions are made lightly. Family involvement should therefore be strongly encouraged and fostered. Giangreco et al. (1993) also state that families have the power to influence change in their local community with regard to educational services. Often they have voices in the community, which could be very instrumental in bringing about radical change.

D. General educator ownership

Giangreco (1997, p. 196) contends that when "quality inclusive education" exists, the class teacher views herself as the primary educator for the learners with special educational needs who have been placed within her class. In his opinion, these children are fully-fledged members of the class. Giangreco states that the teachers he observed started by merely engaging with the learners in their classes and once a relationship had been established, they took responsibility for these learners and in turn, ownership of their education. Giangreco's sentiments are echoed by Downing (2010, p. 103) who states that when learners with SEN are on a teachers class list and are "technically" in her class but are taken out for various lessons she loses her "general educator ownership". This is because the education of the learner has been taken away from her and all lesson planning is handed over to a paraprofessional.

Downing (2010) claims that the class teacher also loses touch with the way in which the student learns and acquires information. This practice also prevents the teacher from acquiring the skills necessary to both work with and educate learners with barriers to learning. It can therefore not be stated clearly enough, how important it is that the class teacher take ownership of the learners in her class.

E. Use of Paraprofessional Staff

Giangreco (1997) explains that due to an increase in the number of children with special needs being included into mainstream classes, so too has the number of paraprofessional staff (supportive educators, therapists etc.). He draws attention to the fact that whilst these paraprofessional staff members are crucial to the development of the child, there are certain aspects of their presence in the classroom, which need to be looked at. He notes that these professionals often spend a great deal of time working in very close proximity to the child. In the opinion of Downing (2010, p. 8) these paraprofessionals should not be hired to merely "hover" around the student. Their role should be to facilitate learning while knowing when to step back and allow the student to learn independently. Downing (2010) feels that what often happens is that their role seems to be one of fetching and carrying equipment for the student and making sure that they are working quietly. When the paraprofessional role is viewed this way, training of the paraprofessional would need urgent attention. When the paraprofessional has received adequate training, they can understand the goal of inclusive education and also be fully aware of the Individual Educational Programme (IEP) of the learners. The IEP refers to the educational programme which has been worked out with a specific learner in mind and caters to his specific educational needs.

However, Giangreco et al. (1997) and Pienaar and Raymond (2013) are of the opinion that working with paraprofessional staff members could result in general educators having feelings of a lack of ownership and general responsibility of the learners. These children are often removed from class during the day for individual tutoring which could have the dual impact of separating them from their classmates and have a restricting impact on peer interaction. They also state that this could result in dependence on adults on the part of the children and result in them not receiving competent instruction in class. Giangreco, Edelman, Luiselli and

MacFarland (1997) further state that learners experienced a loss of personal control when paraprofessional staff made decisions for them based not on what the learner wanted but rather on their own tastes or biases.

Another interesting point that Giangreco et al. (1997) noted was that there appeared to be a loss of gender identity reported in cases where the instructional assistant and the learner were opposite genders. Giangreco et al. (1997) are of the opinion that the gender of the assistant superseded the gender of the learner and activities were not centred on the learners needs. Downing (2010, p. 8) echoes the sentiment that the learners should be given the opportunity to be instructed by a competent and qualified educator (such as the class teacher) without the constant interference of a paraprofessional. The danger of being constantly shadowed by someone is that the learner eventually becomes highly dependent on the paraprofessional and soon starts to lack confidence in their own abilities. Downing (2010, p. 33) also points out that these paraprofessionals need to be taught the benefits of "fading". Fading refers not only to the gradual decline of assistance but also to the gradual removal of small rewards often used in initial stages to encourage students to produce work. In this way, the student is encouraged to work independently. Paraprofessionals therefore have a vital role to play in classrooms, provided that they have received adequate training in dealing with SEN learners in the inclusive classroom. WP6 (DoE, 2001, p. 23) echoes this sentiment and stresses that there needs to be an establishment of "district based support teams to provide a co-ordinated professional support service that draws on expertise in further and higher education".

Rose and Howley (2007, p. 5) further contend that children diagnosed with ASD have often been accommodated in mainstream classes, but because children diagnosed with ASD are on the rise, teachers have to make sure that their "professional skills, knowledge and understanding" are of such a standard that all children are offered learning opportunities which will benefit them.

F. Experiences of Parents

In this section, I have used the term "parent" to identify the person(s) who is/are the primary caregiver(s) of the child with SEN. Wherever possible, I have referred to learners who have ASD, but reference has also been made to learners with SEN in general, since there are many areas in which the two overlap and have the similar requirements.

Belknap et al. (2010, p. 171) note that parents in South Africa, as in other countries, have united in a bid towards inclusive education. Parents have made their voices heard at two levels, namely at "structural level and at grass-roots level". At a structural level, parents are making themselves heard on policy forums e.g. the National Commission on Special Needs in Education and Training (NCSNET). This included "mobilising and galvanising" of parents at grass-roots level and the creation of social movements e.g. the Parents" Association for Children with Special Education Needs (PACSEN). In doing so, these parents made known the need to take the learners with SEN, as well as the rights of the disabled, seriously.

In 1969, the "Promulgation of the normalisation principle" was held in Scandinavia, led by parents of children with barriers to learning. This principle is best explained as being the right of the child to all things "normal" and ensure the fundamental rights, which everyone is entitled too. Based on the United Nations Convention on the rights of persons with disabilities Article 7 (United Nations, 1945), parents are "to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children". This has been taken to mean the inclusion of all learners in all classes regardless of their barriers to learning (Dyson and Forlin, 2010).

South African parents started their action campaign in the 1980's when parents started to push for the inclusion of their children with SEN in neighbourhood schools. Belknap et al*.* (2010) observe that whilst some parents were aware of the benefits of inclusion, others merely wanted their children's rights to being educated adequately addressed. They explain that many of these parents were African parents who had historically suffered from forced segregation and poor service delivery and who now finally had the chance to have this addressed. Belknap et al*.* (2010) maintains that whilst these learners were then accepted into schools, they were given very little or in some cases no educational support. The result of this was that parents felt that inclusive education was not in the least bit effective and became quite negative about it, but Belknap et al*.* (2010) felt that a major contributing factor was that the parents were unaware of their rights.

A crucial quote from Salamanca Conference is a statement known as the "Salamanca Statement on Principles, Policy and Practice in Special Needs Education" (UNESCO, 1994, p. ix) which states:

> "Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system."

The Salamanca Statement provides an assurance for parents that inclusion is a universal right, and in doing so, it re-affirms the right that all children have in an inclusive society. This sentiment is further echoed in WP6 (DoE, 2001, p. 33) and emphasises the need for the "establishment of an inclusive society". The hope is that these sentiments will become a reality within the classroom.

Evans (2007,) further contends that any barriers to learning should be identified as early as possible. This early diagnosis is not intended to label or set the child apart in any way, but is necessary to ensure that each child is assigned the correct intervention strategies. She stresses the need to consult with parents of SEN learners to ascertain their wants and needs for their child. Cooper and Jacobs (2011, p.194) point out that "schools and teachers" are often perceived as both menacing and bewildering by the parents of learners with SEN. This could lead to a lack of open communication between them and the school. Teachers and schools should therefore not simply expect parents to participate in their child's schooling, but it should rather be something which the school actively seeks to encourage; especially considering that many parents might be coming from communities where parental involvement has not in the past been actively encouraged.

Evans (2007, p.16) advocates the need to have a detailed baseline assessment done on all learners with SEN. Furthermore, she believes it is important for staff and parents to have an open relationship. This affords staff the opportunity to compile a comprehensive picture of each learner and allows staff to make suggestions to parents, which could assist them in providing appropriate help for their children at home. From a parent's point of view, an open dialogue with the teacher provides vital information of experiences in the home environment and adds another dimension to teacher's perceptions of learners.

2.2.4 Factors affecting the implementation of inclusive education

Pienaar and Raymond (2013, p.11) draw attention to the fact that WP6 has not yet been correctly implemented, and they point out that the very teachers expected to implement it, were educated and trained under apartheid education. Under this system, they were taught that learners with SEN needed to be taught by teachers with specialist skills and an "inflexible and prescriptive curriculum characterised education". Pienaar and Raymond (2013, p12-13) state that the following three areas are in need of urgent attention: Firstly, teacher development is necessary to give teachers confidence in what they are being required to do in the classroom. Professional development will also affect a mind shift in teachers as without this change in outlook; the proposed changes will never be implemented. This development should include being made aware of potential barriers to learning and more importantly, strategies to assist in removing these barriers. Pienaar and Raymond point out that this would involve a paradigm shift in the way that the teachers view barriers to learning, including looking at extrinsic factors affecting learning and ways of alleviating these extrinsic factors. The overarching idea is to change teacher opinions and understanding of inclusive education, why it is needed and how to implement it correctly.

Secondly, school and educational system development is necessary to ensure that the innovation being implemented in the school is completely understood and embraced by all staff and not just those with teaching responsibilities (Pienaar and Raymond, 2013). Thirdly, Raymond and Pienaar (2013) believe community development and partnerships are essential in ensuring academic success. Learners coming from impoverished communities are more likely to have parents with lower educational backgrounds, which would influence their ability and confidence to make informed decisions. In these environments, learners are also more likely to have poorly equipped schools and a higher teacher turnover. This would affect the way in which teachers interact with their learners and their abilities to effectively identify and remediate barriers to learning.

According to Macbeath, Galton, Steward, Macbeath and Page (2006) one of the dominant reasons why inclusive education fails is due to lack of expertise in dealing with learners with SEN. Teachers feel that they are not adequately equipped to handle children who have any type of special need. This obviously affects their confidence and willingness to work with such children. It is encouraging to note that according to the National Department of Education and their "Schooling 2025" plan, mention has been made to provide teachers with the necessary training required to improve their capabilities. If this does indeed come to fruition, the implications could be vast improvements in teacher qualifications and the implementation of inclusive education.

Dyson and Forlin (2010) believe that although the rights of the learner have been taken into consideration, it seems that the rights of the teacher and the other learners in the class might not. This has led to a great degree of despondency on the part of the teachers. They point out that WP6 refers to the "unique learning needs of all South African children and youth, including those with milder impairments or intellectual gifts and talents". The way in which inclusion is viewed is often dictated by the policy of the school. In some instances the class teacher may focus on the individual barriers to learning and in this way prepare work, which helps the child overcome these barriers. This approach can lead to the teacher highlighting the individual needs of the pupils and finding the most effective way of addressing these needs. By doing so, the teacher focuses on the pupils' abilities rather than emphasising their difficulties. The teachers often develop an "image" of the child even before meeting them based solely on the attached label (Rose and Howley, 2007, p. 2). This image is often created in staffroom situations, during which children are discussed informally by members of staff. In this way, the teachers either build up a positive or negative opinion regarding the child, based on the opinions of another staff member.

Rose and Howley (2007) continue to say that whilst it can be to the teachers' advantage to have an understanding of the children that they are about to teach, it can also be to the detriment of the child if the label gives the teacher a low expectation of the child’s abilities. These labels can also in their opinion, often deny the child access to "appropriate learning opportunities". When there is a focus on what the pupil is unable to do, there is a risk of containing the learner thereby further isolating and damaging his self-esteem. Once pupils are removed from a classroom situation for any additional work, those children are perceived as different and discrimination can occur. The result is that the teacher, who already feels poorly prepared to deal with the challenges of inclusion now, also experiences a great sense of responsibility in the ultimate success or failure of the inclusion of the learner within the mainstream classroom (Rose and Howley, 2007).

Giangreco (1997) makes some observations regarding the successful inclusive classroom. He states that within a model inclusive classroom, it is imperative that the ratio of learners with or without disabilities should be in direct proportion to the surrounding population and that the learner with SEN should be made to feel welcome in his local school. He also stresses the necessity for learners with SEN to be educated with peers of the same age who do not experience barriers to learning. In doing so, learners with varying characteristics and abilities experience what Giangreco calls "shared educational experiences" but at the same time, each learner will pursue learning outcomes which are appropriate for that learner. Giangreco does however explain that these experiences can only enjoy success when appropriate supportive measures are in place and all learners experience equal accommodation. Shared educational experiences are, in his opinion, most effective when they take place in general education classrooms, and community work sites, which are mostly frequented by those without disabilities. He also states that educational experiences should be designed to improve life outcomes for students and should endeavour to bring balance between academic/functional and social/personal aspects of schooling. He concludes his analyses of the inclusive classroom by stating that inclusive education can only exist when each of the previously listed characteristics occurs on an ongoing basis.

2.3 AUTISTIC SPECTRUM DISORDER

Giordano and Lombardi (2009, p. 8) explain that the terms "autism and autistic" are derived from the Greek word "autos" meaning "self". Since most people with autism have a "pathological impairment in socialization and nonverbal communication" this word seems to describe the condition of autism quite succinctly. Myles, Swanson, Holverstott and Duncan (2007 p. 64) describe ASD as being a "developmental disability that begins before the age of 3". The three "main areas of impact are in the domains of social interaction, communication, as well as restricted repetitive and stereotyped interests and behaviours".

The term Autistic Spectrum Disorder (ASD) is a broad term used when referring to the following categories according to the American Psychiatric Association (as cited in Mastropieri and Scruggs, 2010, p 87): Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified. Since it is referred to as a *spectrum* disorder, the implication of this is that individuals with this diagnosis may function from mild to severe and accommodations would therefore have to be made based on the individual's functioning level. However, although symptoms may vary from individual to individual, communication and social competence are generally the areas that individuals with ASD find most challenging (Mastropieri and Scruggs, 2010).

Powell and Powell (2010, p. 99) define autism using the definition given by IDEA, (Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act of 1973):

> Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, which adversely affects educational performance.

Powell and Powell (2010, p. 99) note that children with autism often display the following symptoms namely "repetitive activities and stereotyped movements, resistance to change in daily routines or the environment, and unusual responses to sensory experiences". Nel et al (2013, p. 20) give further insight into ASD by describing it as a "lifelong, complex, pervasive developmental impairment, which appears to have a genetic predisposition and stems from multifaceted origins, causing disturbances in brain development and functioning". They further elaborate that ASD has a fourfold likelihood of occurring in boys than in girls and current trends suggest that the occurrence of ASD seems to be on the rise. They also mention that ASD diagnoses seem to be from birth to approximately the age three in children; and that ASD is often accompanied by additional impairments, including sensory and intellectual impairments.

Nel et al (2013, p. 20) also explain that there are no "typical" learners presenting with ASD. However, what is common across the board is the fact that all of these learners are to a greater or lesser degree affected by what is termed as the "Triad of Impairments". The "triad" refers to a small range of actions or activities characterised by a lack of "social interaction, language and communication, behaviour and imagination, and a fierce opposition to any change." In many children who experience ASD, change is often a source of great distress to them. Routines, which are familiar to them, should remain unchanged as far as possible, in order to reduce stress and anxiety.

The Diagnostic and Statistical Manual of Mental disorders (DSM-IV) (American Psychiatric Association, 2014) is used to define the many mental disorders currently known and these definitions are accepted globally. The following description of ASD characteristics has therefore been taken directly from the DSM-IV, 4th edition (2014, p. 75). These six characteristics typically appear before the age of three in a child with ASD:

A.

A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3) should be evident, before a diagnosis of ASD can be made:

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

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

b) Failure to develop peer relationships appropriate to developmental level

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

d) Lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least **one of the following:**

a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

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

c) Stereotyped and repetitive use of language or idiosyncratic language

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

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

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

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

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

(d) Persistent preoccupation with parts of objects

B.

Delays or abnormal functioning in at least ***one of the following areas,*** *with onset prior to age 3 years*:

1. Social interaction
2. Language as used in social communication
3. Symbolic or imaginative play

C.

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

From the above one can understand the saying "when you know one child with Autism, you only know one child with Autism". This is largely due to the fact that the symptoms of autism can differ greatly from one person to the next. One person with autism may have an excellent command of speech, appear to engage readily with others, whereas another individual may exhibit the exact opposite and appear unable to communicate, show signs of being intellectually challenged, and appear completely self-absorbed (Rudy, 2011 p.1). Ideally, regardless of the needs of each individual case, every child is deserving of equal learning opportunities and inclusion.

It should however be pointed out that WP6 makes no mention of Autistic Spectrum Disorders (ASD) specifically, but rather refers to the full spectrum of barriers to learning as experienced by many learners in South African schools. It is for this reason, that I feel a thorough investigation into the perceptions of South African parents, with children who experience ASD, is warranted. Parents are the very people who can bring about the necessary change in the education of their children. Currently there seems to be very little documentation regarding the way in which parents of children who experience ASD view the education offered to their children.

2.3.1 The Prevalence of ASD

Hughes (2012) argues that about four out of five people living with psychiatric disorders live in developing countries and therefore have few opportunities for treatment. Whilst this has also largely been true for people living in Africa, awareness is certainly starting to improve. Hughes quotes statistics from the December issue of the "South African Journal of Psychiatry" in which six studies were done between 1982 and 2010. These consisted of three studies done in Nigeria and one each done in Tunisia, Tanzania and Kenya. These studies showed only a few dozen children diagnosed as being ASD, and the ages of the children ranged from about eight years old and included some teenagers. What this study proved was that children in Africa are diagnosed relatively late compared to their counterparts in the United States (USA) who are diagnosed relatively early.

The studies also showed that 51% to 71% of children diagnosed with ASD in African counties were classified as non-verbal compared to only 25% in the USA. This high figure could be attributed to a number of factors such as, being diagnosed later, a severe lack of resources, and a poorer medical infrastructure. This study also revealed that cultural and educational factors play a large role in both the treating and approach to ASD within the general African population and the medical community. When Nigerian nurses, specialising in paediatrics and psychiatry were questioned regarding the causes of Autism, 40% regarded pre-natural or supernatural cause's e.g. ancestral spirits, enemies, sinning or actions of the devil as being the reason for the child having ASD. This research showed that if a child has developmental or neurological delays, help is often sought from a traditional healer before the services of a medical practitioner are sought. This therefore largely accounts for the late diagnosis, which in turn accounts for lack of language due to the lack of appropriate intervention strategies in the form of speech or occupational therapy.

Some schools report a sense of apathy amongst parents, and that parental involvement in their child's school can sometimes be problematic. Van Wyk and Lemmer (2009) believe that the term parental involvement can have different meanings to different people. Parental involvement can be seen as participation in Parent Teacher Association (PTA) committees and involvement in various other parent committees that focus on fund-raising or serving on school governing bodies. However, they maintain that for other parents, involvement in their child's school may only extend to their financial contribution to the school. The true definition of parental involvement is therefore difficult to determine but Van Wyk and Lemmer (2009, p14) believe that the commonality which binds these definitions together is the desire to bring together the domains of home and school in order to further the child's development and learning. They are of the opinion that increased parental involvement can both improve academic achievement of learners, as well as an improved attitude towards learning. They report a decrease in dropout rates of school going learners when parental involvement increases, as well as an increased sense of security and emotional stability. They further state that parental involvement leads to improved behaviour and better school attendance.

Downing (2010, p. 12) states clearly "family input is critical". She postulates that the family not only knows the strengths and weaknesses of the child, but can also provide invaluable information regarding prior intervention strategies and the responses to these strategies.

2.4 THEORETICAL FRAMEWORK

Whenever there is a discussion regarding inclusive strategies, the topic of "inappropriate and inadequate support services" (DoE, 2001, p. 18) is usually highlighted, as well as the need for educational institutions to "uncover and minimise barriers to learning" (DoE, 2001, p. 16). According to Engelbrecht et al. (2007, p. 175) legislation and policy in South Africa stress both the roles and responsibilities of teachers and parents in creating a truly inclusive environment for the learner. This spirit of collaboration is essential in the creation of a school where "everyone belongs and participates in meaningful activities, affiliations and alliances among community members" and "mutual support is the norm". From this statement it is clearly evident that in order for inclusion to be successful, all participants in the life of the child need to be aware that every decision made, will in some way influence every other sphere in the development of the child.

Bronfenbrenner's ideas on human development have stood the test of time and remain relevant to current views. He strongly advocates the belief that “human development is a product of interaction between the growing human organism and its environment” (1979, p. 16). His bio-ecological theory states that development is defined as “a lasting change in the way in which a person perceives and deals with his environment” (1979, p.3) and he emphasises the importance of interrelated ecological levels that work as nested systems in human development.

According to Santrock (2004, p. 70), Bronfenbrenner’s theory has gained popularity as it encourages “systematically examining social contexts on both micro and macro levels,” and calls to attention “the importance of looking at children’s lives in more than one setting.” In other words, when looking at the development of a child, one needs to understand not only what happens between a parent and a child in the home, but also what happens in his/her extended family, the neighbourhood, the classroom, the school, the peer group and the culture in which he/she exists. By considering all these factors, one sees the child as “embedded in a number of environmental systems and influences” (Santrock, 2004, p. 70).

Woolfolk (2007, p.72) believes that Bronfenbrenner’s bio-ecological model of development “maps the many interacting social contexts that affect development.” She believes that the “*bio”* facet acknowledges that people bring their biological selves to the developmental process. The “ecological” aspect is an acknowledgement that the social contexts we find ourselves in are ecosystems due to the fact that these ecosystems are in interaction with each other and thus exert an influence on each other. Coleman (2013, p 48) observes that the word "ecology" would normally lead to considering the interactions between plants and animals and the connections that exist between them, as well as physical ecosystems such as rivers, mountains and deserts. Bronfenbrenner (2005, p. 6) built on this idea to describe a human ecology of interacting social systems as "a process of reciprocal interactions".

Bronfenbrenner (2005, p. 6) states one particular defining property behind his ecological model, namely his belief that “human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving bio psychological human organism (the developing child) and the other persons, objects, and symbols in its immediate external environment”. He believes that these interactions need to occur regularly over extended periods to be effective, and he refers to these interactions as “proximal processes” (Bronfenbrenner, 2005, p.6). Examples of these proximal processes are the interactions between parent and child, child-child activities, group or solitary play, reading, learning new skills and performing complex tasks.

An additional ecological principle that Bronfenbrenner feels is necessary in the world of the developing child is his belief that the child needs to form a "strong, mutual and emotional attachment" with one or more people in his life. This attachment is created through interactions, which the child may have with people who are involved in his life. Through these interactions, the child is also, in a sense, forced to respond to his environment. It is through these interactions that the child's psychological development is accelerated since his "exploration, manipulation and imagination" are being stimulated (Bronfenbrenner, 2005, p. 9).

Bronfenbrenner (2005, p. 10) further explains that the child, through his complex interactions, also needs the involvement and admiration of a third adult who "assists, encourages, spells of, gives status to, and expresses admiration and affection for the person caring for and engaging in joint activity with the child". He also explains the importance of "socially supportive exchanges" in terms of communication between those individuals or third parties, who work closely with the child. This “third adult” could be a spouse, relative, friend, or neighbour. Bronfenbrenner (2005, p.52) believes that if “third parties are absent, or if they play a disruptive rather than a supportive role, the developmental process, considered as a system, breaks down.”

Bronfenbrenner (2004) recognises that when teachers consider the education of learners in their classroom, they should not only look at the learner within the classroom, but should also take into account the environment outside of the classroom. The child's environment is influenced, to a large extent, by his family circumstances, the neighbourhood he lives in, and the peer groups he socialises with. Never is this more important than when parents have a child with SEN. This understanding of human development has been used as the theoretical foundation on which this study is built.

Bronfenbrenner's bio-ecological model consists of five concentric rings or systems namely: the microsystem, the mesosystem, the exo-system, the macro-system and the chrono-system. This model (1979, p. 16) essentially focuses on the investigation of both the person and the environment, and pays special attention to the interaction between the two. Bronfenbrenner's bio-ecological model asserts that we all live within a microsystem, which is encased within the mesosystem. This in turn is surrounded by the exo-system all of which form part of the macro-system; thus the reference to the Russian nesting dolls. These sub-systems and the individual roles they play within the development of the child experiencing barriers to learning are discussed further, below the visual representation of Bronfenbrenners ecological and bio-ecological model, Figure 2.1.

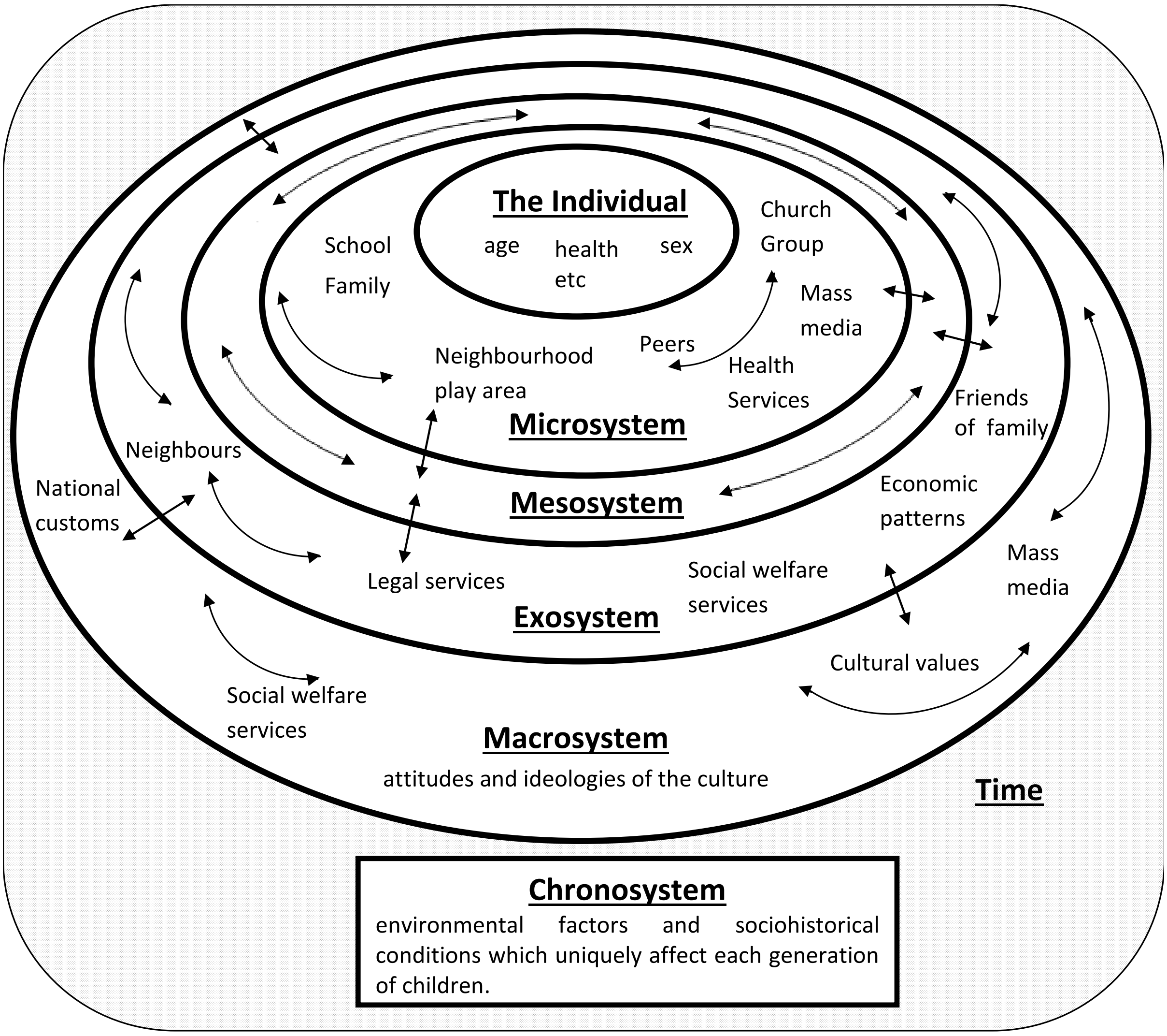


Figure 2.1 Bronfenbrenner’s Social Ecological model (adapted from Santrock, 2004, p. 69 and Woolfolk, 2007, p. 73)

Bronfenbrenner (1979, 2005) was of the opinion that the ecological environment of the child could be likened to set of Russian nesting dolls. He used this example to explain that each system is contained, or nested inside the next. This visual representation clearly explains how the child is seen as the very central piece within a microsystem (a family unit), with the mesosystem, exo-system, macro-system and chrono-system making up the outer layers of the "nested structure". These structures are interdependent of each other and constantly interact with each other, constantly causing or influencing change in each other.

Each individual system will now be discussed to show its effect on the child with ASD.

2.4.1 The Microsystem

Bronfenbrenner's (2005) microsystem refers to the interrelations with the immediate setting. It is important to note that relationships within the microsystem are reciprocal in nature since they are between the child and the significant people within his immediate environment. This means that the relationship therefore flows in two directions (Woolfolk, 2007). In other words, the microsystem is the direct environment that has an immediate effect on one’s life and refers not only to parents but also to siblings, grandparents and extended family, friends, and as well as neighbours, who interact with the child on a regular basis. The microsystem also refers to his immediate relationships, school environment, including any members of staff (as well as supportive staff) and peers that are in regular contact with the child (Woolfolk, 2007). Bronfenbrenner (2005, p.160) states that within the school environment, the child is not a passive participant and that "the developing person is viewed as an "active agent who plays some part in any developmental process taking place in the microsystem".

Each member of the microsystem impacts on the other members in some way (Bronfenbrenner, 2005). Bearing this in mind, relationships of people close to the child (i.e. mother/father/siblings) should also always be considered when trying to understand a child’s behaviour. Bronfenbrenner (2005) further explains that if the child's living conditions are considered unstable (i.e. moving houses, schools, family absences, divorce etc.) that this would have a significant effect on the child with regard to aggressiveness, anxiety and social problems. He states that these factors have a greater influence on the child than factors such as socio-economic status.

According to Berry (1995), at a microsystem level, couples who have a child with SEN often experienced strain on their marriages and siblings were often noted as experiencing stress when dealing with a sibling who displays antisocial behaviours. She further points out that these families also faced additional rejection from society, additional strains on family finances and a general feeling of being separated from society. One of the greatest fears that these parents faced was that their children with disabilities would outlive them. The fear then was that there would be no one left to care for the child.

2.4.2 The Mesosystem

The mesosystem is the "set of microsystems constituting the individuals developmental niche within a given period of development" (Bronfenbrenner, 2005, p. xiii). In other words, the mesosystem is “a system of microsystems" (Bronfenbrenner, 2005, p. 80.) Both the mesosystem and the exo-system share a commonality in that they both deal with the relations between two or more settings, but these relations in the mesosystem involve the participation of the same persons in more than one setting (Bronfenbrenner, 2005), while the exo-system relations do not directly involve the developing child. The mesosystem relations refer to the different relationships the child has with his parents and any siblings, and other members of his extended family including grandparents, aunts, uncles etc.

Also, within this mesosystem is the relationship that the child has with his school. In the school environment the child interacts with many different people including members of staff, his peers, any support team i.e. physiotherapists, and speech therapists. The mesosystem is therefore seen as the exchanges and associations between the elements of the microsystem. The relations are always reciprocal, for example, the relationship between teachers and parents and how they influence each other. These interactions could be positive or negative and have an influence on the child (Woolfolk, 2007).

In an ideal situation, all schools would be fully equipped to deal with learners with any special needs. However, this is seldom the case in most South African schools, and usually, teachers feel ill-equipped to deal with learners with special needs.

2.4.3 The Exo-system

The exo-system is "composed of contexts that, while not directly involving the developing person (e.g. the workplace of a child's parent), have an influence on the child's behaviour and development." An example here would be if a parent has had a stressful day at work, there is a strong possibility that the parent would not be focussed on taking care of the child when they get home (Bronfenbrenner, 2005, p. xiii). The exo-system therefore includes all social settings which ultimately affect the child (Woolfolk, 2007).

At an exo-system level, Berry (1995, p. 380) states that very often the families of children with barriers to learning "did not receive the help/services they needed with their children." She further explains that these children were often given poor service and "denied access to public schools" In addition to this, parents could often not get the therapy they needed for their children and that which was available, was extremely expensive. Bronfenbrenner (2005, p. 47) clearly states that "any social institution that makes decisions that ultimately affect conditions of family life can function as an exo-system." Therefore, schools, neighbours, social services, mass media, local politics, and industry all form part of the exo-system.

2.4.4 The Macrosystem

Bronfenbrenner states that the macrosystem refers to the larger society. This means that the macrosystem refers to the ideologies, beliefs, values and attitudes within a society and therefore plays a role in what policies and theories they accept or reject. The macrosystem encapsulates the whole system, including all sub-systems that surround the learner. It can therefore be seen as a "societal blueprint for a particular culture or subculture" (Bronfenbrenner, 2005, p. 81). The attitudes of teachers towards inclusive education policies and their implementation can therefore affect the acceptance of learners with ASD and this in turn can affect the attitudes and subsequent involvement of parents.

2.4.5 The Chronosystem

The chronosystem "permits one to identify the impact of prior life events and experiences, singly or sequentially, on subsequent development" (Bronfenbrenner, 2005, p. 83). He believes that these experiences may originate in the external environment such as the birth of a sibling, or within the organism such as first menstruation. Depending on the age of the child and the severity of the event, these may often serve as an impetus for developmental change (Bronfenbrenner, 2005). Santrock (2004) refers also to the socio-historical conditions learners find themselves in; stating that as an example, children today are the first generation to grow up in environments defined by electronics and computers and new forms of media. He believes that this will have a marked impact on the way in which the child experiences his world.

For this reason the point at which events occur could have far reaching effects. For example, a family inheriting a large sum of money could mean extra support services being offered to a child with ASD, which could prove to be a turning point in his development. But should this happen too late in the child's life (timeframe) the effects could be negligible.

With reference to WP6 (DoE, 2001, p. 38) the recommendation is that a timeframe of 20 years be put in place for the attainment of inclusive education and training. This point is further emphasised by the Ministry of Education (DoE, p. 31), where a commitment is made for higher education institutions to “increasing the access of learners with special education needs". The relevance of this to my study is that should these intentions become reality, the outlook for children with all special education needs would suddenly drastically and dramatically improve. Once again proving the point that the time at which dramatic events occur in a learner's life could change their prospects forever.

Woolfolk (2007) states that Bronfenbrenner's ecological model has two overarching lessons. Firstly, she states that influences in all social systems are reciprocal in nature and secondly that there are many dynamic forces which interact with each other and in this way create a social context which influences our individual development. Engelbrecht (2010, p.10) believe that we need to look at a school as being a reflection of a democratic society. Within this microcosm of society, the school has to recognise that all its members have both rights and responsibilities. Engelbrecht (2010) further indicates that the inclusive school should make itself accessible to all members who find themselves in it. This not only refers to the physical accessibility of buildings, but refers also to the curricula and support systems which should be accessible to all members, regardless of their individual barriers to learning. This inclusive school therefore should have a philosophy of acceptance, which celebrates diversity. This sentiment is echoed by Mastropieri and Scruggs (2010) who assert that learners with SEN should only be educated in separate educational settings if the student's needs specifically dictate it. In any other circumstances, inclusive education with all its benefits is highly recommended.

After 19 years of democracy, there are still many parents lacking understanding of and accessibility to their constitutional rights. Some parents are influenced by socio economic status and others, their ability to exercise their individual and collective power. The solution to this would be a closer working relationship between parents and teachers. This relationship is however influenced by many factors "historical, economic, cultural and personal variations" (Engelbrecht & Green, 2007, p. 189).

2.6 CONCLUSION

In this chapter, literature on inclusive education and educational policies in effect in South Africa were discussed as well as international trends on inclusive education; highlighting the steps made towards these global trends in the South African context, from initial implementation to current implementation. Furthermore, the inclusive classroom was analysed, looking at support services needed to ensure that learners are able to reach their full potential. The necessity for full parental involvement was also examined, to ascertain the benefits which can be derived from schools collaborating with parents.

This chapter also dealt with the experiences of parents looking at the ways in which parents have in the past changed the way in which their children were educated.

This also included looking at the ways in which children in Africa are diagnosed with ASD. In addition, ASD was discussed at length, looking at the diagnosis thereof as well as suggested ways of fully including children with ASD into the inclusive classroom. The chapter concludes with an assessment and explanation of Bronfonbrenner's ecosystemic model and how it relates to this study.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

This chapter provides insight to the chosen research design and the processes involved in the methodology used in the study. It focuses specifically on the methods used within this qualitative enquiry, which seeks to understand the parents' experiences regarding the education of their child who is on the Autism Spectrum.

The chapter begins with a reminder of the chosen research paradigm and approach and includes a discussion regarding the choice of methodology and the reasons for its selection. Also included, is a discussion of the methods used for data production, as well as the sampling method used. From the outset, I have placed myself as a participant researcher, and therefore acknowledge my position as both the researcher and a participant, responsible for obtaining information from the participants as well as contributing to the data itself. Data analysis strategies are also discussed in detail, including methods of analysis and explanations gleaned from literature, on the use of this type of analysis. I then discuss an outline of the measures taken to ensure the trustworthiness of the study, as well as a description of the ethical issues taken into consideration whilst conducting this study. The chapter concludes with a discussion of what happened during the fieldwork!

3.2 RESEARCH DESIGN

According to Mertens (2010), research is the process of systematic inquiry, which involves the collection, examination, elucidation and subsequent use of the data, and in this way, provides further insight and better understanding of a chosen topic. A current view held by de Vos, Strydom, Fouche and Delport (2012) is that there are predominantly two recognised approaches to research, namely a qualitative and a quantitative approach. Since the purpose of quantitative research is to "quantify a research problem, to measure and count issues and then to generalize these findings to a broader population" (Hennink, Hutter & Bailey, 2011, p. 16), this approach was not suited to the study.

This study is aimed at eliciting information-rich data from the participants by looking at behaviours, beliefs and understandings of the context of people's experiences (Hennink et al., 2011), therefore a qualitative approach was deemed more appropriate. This is an empirical study since it is largely based on the building on of existing knowledge. Mertens (2010) explains that this existing knowledge can be derived from written resources, as well as interaction with the community. The community in this case, refers to parents who live with a child diagnosed as having ASD and therefore are able to provide a wealth of information regarding the schooling of their children. Boeije (2010) similarly states that participants play an active role in the construction of their social reality and the meaning they ascribe to it.

3.2.1 Research paradigm

Creswell (2009) believes a worldview or paradigm is a way of looking at the world and feels that all researchers bring a worldview to a study that informs his or her decisions. He further states that paradigms differ according to a number of philosophical elements, which underpin the particular study namely: ontology, epistemology, axiology, methodology and rhetoric.

As previously mentioned, a qualitative approach has been followed in this study where the researcher seeks a better understanding of complex situations by describing and considering the phenomena from the participant's point of view (de Vos et al*.,* 2012). By placing myself as the observer within the participants’ world, I have been able to turn observations of this world into a series of representations through the interpretations of notes, interviews and conversations with my fellow participants. Springer (2010) explains that this type of study is aimed at giving a holistic view of the situation, as seen by the participants. Schneider, Pierson and Bugental (2015) state that this type of research allows the researcher to gain a clearer understanding of a situation than would be possible through the use of questionnaires. This is due to the fact that the researcher gains insight into a situation by asking for complete details of the event including what led up to said event. In this type of research the descriptions are obtained either from individuals who have lived through the phenomenon or by someone who witnessed someone living through the phenomenon.

De Vos et al (2012) believe that the researcher should, at the outset, decide how to view social reality. They further contend that this can be viewed either objectively, as an external reality "out there", or subjectively. When viewing reality objectively, the researcher does not involve himself in this reality, but rather maintains a distant or separated position. However, when using a subjective view, the researcher immerses himself into that world where reality is then *constructed* through the research participant's meaning of his or her life world.

For the purpose of this study, this subjective view is more viable since I fulfilled the roles of both researcher and participant, and as I am also the parent of a child with ASD, I am automatically ”immersed” in this life-world (Thomas, 2009, p.75). Also, each participant's experiences are unique and were thus subjectively interpreted in the search for a new understanding of the inclusion of children with ASD in the South African schooling system from the perspective of their parents. This qualitative study is therefore interpretive in nature and aims to give "depth rather than breadth" to the collected data (Basit, 2010, p.16). Since an interpretive paradigm places the participant in the very centre of the study, it was deemed the most suitable paradigm for this study.

3.3 METHODOLOGY

King and Horrocks (2010, p. 6) clearly explain that there needs to be a clear differentiation between "methods and methodology". They state that "methods" can easily be explained as being techniques or procedures, which are used to "collect and analyse data". The word "methodology" however, relates to the process underpinning a study. In other words, the "design of the research and choice of particular methods and their justification in relation to the research project are made evident" (King & Horrocks, 2010, p. 6). The methodology requires that the researcher has a very specific reason for her choice of a particular technique for data collection or analysis. Methodology therefore, is best described as being an approach or perspective that in turn has "implicit and explicit expectations about how research is undertaken" (King & Horrocks, 2010, p. 7).

For the purpose of this study, the methodology of choice was phenomenology. Springer (2010, p. 20) sheds light on the term "phenomenology" by explaining that this term refers to qualitative studies focusing on the experiences as perceived by the individual. He explains that the study is aimed at giving a holistic view of the situation as seen by the participants. Johnson and Christensen (2008, p. 48) state that "when conducting a phenomenological research study, a researcher attempts to understand how one or more individuals experience a phenomenon." Since this research has been conducted from the point of view of parents with children who display ASD, a phenomenological approach was thus best suited. It allowed me to understand the phenomena under study, on the participants own terms, and provided a description of their experiences as perceived by them.

According to Johnson and Christensen, (2008, p. 397) phenomenological researchers not only look at how individuals' experiences of a phenomenon differ, but are particularly interested in searching for commonalities of the experiences consistently found among all the research participants and then trying to understand these commonalities. The emergent commonality is then known as the *"essence"* of the experience (Johnson and Christensen, 2008, p. 397). This search for the *"essences of a phenomenon"* is considered by Johnson and Christensen (2008, p. 397) to be "the defining characteristic of phenomenology as a research technique". The result of the research is therefore a "careful description of the conscious everyday experiences and social action of subjects" (de Vos et al, 2012, p. 316).

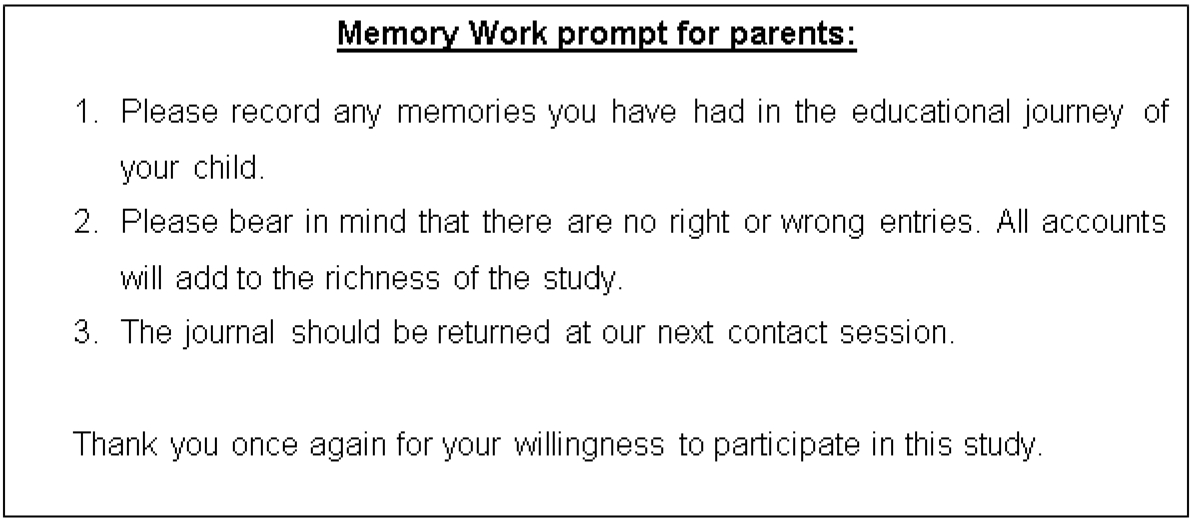
3.4 METHODS OF DATA PRODUCTION

This section focuses on the process and procedures employed in this qualitative inquiry which seeks to gain understanding of the perceptions of parents educating their children who experience ASD. I locate myself from the outset as a participant researcher. I acknowledge my own position as both researcher and producer of part of the narrative of the group. The first technique employed to elicit data was making use of memory work. The technique is discussed below.

3.4.1 Memory work

According to Lapadat (2010, p. 82) "memory work is a flexible methodological approach that can be adapted to a variety of purposes, settings and groups". For the purpose of this research, I asked the participants to record their remembered experiences of living with a child with ASD. Memory work can generate "emotional responses" (Holland, 2007, p. 199) which are crucial in qualitative research. I was extremely cautious in my initial discussions with them to not in any way influence their line of thinking, by giving them any indications of the types of responses I would be expecting from them. Table 3.1 below shows the prompt given to the participants to record in their journals.

Table 3.1: Memory work prompt



Memory Work prompt for parents:

1. Please record any memories you have had in the educational journey of your child.
2. Please bear in mind that there are no right or wrong entries. All accounts will add to the richness of the study.
3. The journal should be returned at our next contact session.

Thank you once again for your willingness to participate in this study.

The participants' thoughts, experiences and perceptions were written into their own small journals, which they then brought back to the next session in order to share the contents with the group. The participants were asked to firstly discuss how they experienced recording their lived experiences. They were then asked about incidents, either positive or negative, which stood out whilst they were writing their memories into the journals. Lastly, the group discussed how they felt having a child with ASD had changed them as people. The contents of these diaries were transcribed afterwards and then used to establish common themes and trends, or as Johnson and Christensen say, “essences of the phenomenon" (2008, p.397).

In the opinion of Lapadat (2010, p. 99), memory diaries afforded the participants the opportunity to reveal specific events and by allowing them to put these memories into words a therapeutic effect was experienced by the participants. Burman (2003, p. 274) refers to this approach as allowing the participant to have an "experience-distant" of their personal accounts. Since this group is essentially a support group, these diaries were also a tool, which could be used in the telling of their personal stories to "empathetic listeners" and "witnessing the stories of others". By sharing these very personal stories, it created an "open sharing of personal vulnerabilities" within the group, and in doing so, created a "deeper understanding of oneself and the others" (Lapadat, 2010, p. 100). What was of particular importance, according to Lapadat (2010, p.82), is that in order for these memory accounts to have "breadth of scope," the subject material must have significance for each member of the group as is the case in this study. By using an approach to inquiry such as memory work, participants were given the opportunity to "make meaning of their lives" (Lapadat, 2010, p. 101).

These journals were brought to our first group session, held at my home. We discussed the contents thereof during the meeting. However, the participants felt that once we started discussing the journals, this triggered memories and feelings which they had forgotten and they felt they needed more time to complete the journals. After the meeting, they expressed a desire to take the journals home and continue working on them during the week and then to return with them the following week.

3.4.2 Drawings

The second technique used to obtain information-rich data was making use of drawings. Haney, Russell, Michael and Bebell (2004, p. 241) contend that drawings have been used for "decades and are markers and mirrors of personal identity." They further claim that drawings offer a "unique window on events and their meanings". The introduction of drawings into the qualitative research study, not only changes the way in which the information needed for the study is presented, but it also affords the interviewee the chance to "escape the linearity of the spoken or written word" (Zweifel & Van Wezemael, 2012, p. 2). According to Mays, Stum, Rasche, Cox, Cox and Zimet (2010, p. 330) the use of drawings as a "projective technique" allows the researcher to "expose motivations and perceptions about an object, situation or condition". They further contend that visual representations provide a "window into themes that are not easily or comfortably expressed through words".

The participants were asked to depict themselves in a drawing. The "trigger" or way in which the drawing process was started (Gillies, Harden, Johnson, Reavey, Strange and Willig, 2005, p. 202) was by asking the participants the following:

Table 3.2: Drawing prompt

Drawing prompt for parents

"Make a drawing of how you see yourself as a parent of a child with ASD"

- We are not aiming for the artistic beauty of the drawings, but the portrayal of how you see yourself. So, any drawing is welcome.
- When you are done with your drawing, please write an explanation of why you chose the particular depiction and what it means to you.
- Prepare to share your drawing with the rest of the participants, but share only those aspects that you feel comfortable with.

The drawings were also discussed in depth during a second group meeting at my home. Participants were given the opportunity to firstly complete the drawing with an explanation. Each drawing was accompanied by a written explanation of the drawing. Participants were then given a chance to explain the reasons behind the drawing and were given the opportunity to view the other drawings in the group. The rationale behind this exercise was for me to get a clearer understanding of the way in which these parents viewed themselves; that is, did they have a clearly defined role in the lives of their children? This led to a discussion of the reasons why they felt their drawings represented their true "role" and of the successes and failures they had experienced in fulfilling this "role".

3.4.3 Focus group discussions

The final technique used to extract information for this study, was the use of focus group discussions. In terms of this study, the use of a focus group allowed me to gain a deeper understanding of the journeys each parent was on, trying to educate their child with ASD. Liamputtong (2011) states that focus groups are particularly useful when investigating the manner in which participants think, as well as the manner in which they view matters deemed of importance to them. Liamputtong (2011) further states that the focus group discussions afford participants the opportunity to state their opinions without being forced into making decisions about the topic being discussed or having to reach a consensus. This statement is further endorsed by) who believes the focus groups are most suited for examining the "stories, experiences, points of view, beliefs, needs and concerns of individuals". Kitzinger (2005, pp. 56-70) also states that this group work affords the researcher the opportunity of gaining insight into many forms of communication which people use in their every-day interactions, such as "joking, arguing, teasing and recapturing past events". These interactions give the researcher valuable insight about the participant’s knowledge and experience. For these reasons, focus group discussion was very suitable for this study.

According to Johnson and Christensen (2008, p. 209), a focus group is a type of "group interview" in which a facilitator leads a discussion with a small group of individuals, in this case parents of children with ASD, to "examine, in detail, how the group members think and feel about the topic." The role of the group facilitator therefore, is to keep the participants "focused" on the topic under discussion. Dahlberg and McCraig (2010, p. 120) describe a focus group as being a group discussion which is facilitated by a "researcher who asks the group to discuss experiences and attitudes to a particular issue or to respond to specific questions". They re-iterate, however, that focus groups are not merely discussion groups since the proposed result of a focus group is to gain insight into the opinions and feelings of the group about a specific topic. I therefore encouraged the group to interact not only with me, but also amongst each other in order to gain deeper insights into their experiences.

The participants of a focus group are seen as coming to the group with certain "fundamental orientations and ideas (held truths) that may better be elaborated through interactions with others" (Belzile & Oberg, 2012, p. 461). For the purpose of this study, I made use of a focus group to obtain part of the information needed. The participants consisted of members of a support group, of which I am also a member. We meet once a month to share experiences of living with children with ASD. This group meets with the purpose of providing a safe environment in which members can safely talk about their joys and frustrations as well as the needs of their children in a non-judgemental setting. As this group has been in existence for a while, there was already a level of established trust within the group and members were comfortable speaking amongst each other, and I hoped that this would facilitate discussions within the group. I had the focus group sessions at my home and ensured that there were no distractions in order to facilitate open discussions.

As I was both facilitator and participant in the focus group, I needed to ensure that I did not, in anyway, influence the responses given by the participants. In doing so, I was striving to limit any biases or preconceived references, which could cloud the integrity of the study (Dahlberg and McCraig, 2010, p.120-121; Denzin and Lincoln, 2005, p. 730). I also ensured that the participants were aware of my dual role within the group.

3.5 SAMPLING

In order for me to get a deeper understanding of how parents experience educating children who present with ASD, I had to select parents who had experience of the phenomenon. Thus, the sampling had to be suited to selecting the right people. Johnson and Christensen (2008, p. 222) describe sampling as the process of selecting a sample from a population. They believe that sampling allows one to "study the characteristics of a subset (called the sample), selected from a larger group (called the population), to understand the characteristics of the larger group."

In qualitative study, the researcher uses sampling to gain insight into the research topic. Hofstee (2011) takes the view that it would therefore be necessary that the researcher investigates where the relevant data is likely to be found. In other words, the researcher needs to discover who else would be interested in the type of data required and where would this data most likely originate, be generated or stored. For the purposes of this study, the information which I needed was found within a group of parents who meet on a monthly basis to discuss their children living with ASD.

Basit (2010) states that the sampling strategy primarily used when working with an interpretive paradigm is non-probability sampling. Creswell and Clark (2011, p. 173) refer to sampling in qualitative research as “purposive sampling.” Here, the researcher purposefully selects participants "who have experienced the central phenomenon or the key concept being explored in the study" to form his or her sample. Although a number of purposeful sampling strategies exist, for this particular study, I made use of homogeneous sample selection (Creswell & Clark, 2011; Johnson & Christensen, 2008).

Homogeneous sampling consists of selecting a relatively small, homogeneous group of around six or seven individuals that "have a membership in a subgroup with distinctive characteristics" (Creswell & Clark, 2011, p. 174). Researchers that wish to employ a focus group strategy, often select this type of sampling, as the facilitator is able to obtain in-depth understandings of how individuals think about a phenomenon, by generating group discussions with open-ended questions (Johnson & Christensen, 2008, p. 244). The homogeneous sample selected for this study therefore consisted of a group of parents who have children presenting with ASD. These parents were selected from an autism support group in the Port Elizabeth area to which I belong. Thus, besides being convenient, costs and time constraints were significantly reduced. The group consisted of 4 parents, including myself.

As the sample group of this study was rather small, it was impossible for it to be representative of the larger population. Therefore, as the researcher, I was not concerned with generalizing the findings to the larger population, but instead relied heavily on information-rich data, gleaned from these parents.

3.5.1 Biographical details of participants

The table below provides information on the parents who participated in this study and their biographical details in order to assist the reader in understanding who they are. This information is also important in assisting the reader with understanding what shapes the individual participants' experiences of educating their child who is on the autism spectrum.

Name	Age	Relationship Status	Occupation	Number of children altogether	Details of child with ASD
Wanda	45 years old	Married	Working mom - teacher	1 (a boy)	1 boy 11 years old
Hilda	45 years old	Married	Stay at home mom	2 children (a boy and a girl)	1 boy 14 years old
Nellie	34 years old	Married	Stay at home mom	3 children (2 boys and a girl)	1 girl 5 yrs old
Betty	28 years old	Married	Working mom- shop assistant	1 (a boy)	Boy 4 years old

Table 3.3: Biographical details of participants

3.6 DATA ANALYSIS

In this section I discuss how I worked with the data from the memory accounts, drawings and group discussions. I discuss the methods employed to make meaning of the data, from transcriptions of recordings to how themes were determined in this exploration of parents’ experiences of educating a child presenting with ASD.

3.6.1 Transcription of recorded data

In order to facilitate the analysis of the data collected during the field work, the sessions were recorded. These recordings were carefully transcribed after the sessions. King and Horrocks (2010, p. 142-143) described transcription as "the process of converting recorded material into text". In order for this transcription to be as accurate as is possible, the recordings had to be of a decent quality. The transcription of the materials was therefore made considerably easier. Only once the field work transcription was completed could I ascertain whether I had reached a saturation of the data (King and Horrocks, 2010, p. 144).

Since the participants were fluent in English, the group sessions were conducted in English and I did not need to translate any of the focus group sessions or the written explanations in the journals and the drawing explanations that had been handed in from the participants.

3.6.2 Determining common themes and coding

Basit (2010) states that the collected information needs careful analysis. Creswell and Clark (2011) believe that the core feature of data analysis in qualitative research is the coding process. Lichtman (2010) adds to the discussion by stating that the purpose of coding is to enable the researcher to separate the essential from the non-essential information. Lichtman further contends that by doing this, the researcher is able to sort and organize text according to recurrent themes and concepts.

Since the qualitative researcher deals primarily with "words" as opposed to "numbers", this requires the researcher to deal with multiple meanings and interpretations of data. However qualitative data can reveal very meaningful information. The challenge is for the researcher to retrieve important data and in doing so discard less important data. This has to be done whilst being cognisant of the fact that the crucial essence of the data should not be lost. Careful coding of data is therefore essential. Miles & Huberman (1994) further determine that coding is the analysis of field notes. The researcher dissects these notes meaningfully whilst keeping essential parts intact. This analysis requires the researcher to differentiate between important and less important information and to combine similar data, and then to make meaningful reflections regarding this information.

Shank and Brown (2007) argue that one of the most effective ways to look for patterns in a qualitative study is to look for themes. These patterns can best be described as being the principles within the data, which in turn help to give the research coherency and to make it understandable to the reader. In establishing patterns of themes, the researcher establishes her "take" on the data being presented. In this way, her understanding of the topic is shown. Codes are tags or labels for assigning units of meaning to the descriptive or inferred information, compiled during a study. These codes are attached to chunks which may vary in size, for example, words, phrases, sentences or whole paragraphs (Miles & Huberman, 1994). These codes then allow the researcher to retrieve and organize chunks of information, thereby ensuring that all relevant information is readily accessible. The information is then clustered according to specific research questions, hypotheses, constructs or in this case, themes. Through this clustering of information, the researcher is then able to draw conclusions, which ensure that the information collected can be properly analysed (Miles & Huberman, 1994).

This method of grouping together information in chunks or clustering was used in reviewing the generated data in this research. Lichtman (2010) further explains that once the coding process has been worked through, the researcher needs to return to the documents to search for additional information which would further enhance the interpretation and the depth of the study.

Tesch (1990) presents the following eight steps, which I followed in the analysis of my data:

1. I randomly selected one document (e.g. written memory work) and carefully scrutinize it, whilst asking myself "What is this about?" The objective was not to think about the substance of the article but rather to ascertain the underlying meaning or theme.

2. This process was repeated for the remaining data documents. Lists were made of all topics and similar topics were clustered together. These topics then needed to

be arranged into columns and in doing so major topics, unique topics and then those which did not "fit" into specific topics emerged.

3. Topics were then abbreviated as codes and codes written next to appropriate segments of text. This initial organizational scheme also helped me to ascertain whether any new categories or schemes were emerging.
4. I then needed to find the most descriptive wording for the topics, which could be turned into categories. These categories were then reduced by grouping together those with similarities.
5. I then made a final decision regarding abbreviations for each category. Codes were then alphabetised and colour coded.
6. The data materials belonging to each category were assembled in one place and a preliminary analysis was performed.
7. The last step was to recode of the existing data if necessary.

Through the careful following of the steps mentioned above, I ensured that every aspect of the research was thoroughly analysed and used to ensure a study which should stand up to close scrutiny. According to Creswell and Clark (2011, p. 209) the next step in the data analysis process is to "represent the results of the analysis in summary form in statements, tables or figures." In this qualitative study, I represented the results by building a discussion that could convince the reader that the themes or categories emerge from the data. The strategies involved in providing this evidence included:

- conveying subcategories or subthemes
- citing specific quotes
- using different sources of data to cite multiple items of evidence
- and providing multiple perspectives from the participants to show divergent views (Creswell and Clark, 2011, p. 209)

The last phase of the data analysis process was an interpretation of the results or findings. Here Creswell and Clark (2011) suggest taking a step back to get an overview of the research and to determine how the results relate to the research problems, the existing literature, the aim of the study and personal experiences.

3.7 TRUSTWORTHINESS

When the data generated has been analysed and interpretations made, it is important to ensure that the research process and its findings are credible to an external audience that was not involved in the study. Thus several steps have to be taken into consideration to ensure trustworthiness of research and its findings. Johnson and Christensen (2008, p. 275) emphasize the importance of research validity or "trustworthiness" in qualitative research and feel that this usually refers to research that is "plausible, credible, trustworthy and therefore defensible" and insist the researcher employs certain strategies to maximize validity.

Creswell and Clark (2011) believe that qualitative researchers focus on validity (rather than reliability such as in quantitative research), which can be achieved by using more than one procedure or strategy to assess whether the information gleaned from the participants is accurate, credible and can be trusted. To ensure validity in this particular study, I employed the following strategies:

Member Checks (Creswell & Clark, 2011, p. 211, Mertens, 2010, p. 257) or **Participant Feedback** (Johnson & Christensen, 2008, p. 276) – Here, the researcher seeks verification from the participants regarding the findings, analyses and interpretations of their experiences. My interpretations and conclusions were therefore discussed within the established participant group to verify whether the findings were accurate reflections of their experiences.

Triangulation of Data (Creswell & Clark, 2011, p. 211, Mertens, 2010, p. 258, Johnson &Christensen, 2008, p. 276) – Triangulation occurs by cross-checking information and conclusions through the use of multiple data collection procedures and sources. Corroboration occurs if these findings are in agreement and consistency of this is evident across the sources. The multiple sources of data employed in this study ensured triangulation of the data.

Reflexivity (Johnson & Christensen, 2008, p. 275) – Researcher bias is considered a serious threat to the validity of a qualitative study. This may result from selective recording of information or from allowing personal views to cloud the interpretation of data. To limit this potential threat, a strategy known as reflexivity is used by the qualitative researcher. Here, the researcher is expected to be critically reflective about his or her potential biases and predispositions. Mertens (2010, p. 249) believes that in a qualitative study, the researcher becomes "the instrument for collecting data" and therefore to determine the impact on the research data and limit researcher bias, he or she should reflect on "their own values, assumptions, beliefs, or biases" which they may bring to the study. As the researcher therefore, I openly discussed any pertinent personal background which may have affected the research by influencing my interpretation of the data. I have also included a statement in which I position myself and lay out all my biases in the open.

Confirmability (Mertens, 2010, p. 260) – When doing qualitative research, it is important that all data can be traced back to its original source and the logic employed to interpret this data should be clear. Saldana (2011) believes that the researcher has to, at all times, maintain honesty and integrity. The researcher can ensure this by keeping accurate records of all work done, which allows for auditing of the data and this in turn, increases the credibility and trustworthiness of one's research. For this reason, I kept a confirmable audit trail of all field notes, consent forms, transcripts, written memory work and drawings.

Intercoder agreement (Creswell and Clark, 2011, p. 212) – Although reliability seldom plays a part in qualitative research, it can be used to compare coding among a few coders. Once a coding scheme is determined, coders are asked to code the same text passages that the researcher (myself) has already coded, to determine if they assign the same codes to the texts. Findings from this coding procedure should help to formulate rates of percentage codes (i.e. majorities and minorities) among commonalities and these reliability statistics can be computed for systematic data comparisons. I worked closely with my supervisor and another NMMU lecturer as intercoders on this study.

Saldana (2011, p. 135) states that credibility ensures that qualitative research presents a convincing story and conclusions drawn are in fact accurate. Thus, even though research cannot be "proven" as being right, we need to persuade the reader to consider viewing the situation as we have. To achieve this, credibility was obtained through the citation of related articles by prominent authors in the fields of autism and inclusion.

3.8 ETHICAL ISSUES

Conducting research is not only about generating data from the participants, but it is also about ensuring that the data is generated in an ethical manner. Boeije (2010,) states clearly that whilst, in theory, we can gain knowledge in any number of ways, social scientists follow ethical rules of conduct which serve to protect both the participant and the researcher. It stands to reason that any information which is gained unethically can potentially cause great harm to participants and call into doubt the validity of any findings the researcher might uncover. Miles and Huberman (199, p. 290-295) clearly point out that there are a number of specific issues and ethical measures that need to be considered before, during and after a qualitative study. The following points reflect the measures that I have considered during the course of this research study:

- **Competence boundaries**: I had to consider whether I had the competency to carry out a study, which would produce results of a high standard, and if in any doubt, I made the decision to allow myself to be led or trained accordingly. I also ascertained that appropriate help was available if needed, from my supervisor.

- **Informed consent**: I had to ensure that all the participants were completely aware of their rights both during and after the study. Consent was given "freely" without any intimidation from me, the researcher. The required consent in this case was needed from the parents participating in the study. All participant signed informed consent forms, whilst I made myself available to answer any questions, which arose.

- **Benefits, costs and reciprocity**: Whilst I might be "paid" for my work in terms of getting my master's degree, the parent's involvement was not for any financial gain but rather for the greater social good. It was however hoped that through the participation in the study, the parents would also gain a deeper understanding of their child with ASD and the knowledge that the situations in which they find themselves are not unique, but shared by other parents. I did however, bear the costs of all materials to be used in the completion of the study i.e. journals for memory work. Parents were also given refreshments and a small gift during focus groups and transport, to or from the venue, were made available to them.

- **Harm and risk**: I needed to consider whether this study might harm the participants in any way. In a qualitative study, the risk of participants being hurt can occur in many ways: from self-esteem injuries, to privacy violations or even being sued. I therefore had to ensure that data was not altered or misrepresented, as this could have affected the integrity of the study. As facilitator during focus group sessions, I needed to ensure that all group sessions were conducted in a professional, yet comfortable manner. Thus participants were free to share their stories in a language they felt comfortable with between Afrikaans and English.
- **Honesty and trust:** Since the participants consisted of members of my autism support group, a positive relationship between the participants and myself already existed. This relationship was built on trust and honesty which had been built up over a period of more than a year. This level of trust was essential since participants had to trust me, to portray events both honestly and accurately. In doing so, the risk of participants being unhappy with the final product was minimised.
- **Privacy, confidentiality and anonymity**: The participants were assured that their privacy would be respected as well as their anonymity. To achieve this, I ensured that the participants could not be identified when the information was read. All participants were therefore given pseudonyms once the information from the discussions had been transcribed.
- **Research integrity and quality:** A Qualitative Researcher needs to ensure that collected information will stand up to scrutiny. To ensure this and to

maintain the ethical authenticity of the study, I have implemented the following measures:

1. A letter of informed consent from each parent participating in the study, explaining the reasons for the study and what the findings would be used for, as well as assurance of confidentiality and anonymity, particularly as focus group sessions would need to be recorded. As part of the signed document, a statement informed them that their participation was voluntary and they were free to leave the study at any time. They were also given the assurance that they would not come to any harm whilst participating in the study and that their participation would add to the body of knowledge regarding the research topic.

2. Approval for research was given by the NMMU Ethics committee, Faculty Research, Technology and Innovation Committee of Education (ERTIC) on 6 August 2013. The ethics clearance reference number is **H13-EDU-ERE-024**.

3.9 POSITIONING MYSELF

I felt it was necessary to provide pertinent background details about myself, as I was both researcher and participant in this study. I am a qualified Foundation Phase teacher. I have been married for 19 years to a wonderful man, who fortunately, is a very involved husband and father. We have one son, who is eleven years old and he has been diagnosed with ASD

When we decided to have a child we never thought that this would be such an incredibly tough journey. We miscarried 2 children before managing to carry our son to a viable gestation period. Our son was born prematurely at 30 weeks and weighed 1.3 kg at birth. He spent the first 3 months of his life in the Neonatal Intensive Care Unit. This was an incredibly tough time for our family with emotions ranging from utter joy because he managed to drink 1ml of milk, to utter despair because the doctors could not give us any indication of when he could possibly be taken home. Our stay in hospital was difficult because our son's progress was slow due to birth complications such as meningitis which caused a block in his brain. This blockage caused hydrocephalus and resulted in his having to have a shunt fitted at the age of two months. Due to all of this head movement he also developed a condition known at Single Suture Cranial Synostosis. I think there was a small part of me that always waited to find out what the "damage" would be from all of these birth complications and for that reason I was always on edge waiting something to happen.

After we received our son's diagnosis, I resigned from my teaching post to spend more time with him and to take him to the different therapies he needed, to facilitate his progress. We felt that we needed to do every therapy available to enhance his development. What followed was years of expensive therapies and intervention strategies, all of which I would do again in a heartbeat if need be. These years contained both very high points and very low points, but it afforded me the opportunity of meeting such amazingly supportive people, whom I might, under other circumstances, have never met. When your child has been diagnosed as having a disability of any sort, there are only two routes you could take. One would be to ignore the situation and pretend that it is only a very bad dream or you could, as we did, embrace the diagnosis and the closure which that knowledge brings with it. I immediately sought out other parents with children who are also on the Autistic spectrum and joined a support group. In situations like these I have found the saying "a sorrow shared, is a sorrow halved" really holds true.

Once our son was settled in a main stream school and had a full time tutor accompanying him to school. I felt that I could return to part time teaching and for this reason accepted a 3 day a week position. This still gave me the chance to spend afternoons with him and also gave me the freedom to be able to accompany him on class outings. It was also during this period that I decided to return to University to obtain my Honours Degree. I credit my son with giving me the reason to study, since I felt that, if I was to make any difference in society's perception and attitude towards inclusive education, I needed to have more than a four year teaching diploma behind my name. On completion of my Honours Degree, I knew that I had to continue and complete my Master's degree. I felt very strongly that parents needed to have a voice and have their stories told. I sincerely hope that I have done their journeys justice.

3.10 IN THE FIELD

My initial excitement in doing the data generation waned considerably in the beginning stages due to the fact that the group struggled to find an appropriate time to meet. To find a suitable time, where all four of us would be present, proved rather difficult, but I felt it was crucial that all four participants (including myself) were at the initial session where the expectations regarding the journal requirements would be explained. In this way, everybody received the same information and this limited confusion of possible verbal omissions or misinterpretations of the written instructions. Interestingly, even though I did it in this way, the journals were still interpreted very differently. Three of the four participants interpreted the instructions in the same manner, while one participant did her journal completely differently.

Our first official group meeting took place in early November, 2013, where expectations were explained regarding the journals. Each participant was given a small journal and a pen, and was also asked to complete their letters of consent. All contact details and critical information regarding anonymity and confidentiality were included in these letters of consent. The participants were then given a month to complete their journal entries. During this month, I sent out numerous reminders via text messaging, to the other three participants, to encourage them to stay on track with their journal entries and to ask questions if necessary.

I was also required to keep a journal since I was a participant researcher. From my point of view, I found the journal to be fairly time consuming and had to force myself to make time to complete the journal. I also found that I felt quite protective of the information I was writing in the journal and was reluctant to even let my husband read it at first, as it was a reflective journal which required me to dig up fairly deep-seated emotions and memories. I found that as I thought about incidents which had happened years ago, more memories came to the surface. Some of these memories that I had suppressed, proved to be fairly painful, but at the same time also cathartic.

When doing a journal like this, the participants found their emotions swung between sadness as to what had happened to their families since their child had received the ASD diagnosis, and being grateful for the journey and growth they had made in terms of their families' acceptance of the child with ASD and the academic and personal growth their child had experienced. This was especially pertinent when the child was given a particularly negative prognosis from a so-called professional (in our case, our son's neurosurgeon) and he/she manages to surpass the initial expectations.

December proved to be particularly tricky to organize a group session with family commitments, a wedding, Christmas celebrations and family holidays. Therefore, our second session only occurred in January 2014. This meant that participants had two months to complete their journals, instead of the planned one month. In spite of this extra time, participants still felt they could have had even more time.

On the morning of the second session, I also had to explain to one of the participants that her visiting sister would not be able to attend our session. She thought that there would be no problem in allowing her sister to sit in with the group. I had to explain that having a person who was unknown to the group would firstly affect the dynamics of the group and would mostly likely inhibit the openness of the discussion. I then had to also explain how the format of the group had changed from our monthly support group sessions to this more formal research session. Luckily the participant understood my reasons completely and arrived at our group session alone. When the participants arrived for the sessions, they were excited to be participating and were completely at ease with each other, probably due to the fact that we had all been meeting once a month for more than a year for our support group sessions. Once I had thanked them for coming and explained the basic "rules" for the sessions, we began our discussion of the journals.

I found that the discussion flowed easily but I had to constantly be aware of the fact that I was the researcher in this group and that I could not let discussions get side-tracked. This role as group leader was quite unfamiliar for me and I found this aspect quite challenging. What I found particularly heartening though, was the fact that the participants were very enthusiastic to be part of the research and seemed genuinely keen to assist me. Since this was a topic very close to their hearts, these participants felt this type of research was necessary so that misperceptions of ASD can be altered. This session was recorded and transcribed by me later. I tried to make the session as comfortable and relaxed as possible. My house was quiet as no one else was home and I provided refreshments for all to enjoy. Everybody was very controlled and there were no emotional outbursts of any kind. At the end of this session, I informed the participants that they would be doing drawings at the next session. I explained that I wanted them to draw themselves in the role that they perceive themselves in the life-world of their child. I asked them to think about it over the next month so that they would have an idea of what to draw.

The final session occurred in February, 2014 and followed a similar agenda to the previous session. The house was quiet and refreshments were provided. Participants were given the necessary paper and stationary to enable them to do their drawings and a lot of fun was had by all. Once the drawings were completed (amidst a lot of rubbing out and laughter) participants were asked to provide a written description of their drawings to ensure accurate interpretation of their works of art. We then took turns to share our drawings and their meanings with the group. As a token of my appreciation for their involvement in my research, I gave each participant a small gift of a coffee mug with an autism inspired message on it, filled with chocolates. This concluded our final session.

3.11 CONCLUSION

This chapter has presented the methods adopted in the process of this study. I have also discussed the problems encountered in obtaining the information, disappointments and elucidating moments encountered in the process of doing this study. I also discussed the emotional issues which are coupled with doing research which is of a highly emotional nature. I discussed the methods employed to gather data needed and the processes undertaken to ensure that data was accurately recorded. I discussed my position as a participant-researcher and the findings of my study. In the next chapter I discuss the implications of this research and possible suggestions for further studies.

CHAPTER FOUR

RESULTS

PARENTS EXPERIENCES OF EDUCATING THEIR CHILDREN PRESENTING WITH ASD

4.1 INTRODUCTION

The purpose of this research was to explore the experiences of parents of children presenting with autistic spectrum disorders (ASD) and the journeys they have been on while educating their children. It is aimed at understanding how parents make meaning of their individual experiences in order to develop guiding strategies to improve the inclusion of children presenting with ASD in the mainstream classroom.

For this study, I was a participant researcher and worked with three women from the ASD support group to which I belong. Being a participant meant that I understood what the participants were going through and how emotionally draining it was to write and talk about their experiences after mentally reliving them. However, as the researcher, it was essential that I separated myself from this role and looked critically at the data, without prejudice or any preconceived ideas or opinions.

The women with whom I interacted in this study are mothers of children who are on the Autistic Spectrum and are currently in various types of classrooms/schools. The facilities at which these children are being educated include:

- **A state-run special needs remedial school** - this is described as being a public school which caters for learners from Grade R to Grade 12 with special educational needs. Learners are offered appropriate therapies whilst still being exposed to the same curriculum offered in mainstream schools. This school strives to re-integrate learners back into mainstream schools where possible.

- **A private autistic school** - this small school is an early intervention centre for children who have been diagnosed as being on the autistic spectrum. These children range in age from two to about six years. The staff includes two qualified teachers and three assistant teachers, a psychologist, a speech therapist and an occupational therapist who are all privately funded by the parents. The school currently takes in a maximum of twenty children.

- **A mainstream classroom in a state-run primary school** - this school is a Christian-based Primary school, catering for learners from Grade R to Grade 7. The main focus of this dual-medium (English and Afrikaans) school however, is on mainstream learners that have no special educational needs.

- **A private Montessori school** - this school is described as being a fully inclusive school where children learn at their own individual pace. This school caters for children from Grade R to Grade 7. Being a private school the school fees are considerably higher than government schools and acceptance to this school is linked to space available.

I asked the parents to recount their experiences of the journeys that they have embarked on in educating their children, recounting both high and low moments. In doing so they had to revisit some, sometimes painful, memories and experiences which they may have almost forgotten. In this chapter, I have presented the data which has been produced through memory work, drawings and focus group discussions.

4.2 MEMORY ACCOUNTS

In this section, I have presented the memory accounts of the four participants in the study, as they had been recorded in their personal journals. These stories have not been edited. Each individual story is presented verbatim, beginning with a short introductory paragraph that describes the situation of the individual participant. Pseudonyms have been used to present each participants story.

4.2.1 Nellie's story

Nellie is a 34 year old, married, stay-at-home mom, with 3 children. Her eldest child is an 8 year old boy who is considered neurotypical. Her middle child, a girl, is 4 years old and has been diagnosed as being on the Autistic spectrum. Her third child is a 3 year old neurotypical boy. This is what she recorded in her memory account:

My name is Nellie. I am a mother of three. My middle child of four, a girl, is presenting with ASD. Our journey started very early at age two. Her formal diagnosis was at age 3. From about age 20 months she was in a normal playschool. We received confirmation from them that not everything was on par with her development, as we had been suspecting for a few months already at the time. In hindsight, we realised that she had regressed since about 13/14 months, not progressing with the skills that she had at the time. At age 2, we started investigating the reason for her development being crippled. Most specialists were cautious to make a diagnosis, as she is extremely high functioning and clinically her "symptoms" were not always clear. We however treated her as autistic from that time, regardless of the fact that we did not have a diagnosis, as we just realised the importance of early intervention.

Due to her sensory difficulties, we decided to facilitate her learning at home with a tutor. Bridging the gap at the time with regards to language development was more important than learning appropriate social interaction… We worked very closely with an Occupational Therapy (OT) and a Speech Therapist, addressing both sensory issues as well as language delays. We had meetings every 8-9 weeks, discussing problems, concerns and measuring milestones.

In Oct 2012, she was diagnosed. Upon recommendation of the paediatric neurologist, we decided to see whether Alice would cope in a mainstream environment. She is handling her challenges at school fairly well, even though she needs down time at home. We would find that home is her safe place where she can let down her hair and have her bad moments. She has amazingly found a way to find her calm at school and keep it together. 2013 and this year finds Alice in the same class at the same school. That is the broad spectrum overview - an in depth story would cover many more pages!

The life of an autist is a very challenging one. No one day is simple without challenges, regardless of how simple and easy a day is. They are the bravest, most loving children I have ever had a relationship with. They are always willing to try again, even if it means failing again. Being a parent of a child with ASD is a great challenge but also a great joy. It is one's biggest fear, but also your biggest hope. It is where one small victory, is a giant leap.

This is a journey of courage, of celebrating small victories and facing your challenges. It is a journey of the unknown. A journey of fear - never really knowing where it will take you. It is a journey of hope - knowing that there will be more victories. It is knowing it is okay to not have a good day. It is a lot of looking back and counting every small victory. It is a journey of faith - trusting the loving God that made your child. It is a journey of always trying to stay just one step ahead - so that the next step will be as easy as possible for your child. Choosing to put your child in a mainstream environment is not easy. It is almost like leaving your lamb with wolves but it is trusting your child, it is assuming competence, even if your child may not be. All in the hope of ensuring a better and safe future.

As a parent you learn by trial and error. All the books, regardless of how thorough they might be, might not have the answers you need. The mainstream environment is definitely not ideal for a child on the autism spectrum. There are no Individual Educational Program (IEP) meetings. Feedback is far and in between. We have been fortunate so far to at least have a teacher with tolerance. Tolerance can go a very long way for an autistic child. To make a change you will have to challenge a lot of ignorant people. My journey has just started; there is still a long rocky road ahead.

The journey so far has presented us with so many precious memories (also the ones that are bitter to swallow), weird obsessions, hearing a question for the first time at the age of three. The simple licking of a fruit she's never eaten before, starting to draw all by herself, way past the age of three years; learning new words and going from almost no speech to all the vocabulary of a seven year old. Her first "natural" interaction with a stranger, making social connections with a new friend. The memories are countless.

Then the bitter ones: all the processing disabilities, the challenges with comprehension and expression and scholastic issues. As an ASD parent, you experience life on a different level, a special needs child and their challenges isn't always child's play. We feel and deal with a lot. I for one, feel blessed to have been chosen for their journey, for being a part of a bigger plan, for being able to make a difference and most of all... for being changed.

The second participant, Hilda, shared many of the sentiments expressed by Nellie. This is her story.

4.2.2 Hilda's story

Hilda is a 45 year old, married, stay-at-home mom, with 2 children. Her eldest, a girl, is 19 years old and is currently studying at university. Her second child, a boy, is 14 years old and has been diagnosed as being on the Autistic spectrum. This is what she recorded in her memory account:

Timetables

When tested and the numbers were not in sequence, he was unable to answer correctly. If the numbers were in sequence, he was able to answer correctly, because he was able to recognise the pattern. Extending number sequences therefore is not a problem. Basic maths caused many problems for instance: 2+2=4 but then to teach that 3+1 also = 4 did not make sense.

Literal thinking

I tried to do homework once while we waited for soccer practise to start and he would not because it is "homework". It therefore has to be done at home.

Generalisation

So often, I would explain a concept at home, but then in class he was unable to apply it. And so also things learnt in class. This has caused many problems and much frustration.

Expressive Language

Expressing himself can lead to much frustration, as he is not able to verbalise his thoughts due to a lack of vocab and sometimes not able to communicate properly. To the outsider he might make no sense, but as a family, we would know what he might try to explain.

Obsession

My son is a big fan of Thomas the Tank Engine, Dinosaurs and lately Transformers. So often he zones out and it takes a second to discover that he is "replaying" a movie in his mind. So keeping him focussed on whatever task is at hand is a great mission. A word, song or picture from either of the above movies can make an appearance in his mind at any time. Then you know you have to give him your undivided attention to finish whatever he wants to explain, retell etc. If you do not listen, he is not able to complete the task at hand. Last year sometimes, the class was busy with a task and due to circumstances they had to move to another class with another teacher. He became very agitated and uncooperative. Unfortunately that teacher was unable to assess the situation properly. I was just told that he was difficult. It did not take me long to realise that the change over to the next class was done without prior warning and that the previous task was left incomplete. Red wanted to complete the task before moving off. Transition time is a vital part of his life.

Imaginative thinking

Preparing an oral "lost on an island" caused some stress because he told me that he has never been lost or been on an island. This is a challenging area of teaching. From very young we realised that Red would not attempt anything new unless it's something he is familiar with or able to master. Social stories have been a great help. He played cricket in grade 3 and after he walked off the field very upset because they bowled him out, I realised I never explained the possibility of being bowled out to him. He is unable to assume the obvious. Sudden deviation can cause major stress. Inflexible thinking is part of his life. The daily routine should not have surprises. I have worked very closely with his teachers to be a strong support team *for him. If something happens in class or at home, that might cause possible stress; we would be in contact to inform one another.*

Visual thinker

It has been a great challenge to find visuals to use to explain certain concepts or ideas. Being such a visual thinker can have many limitations. Abstract concepts can be challenging to teach. The idea of "next week" is far too vague. We put a big calendar in his room every year and on there we mark various events. Questions asked has to be specific and concrete like: "What did you do in the maths class today?" If I asked him what he did at school, he would reply "nothing!" So whenever I ask questions about school, I make them very specific. Assignments, projects etc needs to have sufficient info and guidelines otherwise he is not able to visualise it in his mind. I have had to make many calls and emails to teachers to confirm the basic outline of a project.

Environment

We have been very fortunate to have had him in a small class. Noisy environments cause him stress and distractions. I've requested that he gets permission to take a walk down the passage when he does feel stressed. The teachers at his school have shown much empathy to our situation and are very accommodating. Without a good support structure whether at home or school the child with ASD will not be able to develop emotionally or socially. We look back with much appreciation! All the effort that was put in is paying off. Red has just entered Grade 8. We know that the road ahead will have challenges, but what we have learned from past experience will be our guide. First day in high school, Red decided not to talk to anyone. Why? Answer: "I don't know these people". It is a good thing to teach your child not to talk to strangers, but then for a child with ASD, we must always be one step ahead. "It's ok to talk to them because they are teachers". The last two weeks have had some challenges. Teachers give the kids so many verbal instructions and Red has not been able to keep up. So I've had to meet with them and explain.

Primary school memory

Red played a soccer match against another school and midway through the game; he stopped and was doing something with his hands. By then his best friend stopped playing as well because Red has discovered he could make a crocodile shadow puppet on the grass. I found it at first embarrassing as the two teams continued playing, with a stare or two from the players and then some parents. Eventually I just smiled. He was having fun and it was something he mastered. In grade 1, a boy bullied my son and eventually had a hand print on his back. I immediately went to the school and reported it. Red from time to time will not share events and that has been very frustrating. As a parent, you want to be there for him, but if you are not aware of issues, it is rather a great stress. In grade 3 we were so proud of him, when his class did a short skit on stage. To get him on stage was a major challenge. By the time he reached grade 7, he conquered that fear and would proudly walk on stage to receive whatever award was given to him. Continuous encouragement has always been our motto.

Looking back over the 13yrs with Red, I can only say that it has stretched me in ways I never could imagine: emotionally, physically and spiritually. How often I have wished that there's a manual for my son and the challenges he faces on a daily basis. My heart has felt so broken for him when I know he is struggling with school related issues. Even at birthday parties, my son is always the odd one out; kids are either too busy for him or noisy. Totally overwhelmed at times. It is exhausting to always keep an eye on him, in case others tease or victimise him. Kids can be so cruel. Then again, I have also experienced the amazing care from some kids in his primary school. I made sure my kids know how to have empathy for others. Red will often say to me: "Mommy we feel sorry for..." Always checking that what he feels is ok with me. Spiritually I have asked many questions. I have come to the place where I still do not have all the answers, but I accept my son as he is. God gave me a very special son and I will do my best in guiding him and loving him with all I have. I teach him about God and I am amazed how he has responded. I want him to live life to the fullest and knowing that God is with him; will help him when we are not around. I need him to know that he can reach his full potential with God giving him the strength and wisdom he needs.

Wanda, the third participant, shared her experiences and a number of similar sentiments expressed by both Hilda and Nellie were revealed. This is her story.

4.2.3 Wanda's story

Wanda is a 44 year old, married woman. She works part-time and has one child, a boy, who has been diagnosed as being on the Autistic spectrum. He is eleven years old.

My journey to date has been full of ups and downs. Once we received our official diagnosis I realised that I already "knew". We really noticed it when he started attending a small playschool and he was one of the only children who had not yet been potty trained. My first big wake up was when there was a party at school and I arrived to find all of the children sitting around the table when I saw one empty seat, I knew without even checking that Mark was not there, I found him by himself in the garden shed playing alone. He also at that stage (about 3 ½ years) had no speech. We took him for speech therapy and the speech therapist had just come back from a course on Autism and she suggested taking him for a formal assessment and tentatively suggested ASD. After this we had a formal assessment and then went about finding a school for ASD eventually settling on a small school which offered one-on-one tuition. He was there for about 2 years.

While Mark was in pre-primary, he attended speech therapy, the speech lessons were about 30 minutes long but he would dictate the lesson completely. I would get highly irritated watching this, thinking that we were paying so much for speech which he clearly needed and yet there he would be playing under the table eventually she shortened the lesson to 15 minutes so I would have to make a half hour trip there and back for 15 minutes. Eventually I settled on a new speech teacher who had a reputation for being harder with the children and who did not allow them to dictate the lesson. Mark made more progress with her than with the other teacher and stayed with her for about 4 years after which we parted ways.

While Mark was at the school for Autism, we managed to find a private tutor who used to come to the house to give him private lessons, she would work with him for about an hour at a time doing various activities which she had done with her Autistic *learners at the school she had taught at in London. He luckily loved working with her and because she came to the house, I was able to listen whilst she worked with him. I found it interesting how she worked with him not allowing him to dictate the lesson as he had done with so many of the other people who had worked with him.*

We felt that he made very good progress in a one-on-one situation but after being in this environment for about 2 years, we wanted him in a mainstream environment. The big problem was finding a playschool willing to accommodate him. Eventually the school he had attended previously said that they would take him back but only on condition that the other parents were told of his "condition" and that there were no complaints. Therefore, a general letter had to be sent to all of the parents in the school informing them that an ASD child would be joining the school. We found this humiliating but it was the only way he would be allowed back into the school. He loved going there but because he was older he got quite bored and wanted to help the smaller kids all of the time. Eventually his speech therapist suggested that we try him at a private school, which promotes inclusivity. We applied and got him in on condition that he came with a tutor. Once again, he was the outsider being the only child with a tutor shadowing him but at least he was in a mainstream environment.

That first year I did not even make friends with any of the other moms. I was so convinced that I would receive a phone call to say that he wasn't fitting in and that we had to take him out. The other children treated him nicely, he was invited to all the birthday parties but I think I still felt like an outsider looking in. We didn't tell the others about Mark's diagnosis and initially most parents simply assumed that the tutor was a student teacher assigned to the class. This was on the advice of the class teacher who has extensive special needs experience and who thought that it was unnecessary to "label" Mark from the start. We did however eventually start telling other parents and by then they knew Mark so weren't fazed but also then become very protective of him. Even at birthday parties the other parents would make a point of ensuring that he was OK.

After 2 years of pre-primary we needed to decide where he went next. We found most schools reluctant/hesitant and the prospect of a tutor accompanying him daunting. His teacher suggested that we send him to the foundation phase of the pre-primary he was attending. His grade one teacher was awesome she also had a *son with special needs and was excited at the prospect of having him in her class. His academic progress was slow but at least he was making progress. He still had speech therapy at school and would be taken out of class to attend lessons. He loved computers and would often go there during class time to work on Maths and Reading programmes.*

I was not sure if I liked him being taken out of class for these sessions but didn't always feel that I could interfere. I think I still felt as though they were doing me a favour by allowing him to attend that school and that if I made too many demands this privilege might be revoked. It is terrible to always feel like you are walking on egg shells feeling like the rug could be pulled out from under you. I finally started befriending the other mothers and still felt grateful if Mark was invited to a party. I still didn't easily invite other children to play dates and never allowed him to go to other children on his own. He eventually went on one play date alone the mother insisted that I let him go alone and a part of me wanted to sit in the car and wait "just in case there was a problem"

It was at this point that the other children in his class started asking me questions about Mark and why he was "different"; they wanted to know why he spoke differently and why he couldn't learn like they did. I explained that making a baby is like making a cake, if you take a cake out of the oven too quickly it will flop or not be baked all the way through and it was the same with babies. Mark came out too quickly and so there were some parts that still needed "finishing" and so the this reason he could not do all the things that they could. There were some who were very protective of him and when he had to have a shunt revision the children were very worried about him. I had lots of parents phoning and wanting to visit him in hospital. The children wrote him cards and messages and when he got back to school the classmates all wanted to help him and protect him at break time. That year he also received the "Just Harry" award for being brave and overcoming adversity, this was a very special time for us.

Mark's reading was only starting to develop but his maths was still shockingly bad. It was at this point that I started to doubt that he would ever do Maths easily or be able to read and write with any ease or level of competence. He managed to learn sight words (words which are used with great frequency in reading which should be *instantly recognised rather than sounded out) but was unable to apply the knowledge elsewhere. He also didn't like having books read to him and never made any effort to read "incidentally" in shops or when we were out. It was as though he did not even notice the written word; it clearly had no significance to him.*

Even though I am a qualified foundation phase teacher, specialising in remedial education and have an honours degree, he had absolutely no interest in doing any extra work with me. As soon as he got the slightest hint that I was trying to teach him something he would immediately pack everything up and walk away. Grade 2 proved to be more of a challenge than grade one, he was promoted to grade 2, not actually passing but at this stage he was physically much bigger than his classmates and could not be kept back due to the fact that he had already repeated in pre-primary.

Once again he was "allowed" in due to the fact that he had a tutor; we struggled to find one and eventually used a student teacher who had been at Mark's school. She offered to help out for a month before she started her full time post in Cape Town and offered to help us find another tutor. This tutor was extremely organised and excited to be working with Mark and totally took over creating lesson plans, IEPs, worksheets etc. We initially loved this until we realised that the class teacher was using this as an excuse to do absolutely nothing for Mark. She was not spending any time preparing work for him and he in turn did not view her as his class teacher. She even told me proudly that she had "absolutely nothing to do with Mark" This horrified me and so I made an appointment to see the principal and sorted this out. The teacher then denied having said this and then started working more closely with Mark. So sad that we had to resort to this. She later admitted to me that she had been very afraid of Mark because her previous experience of ASD had been the previous year when the autistic boy had been very violent, and was constantly running away and on a daily basis would come to her and threaten "to come back when he was big and kill her" (this boy did not have a tutor with him). So before she had even met Mark she had an incredibly negative picture of him and felt sure that she would be unable to handle him. When the efficient tutor jumped in, she happily stepped back and allowed her to lead. However, this was totally unacceptable to us.

The other unacceptable thing was the fact that the parents were complaining that the class size was too big for a private school and went to the principal to complain. The *principal responded with "well you can't count Mark into the class because he has his own tutor, so he isn't really part of the class" (bearing in mind that we were paying full private school fees as well as paying for a tutor, and yet he was not truly considered to be part of the class).*

Our second tutor sadly also came to complain to us because she felt that she had been employed to "shadow" Mark but that the teacher expected her to work out all of Mark's work, worksheets etc. So we spent most of the year "fighting" with the teacher and her role in Mark's education. To top this, Mark was starting to hate school because he was doing "different" work to the other children. He couldn't understand why the other children got "a worksheet with a hand and he didn't". By the end of the 2nd term he didn't want to go to school, he always had a tummy ache on a Sunday evening. He would walk into school glaring at me and he didn't understand why he was the only one who had a tutor - he felt that he was different and didn't like it.

I felt that I was constantly on my nerves checking that he was behaving. I was even the only mother who watched every single sports practise Mark attended after school. When he participated in the school play, I also attended all of his practises and threatened to take away TV if he misbehaved. By the end of the show he was the one child who knew everyone else's lines and could prompt them when necessary. The director came to tell me that she had worried about working with him but that he had in fact been the least work.

At one stage in grade 2 he had no friends to play with at break (we think that this was largely due to the constant presence of the tutor). The teacher then introduced a playtime roster, where each child was assigned a day to play with Mark. On the one hand I loved that he had someone to play with but on the other hand they were being "forced" to play with him. In no time he realised that this was happening to him and then "requesting" certain children who did what he wanted, he didn't want to play with the bossy opinionated children. Now in the "right school" he loves going to school, has friends. The teachers all seem to love him and embrace his "uniqueness".

I have always said (and truly meant it) that I wouldn't change my Mark, he was given to me for a reason and I love him with every fibre of my being. What I would however *change is being able to make things easier for him since every single skill he learns has to be taught to him, things which other neuro-typical children just seem to pick up without much effort are only acquired after much repetition. Before Mark, my life seemed much less complicated, but having him has given my life both meaning and direction and for that I am very grateful.*

The fourth and final participant interpreted the memory work differently to the other participants, in that she recorded daily activities as they occurred. I can only assume that because her child is the youngest in the group her memory accounts are not yet as fully developed as the other 3 participants. This is her story:

4.2.4 Betty's story

Betty is a 28 year old, married woman. She works full time. She has one child, a boy, Tom who is four years old and has been diagnosed as being Autistic.

28 November 2013
Tom fell at school and refers to his sore as an "ouch" or an "eina" and says it is sore. He also blows on his sore on command and blows everyone else's sore.

29 November 2013
At Tom's school concert he saw birds in the sky and says "duck". I was so shocked and HAPPY!!!

2 December 2013
Tom says "whoopsie" when he drops something.

4 December 2013
Tom started referring to all drinks as "coke" and every time he wants something to drink he asks for coke.

6 December 2013
Took Tom to the Quick Spar and he was fabulous in the shop (small shop). Felt very positive.

7 December 2013

Tom learnt command words and tells us to sit, lie down, stop, don't, no, go away, come here, up. All in the space of about two weeks.

10 December 2013
Tom sees aeroplanes in the sky and at the airport and says "plane"

12 December 2013
Started stringing sentences together and says "where'd it go?" "Where you going?"

15 December 2013
Took Tom to checkers and he did not enjoy it. Tom becomes obsessed with the pet shop and won't move, so an unsuccessful trip. Felt very FRUSTRATED!!

16 December 2013
Got Tom a cat and he calls it kitty. He also says fish and bird as he has all three animals.

20 December 2013
Took Tom to Makro and it was very successful. He told me to needs to "pee-pee" for the first time and I took him to the toilet. Very proud mommy!!

24 December 2013
Tom learnt his favourite word "DINOSAUR!!!!" He calls everything and everyone a dinosaur. Felt so happy for him.

2 January 2014
Since learning dinosaur, all animal names have come easily e.g. shark, elephant, dolphin, monkey and horse. Extremely impressed with his progress.

4 January 2014
Since learning animal words, animal sounds have developed. When he sees a bee he goes Bzzzzz, a cow, he goes Moooo and a goat he goes Baaa.

10 January 2014
We have a game with Tom where we jump with our hands in the air and shout names/words. Tom says everything you tell him to say such as: Mommy, Daddy,

Ouma, Cindi, Arthur and Oupa. (All family members' names as well as body parts and animal names)

15 January 2014
Tom started at his new school at Autism Eastern Cape. All his homework books and workbooks came home positive.

20 January 2014
Tom says "poo" when he needs a nappy.

21 January 2014
Tom says, "Look" at EVERYTHING! Always wants you to look at what he is looking at.

22 January 2014
Tom's new words are water, bubbles, gone, sies, wow, hello and bye-bye.

30 January 2014
Tom made circles at school and said, "Circle". Tom calls all lions "Simba" - as in the Lion King.

6 February 2014
Tom's new words are flower, open, Alvin (as in the Chipmunks), sorry, Oros and blow. Tom says "sorry" if he messes anything or bumps into you etc in context

10 February 2014
Tom responds to: Let me see your eina. Give it to me. What's that?

13 February 2014
Tom responds to: Where did it go? Go away.

Tom says: come sit, sit here

19 February 2014
Tom can make sounds like a dog, cat, pig, duck, a sheep, a bee and a goat

22 February 2014

When I put a movie on the screen showed the 20th century Fox screen, Tom said: 2, 0 (two, oh)

Tom was completely non-verbal in January 2013.

Since then I have joined the support group. I've seen an educational psychologist and I take Tom to Bxxxxx Sxxxxxx (a psychologist) once week.

Tom also responds to the below:

- *Go fetch your bottle*
- *give me your bottle*
- *Go pee-pee*
- *Go wash your hands*
- *Go eat/drink/sleep/snore*
- *Give me a high five/low five and fist pump*
- *Kick the ball*
- *Fetch your ball*
- *Smell your feet*
- *Up your arms*
- *Pick up*
- *Come here and look, blow, jump, skip, smell, lick, go*

Summary

Being the parent of an autistic child does not make me sad in the least. He is such a special child and an absolute pleasure to have in my life and we do not let autism get us down. Tom improves every single day and I am elated to witness his progress.

The presented memory accounts highlight both the constant battles the participants face in the education of their children with ASD; battles which parents of neurotypical children never even consider and the ever present sense of gratitude they experience when their children master the simplest of tasks.

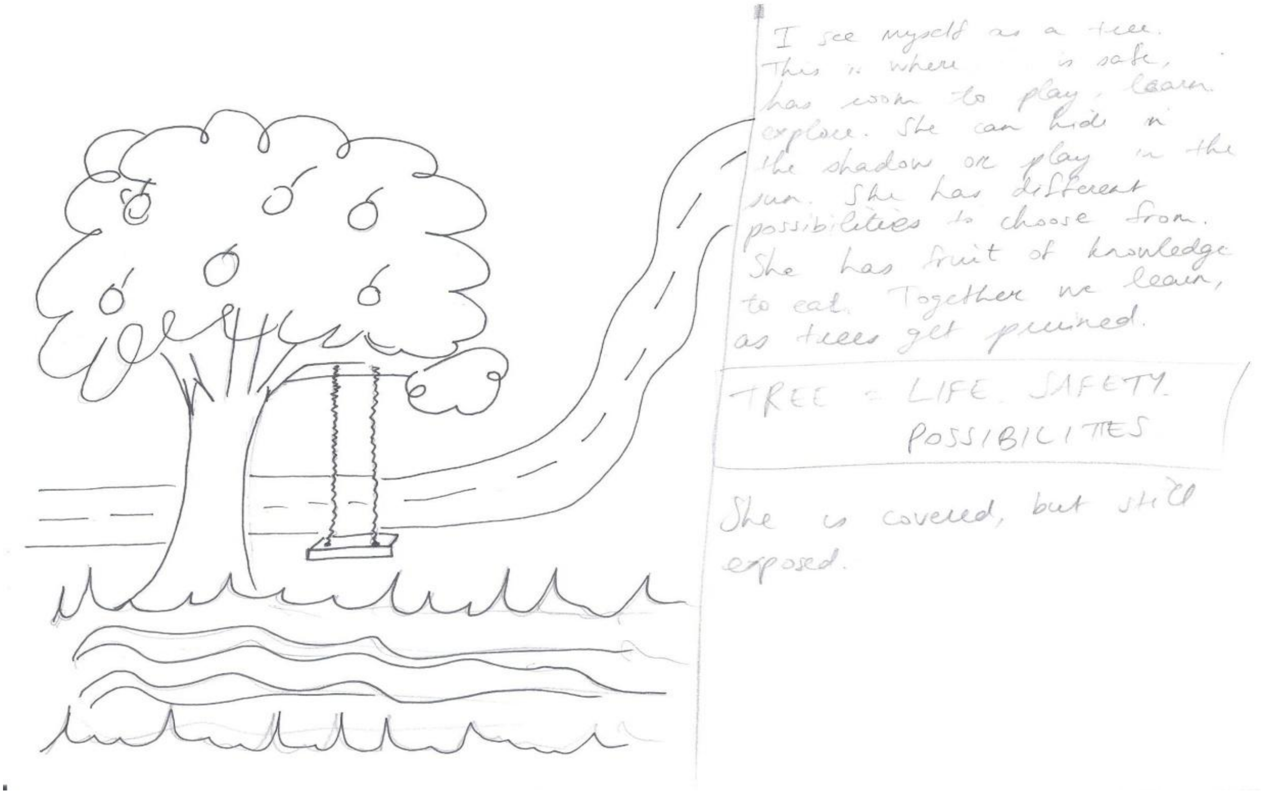
4.3 DRAWINGS

In this section, I have presented the drawings of the four participants in this study. Drawings can be used as a prompt for further discussions of a phenomenon. As mentioned in Chapter 3, Haney et al. (2004, p. 241) believe that drawings have been used for many years as “mirrors of personal identity” while May et al. (2010, p. 330) believe the use of drawings allows one to “expose motivations and perceptions about an object, situation or condition.” Therefore, in this study the participants were asked to make drawings that portrayed the way that they saw themselves in the lives of their children living with ASD. Three of the four drawings are of inanimate objects namely a castle, anchor and a tree and in the last drawing, the participant represented herself as a cheerleader.

Table 4.1: An overview of the four drawings and their underlying significance

Drawing	Type	Significance
Castle	Inanimate	Protective
Anchor	Inanimate	Stability
Tree	Inanimate (living thing)	Protective (nurturing)
Cheerleader	Animate	Supportive

It is interesting to note that the participants did not think of the type of representation they chose when they made the drawings. All they were interested in was the portrayal of their roles in the lives of their children. Thus when reading these drawings caution should be taken to read them only at the level which the participants viewed them. I present each drawing as it was made by each participant together with the explanation that the participants wrote. The explanations from the participants are written verbatim and have not been edited.



I see myself as a tree. This is where is safe, has room to play, learn explore. She can hide in the shadow or play in the sun. She has different possibilities to choose from. She has fruit of knowledge to eat. Together we learn, as trees get pruned.

TREE = LIFE. SAFETY. POSSIBILITES

She is covered, but still exposed.

Figure 4.1: Nellie's depiction: A tree

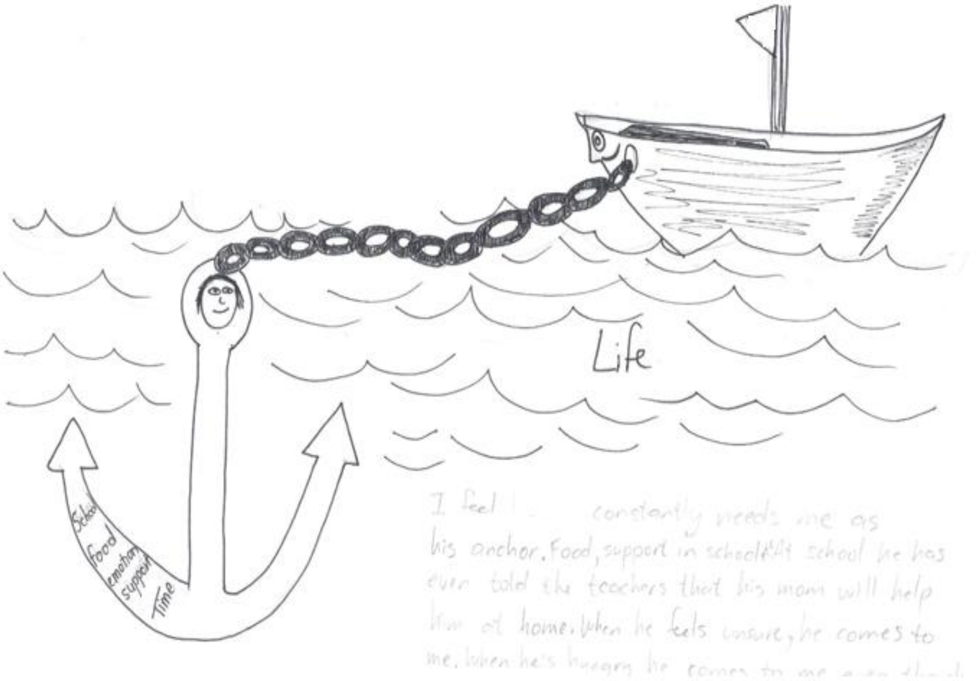
Table 4.2: Nellie's explanation of her tree drawing

I see myself as a tree. This is where Alice is safe, has room to play, learn, explore. She can hide in the shadow or play in the sun. She has different possibilities to choose from. She has fruit of knowledge to eat. Together we learn as trees get pruned.

TREE = LIFE, SAFETY, POSSIBILITIES

She is covered, but still exposed.

The second participant Hilda, portrayed herself as an anchor (see figure 4.2 below), which is also an inanimate object.



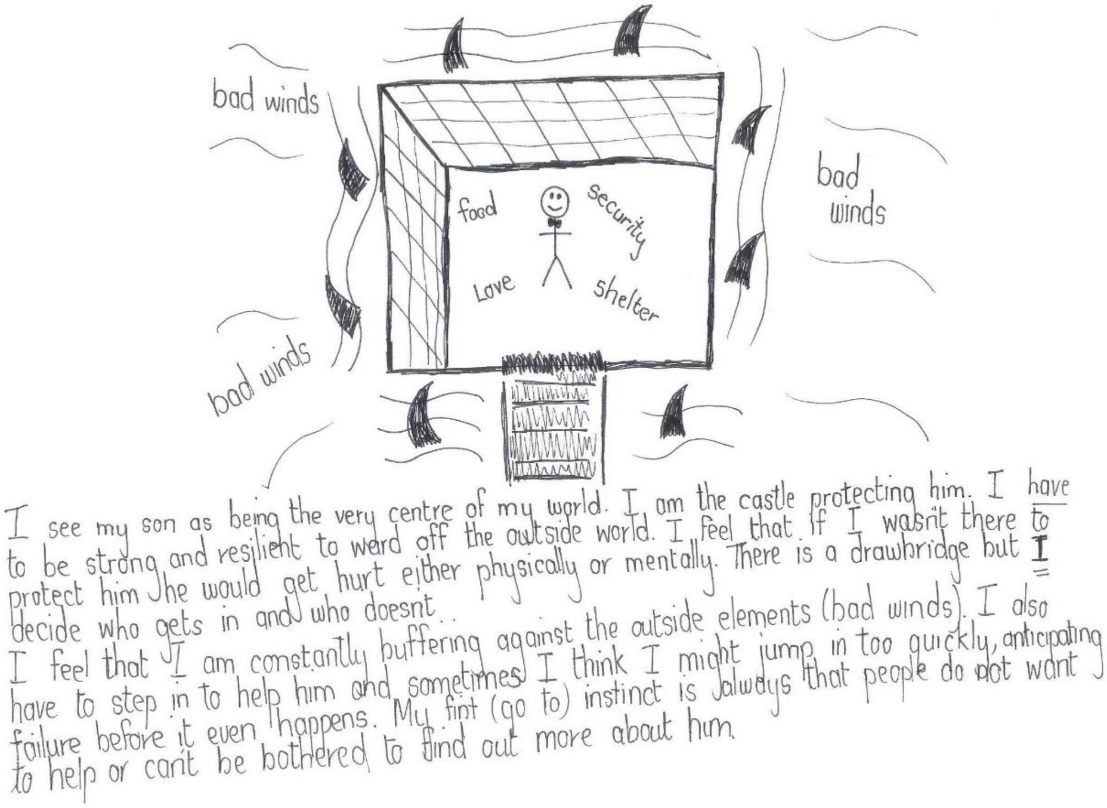
I feel constantly needs me as his anchor. Food, support in school. At school he has even told the teachers that his mom will help him at home. When he feels unsure, he comes to me. When he's hungry he comes to me even though

Figure 4.2: Hilda's depiction: An anchor

Table 4.3: Hilda's explanation of her drawing

I feel Red constantly needs me as his anchor. Food, support in school. At school, he has even told the teachers that his mom will help him at home. When he feels unsure, he comes to me. When he is hungry, he comes to me, even though he is able to help himself. I seem to "anchor" him 24hrs a day. He will check with me whether he should feel sad when there is something sad on TV. Sometimes I feel he needs to "sail" his little boat without me. Hopefully one day.

The third participant, Wanda, also portrayed herself as an inanimate object namely a castle, as can be seen below in figure 4.4



I see my son as being the very centre of my world. I am the castle protecting him. I have to be strong and resilient to ward off the outside world. I feel that if I wasnt there to protect him he would get hurt either physically or mentally. There is a drawbridge but I decide who gets in and who doesnt..

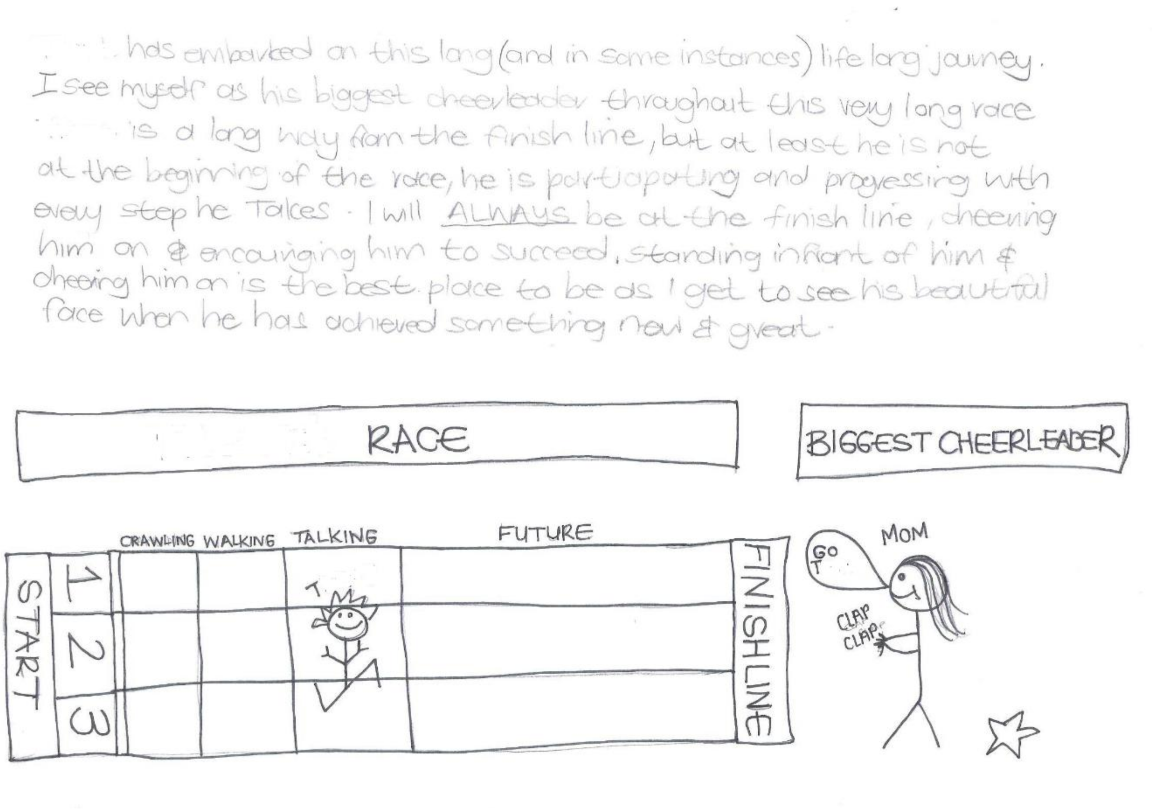
I feel that I am constantly buffering against the outside elements (bad winds). I also have to step in to help him and sometimes I think I might jump in too quickly, anticipating failure before it even happens. My fint (go to) instinct is always that people do not want to help or cant be bothered to find out more about him.

Figure 4.3: Wanda’s depiction: A castle

Table 4.4: Wanda’s explanation of her drawing

I see my son a being the very centre of my world, I am the castle protecting him. I have to be strong and resilient to ward off the outside world. I feel that if I wasn't there to protect him he would get hurt either physically or mentally. There is a drawbridge but I decide who gets in and who does not. I feel that I am constantly buffering against the outside elements (bad winds). I also have to step in to help him and sometimes I think I might jump in too quickly, anticipating failure before it even happens. My first (go to) instinct is always that people do not want to help or can't be bothered to find out more about him.

The fourth participant, Betty, portrayed herself as a cheerleader and was the only participant to portray herself as a human persona as seen in figure 4.4 below.



has embarked on this long (and in some instances) life long journey. I see myself as his biggest cheerleader throughout this very long race is a long way from the finish line, but at least he is not at the beginning of the race, he is participating and progressing with every step he Takes. I will ALWAYS be at the finish line, cheering him on & encouraging him to succeed, standing infront of him & cheering him on is the best place to be as I get to see his beautiful face when he has achieved something new & great.

Figure 4.4: Betty's depiction: A cheerleader

Table 4.5: Betty's explanation of her drawings

Tom has embarked on this long (and in some instances) life long journey. I see myself as his biggest cheerleader throughout this very long race Tom is a long way from the finish line, but at least his is not at the beginning of the race, he is participating and progressing with every step he takes. I will ALWAYS be at the finish line, cheering him on and encouraging him to succeed. Standing in front of him and cheering him on is the best place to be as I get to see his beautiful face when he had achieved something new and great.

I also include in this section a selection of comments as articulated by each of the parents, during focus group discussions, on what they perceived as effects of their experiences of raising and educating children who present with ASD as discussed above. This is some of what they had to say:

Nellie: *I was actually writing in my diary that it is a journey of dealing with tremendous fear not knowing what you're going to deal with but having the hope that whatever is going to come will be okay because along the way there are small victories all the time. No matter how difficult or easy, you always see victory and you walk the road. This journey is not just one of suffering there is always laughter, there is always hope and being grateful for what you have, because I look at Alice and I am grateful I am not dealing with meltdowns.*

Hilda: *I do find it challenging, especially this week was challenging. I had a meeting this week with the teachers, speech therapists and psychologists. They all sat around the table, with the physiotherapists they all assessed him again…I left disappointed, they are not telling me anything new…I know he is struggling with this and I know he is struggling with that. I just thought it is a continuous sapping of the emotions. I am waiting for the place where there is an equilibrium, where it just stays for a while. It's that dip that falls so suddenly that is really so discouraging…but I know that if I just let him be nothing is going to happen, unless I am behind him, helping him with his homework. I see myself as the anchor, or rather he is anchoring himself to me. Red constantly needs me as his anchor, for food, support, school etc. At school he has even told the teachers that his mom will help him at home, when he is unsure he comes to me, when he is hungry he comes to me*

Wanda: *I am always the one who is sheltering him from everybody, I always feel as though he is being attacked. I am sure that it's just a perception I have but I feel as though I am constantly being the buffer between him and mean outside world. You know all the sad faces and the winds that can hurt him. But even at his current school where he is very happy, I always assume the worst when the teacher comes to the car* *to tell me something. I immediately wonder what's wrong, not what's right.*

Betty: *I see myself as his biggest cheerleader on this very long race…he is a long way from the finish line but at least he is not at the beginning of the race. He is participating and progressing at every step he takes. I will always be at the finishing line cheering him on, encouraging him to succeed standing in front of him and cheering him to succeed is the best place to be to see his beautiful face when he has achieved something new and great.*

4.4 CONCLUSION

This chapter has presented the results of the experiences parents have of educating their children who present with ASD and how they think these experiences impact on them as parents. Some of the experiences have been shared through drawings, memory accounts and verbatim quotations of discussions, giving a glimpse into the meanings they make of their experiences.

The next chapter focuses on an analysis of the data which I contextualize within literature.

CHAPTER FIVE

FINDINGS AND DISCUSSION

PARENTS DEALING WITH THE EDUCATION OF THEIR CHILDREN PRESENTING WITH ASD

5.1 INTRODUCTION

The previous chapter focused on the presentation of data as generated by the participating parents. The following analysis is based on the data generated through the use of drawings, memory work and the focus group interviews, to answer the research question: What are the experiences of parents regarding the education of their children presenting with autistic spectrum disorders? The parents had to look at the drawings and memory accounts they had created and the discussions thereof; in answering the research question and then say what they can do to turn things for better. Presented below are the five themes I work within to present the findings.

5.2 THEMES

Five themes were identified from the data as responding to the key research question. The first theme focuses on parents having to deal with the personal vulnerabilities of their children presenting with ASD. The second theme points to parents having to deal with exclusive communities and schools. The third theme touches on the education system and the challenges parents face in it. The fourth theme highlights the financial stress that parents face in educating children presenting with ASD. The fifth theme points to how having to deal with all the challenges parents face in educating their children who present with ASD is a journey of personal growth.

5.3 DISCUSSION

The following discussion shows that parents have challenging experiences of educating their children presenting with ASD. Amongst their experiences, parents find themselves having to deal with personal vulnerabilities of children; having to address the exclusive practices of communities and an unprepared educational system; having financial stressors; and as a result their experiences of educating their children presenting with ASD deeply affect them. Bronfenbrenner's Ecosystemic Perspective has been used to make meaning of the data.

5.3.1 Theme One: Dealing with personal vulnerabilities of children presenting with ASD

This theme focuses on personal vulnerabilities of children presenting with ASD as experienced by their parents. Such vulnerabilities include amongst others children who, because of their disability are rejected or misunderstood by other learners at school, are either ill or do not fit in, and are often not coping well with schools work and extra-curricular activities.

A lot of valuable information, from the drawings in particular, has been gleaned about parents' views of the roles they play in the lives of their children. The participating parents felt that in order to successfully educate their children, they needed to assume different roles. The roles which these parents assume are necessary in order to assist them in coping with the demands of raising their children and enabling them to meet the needs of their children. Since Autism is a spectrum disorder and each child is unique, the parents assume different roles depending on the needs of their children.

Parents generally are considered to be protectors and guardians of their children and this role includes being responsible for the nurturing and rearing of their off-spring. However, it would seem that beyond these usual expectations, parents of children with ASD assume added unusual roles in the life world of their children, such as in this study. The mothers saw themselves as a tree, an anchor, a castle, and a cheerleader. Bronfenbrenner (1979, p. 85) believes that associated with every position in our society (even that of parents), are "role expectations" which include "how the holder is to act and how others are to act toward her" as well as "the nature of the relations between the two parties namely the degree of reciprocity, balance of power, and affective relation."

As children with ASD display a “triad of impairments” (Nel et al., 2013, p.20) which include a lack of social interaction and unusual imaginative play, language, communication, and behaviour impairments, and an adversity to change, it would seem natural that these mothers carry an added protective and motivating role. Betty saw herself as a cheerleader, having to continually motivate and encourage her child. Hilda felt she is her child’s anchor, supporting him and keeping him safe. Nellie believes she is a tree, protecting her daughter and also providing essential knowledge. Wanda saw herself as a castle, keeping her son safe within the castle walls.

Comments such as *“standing in front of him”* (Betty*), “I feel Red constantly needs me as his anchor”* (Hilda*), “I have to be strong and resilient to word off the outside world”* (Wanda) and *“This is where Alice is safe, has room to play, learn, explore”* (Nellie) reveal a common thread between the parents and shows how each parent feels a need to be close to her child to protect him/her. In contrast to mothers' of neurotypical children, not one of these parents thinks their child can stand on their own and become independent, but will always need their assistance. These mothers all seem to view themselves as the primary protector in their children's life world. More evidence of this can be seen in these statements - *"I see my son as being the very centre of my world"(*Wanda)*,* and *"This is where Alice is safe "*(Nellie)

Another role these mothers see themselves playing in the lives of their children is a teaching role, as they believe it is their duty to pick up any shortfalls that may arise in the education of their children. They constantly monitor their children’s progress and whatever could not be covered at school by the class teacher, they feel obliged to teach at home. Kluth (2009) suggests that parents also need to remember to find opportunities to have fun with their children, to appreciate small victories and to remember that besides the fact that the child has an ASD diagnosis he is also a developing child and many of the "meltdowns" are normal developmental milestones and have nothing to do with autism. The flipside to this role of being teacher also meant that the mothers felt that the normal relationship which exists between a mother and child was at risk because of the blurring of lines between being just the mother and suddenly being teacher as well. Comments such as *"I feel with me teaching all the time, I think it breaks the relationship of mom and son"* (Hilda) and

"We are involved and it's important to us that she does well, being able to do so I need communication from you (the school)" (Nellie), clearly depict how these mothers feel they have to be both mother and teacher irrespective of how it affects their relationship with their children.

This dual role resulted in the mothers feeling physically exhausted. They spoke of never having any time to themselves and literally falling into bed at night. They used comments such as:

Very challenging and tiring...When my feet touch the ground I am off, I am very disobedient in not having a bit of quiet time and this was one of those weeks and I am telling you by nine o'clock I am sitting like this (sleeping)...I am so tired"(Hilda)

Bronfenbrenner (1979, p. 85) used an example of the contrasting roles of parent and teacher in a study when describing role expectations. Both the roles of a mother and a teacher require that these significant adults “provide guidance to the young, who in turn are expected to accept such guidance in a relation characterized by high levels of reciprocity, mutual affection, and a balance of power in favour of the adult.” The degree of reciprocity and mutual affection would, under normal circumstances, be considerably higher in the parent-child relation. If these two roles were then merged and played by one person i.e. the mother, it would most certainly upset this balance. Whilst the mothers saw themselves firmly in a teaching role, they found the attitudes of the school both confusing and frustrating.

The schools expected the mothers to be involved, but they insisted it would only be done on their terms. For example this is how Hilda responded to her child’s school "*You (the school) need me to back off a bit, but I can't back off".* This was reiterated by Wanda who stated:

"I am not sure if I liked him being taken out of class for these sessions but didn't always feel that I could interfere. I think I still felt as though they were doing me a favour by allowing him to attend that school and that if I made too many demands this privilege might be revoked”.

Yet according the authors such as McCoy (2011) and Benson, Karlof and Siperstein (2008) the assistance of parents is frequently required in the education of the child with ASD since the parents are able to continue with instruction done in class, in the home and community setting. This type of generalizing of learning concepts from the classroom to the home is extremely important in the education of the child with ASD (McCoy, 2011). McCoy further states that parents of children with ASD need to have greater involvement in the education of their children than parents of children with other disabilities.

The parents also saw themselves as protectors and rescuers and displayed a need to jump in and assist their children very quickly, and in some instances, too quickly, in an attempt to prevent failure before it occurred. This seems to be something which occurs with many parents of children who experience ASD. According to Kluth (2009, p. 49) parents need to become aware of the "dignity of risk" meaning that everyone should experience failure on occasion in order to learn appropriate skills which will give him the coping skills needed for future activities. However this role of constant protector comes instinctively to all of the participants and is done almost without thinking. Comments such as *"I immediately wonder what's wrong, not what's right"(*Wanda*)* and *"You're always watching him"(*Nellie*)* reveal the levels of anxiety these women experience and their need to protect themselves, as well as their children.

5.3.2 Theme Two: Dealing with exclusive communities and schools

The mesosystem of Bronfenbrenner's Ecosystemic theory of human development involves "linkages and processes taking place between two or more settings containing the developing person" (Bronfenbrenner, 2005, p.148). The parents of children with ASD, who are trying to find a place in an inclusive system, encounter numerous negative aspects regarding the relations between home and school and actually find themselves on the outskirts of the home/school system. Parents of children with ASD often experience a sense of isolation in the education of their children. These parents experience a fear of rejection by society, the schools, as well as other parents. This fear leads to anxiety regarding their children's behaviours**,** fear of the unknown, presuming that only other parents of children with ASD understand each small accomplishment of their children, and are constantly expecting the worst and therefore never expecting a positive outcome. To avoid this rejection and anxiety, these parents seem to opt to isolate themselves. Hanbury (2012, p. 24) states that parents of children with ASD report that their social lives and even relations within their extended family became strained once they had received their child's diagnosis. This in turn led to "mistrust and low self-esteem" which further amplified the feelings of isolation since they felt no one would be able to or indeed want to provide them with support or assistance and meant they would then deal with their child on their own,

The overarching feeling was one of constantly being on one’s toes, when it came to having a child with ASD. The participants felt that the other parents, and even the school, were always on the outside watching them and almost expecting them to fail. When the children were sent to school, some of the mothers seemed to feel as if they had abandoned their children by allowing them to go to a place where they potentially could be extremely unhappy. Cooper and Jacobs (2011, p. 194) believe parents of children with Special Educational Needs “find schools and teachers intimidating”. This leads to poor communication between themselves and the school community, and results in parents of children with ASD opting to isolate themselves from the rest of this environment as a form of protection from possible negativity around their child.

This sense of isolation became clear with comments such as:

> "I d*on't even want to befriend the other moms just in case they* (the school) *phone you and tell you that your child doesn't fit in"* from Wanda who also added *"I still felt like an outsider looking in. We didn't tell the others about Mark's diagnosis".*
>
> *"Sharing it with other neurotypical child's parents is just not the same"* argues Nellie who continued to say *"You know and it's scary in a sense that she is in an environment where people don't get it, they don't really care to get it. Um, that's scary."*
>
> *“There are some parents who try to understand what you are going through but generally the feeling is that because they aren't going through what you deal with on a daily basis they just won't get your situation fully (*Hilda*)*

> *"You don't know how you celebrate the small things and you don't know how you weep with the other mothers when they have the same problems you do. We have a very different outlook on our children" (Betty).*

Comments such as those above make it clear that these parents each feel that they are the only person who truly gets their child. The feeling amongst the mothers was that when all else failed they were the ones who were tasked with truly understanding their children and even with all the good intentions possible, no one else could, or would, truly be able to make as big an impact on their children's lives as they could. Hanbury (2012 p. 24) refers to this as a "collaborative attitude", this means that that parents of children with autism form networks built on an understanding of each other's difficulties and the knowledge that they are working towards a common goal.

It is interesting to note that when things do go well at school the overwhelming feeling for these parents is one of being lucky, or extremely fortunate. The parents feel they are always on the back foot, anticipating the worst and then feel extremely grateful when things seem to go their way for once - *"But it went well, we were lucky enough that it went well for us"* (Wanda), and sometimes have to go the extra mile to get things working right for their children as stated by Nellie who argues that *“Nobody gets how hard I have to work to get Alice’s projects done every week."*

Even if children with ASD are allowed into mainstream classes, there are so many restrictions and provisos placed before they are even allowed into the school that the parents of these children always feel as if they are on the outside looking in. Wanda felt "*they were doing me a favour by allowing him to attend that school…if I made too many demands this privilege might be revoked. It is terrible to always feel like you are walking on eggshells*." All that the participating parents want for their children is the right to attend school and to have the same opportunities as all of the other children, but this they found not to be the case.

5.3.3 Theme Three: An unprepared education system

Parents of children with ASD deal with specific challenges when educating a child who does not follow a normal learning path within the conventional school system.

These challenges include inappropriate curriculum, having to prepare the child in advance just to keep up with the class, lack of teacher training, and teacher apathy and intolerance. To complicate matters further, Nel et al. (2013, p. 20)) believe that there are no typical learners with ASD as the “triad of impairments” varies greatly in each one. This makes it very difficult for teachers to fully understand the disorder and how best to educate a child with ASD. Despite this, the participating parents felt that teachers lacked even a basic level of understanding of the needs of children with ASD. This perception has been made, by the mothers through interaction with numerous teachers at different schools who did not understand learners with ASD and then relied heavily on the parents for guidance as to the way to deal with their children. This can also be seen in DoE (WP6, 2001) which does not even make any mention of autism but merely refers to learners with SEN as a general group.

The participants in this study spoke at length about the schools their children are in and the difficulties they face in trying to get their children to fit in and to be accepted. The quotes below depict how extremely difficult it has been for these parents to find schools and teachers who empathise and understand Autism and the specific problems associated with it. Hilda met with the teachers at her son's school and she says "I *left disappointed…the last two weeks have had some challenges. Teachers give the kids so many verbal instructions and Red has not been able to keep up. So I've had to meet with them and explain".* Nellie expressed frustration at the fact that the only thing teachers wanted from her was *"to know the basic triggers...knowing that this child deals with life differently than that child* (referring to a neurotypical child)*"* in order to work with her child with ASD. In addition, Wanda said *"They are intolerant, they don't get them and they don't understand why these kids are struggling."* On the other hand Nellie had this to day about the teachers- *"They aren't aware of autism and dealing with it"*

Interestingly, not all of the parents experienced lack of empathy at the schools their children are at. What these parents noted was that some teachers were actually too tolerant and did not let them know even when there were problems at school. The participants stated that they needed to know what was happening at school and that they needed to be made aware of problems so that they could continue at home with such issues. This is evidenced by Nellie’s comment *"But she is tolerant (the child's* *class teacher)...whereas, I actually want her* (the teacher) *to complain."* There seemed to be consensus over the issue that teachers needed to know how much parents needed to know about their children - enough to help at home but not such an intense barrage of information that the parents felt overwhelmed and despondent.

By staying on the fringe of the school and all its activities, not only did the parents not get the support they needed, but their children with ASD were kept away from establishing important relationships necessary for their own development. Bronfenbrenner (1979, p.104) argues that it is necessary for human development that a child be exposed to “persons in different social positions” as this places the child in new roles, which could help to develop “a more complex identity as she learns to function as a daughter, sister, grandchild, cousin, friend, pupil, teammate, and so on.” In other words, Bronfenbrenner (1979, p. 104) believed that “human development is facilitated through interaction with persons who occupy a variety of roles and through participation in an ever-broadening role repertoire”

An inappropriate curriculum was also a cause for concern since these parents felt that no adjustments were made for their children at school. These children are expected to do age appropriate work even though they are mentally not able to cope with the work being presented. Hilda said *"Why should children have to learn this (referring to her child being taught about sex)?”.* Nellie agreed saying that “we s*houldn't have to give this information to a child who is not ready for it...He might be13 but he is not 13."*

Another challenge is that teachers think the parents do not know what their children are capable of and often do the work for the children and then send this home as the child's work. *" They must think that we are really stupid, that we can't tell what he has done…do you know how much work I would toss away when I knew that it wasn't Mark's work I would just toss it away into the bin? I would just toss it in the bin" (*Wanda)*. "And I know for a fact that he had not done it. You could see that he had not done it" (Betty).*

The participants also discussed that a possible way to make a transition within the school easier would be if the teachers in the various grades spoke to each other more and that when learners (especially special needs learners) were transferred from one grade to another that there was a multidisciplinary team meeting to discuss the child at length. The mothers definitely had a feeling of anxiety because the school is seen as such a potentially hostile environment. Their views on having improved “handover sessions” by having teachers communicate better amongst themselves are noted below and these parents feel this would make the transition a lot less traumatic, *"My son’s disabilities are not there, you can't see it. You need to spend time with him to see that he is (I hate to use this word) challenged in this area of thinking, challenged in that area"(Hilda). "You think to yourself “What am I doing forcing my child into a mainstream environment?”(Nellie)*

5.3.4 Theme Four: Financial stress

Bronfenbrenner’s (2005, p. 261) Ecosystemic theory of human development is often described as being like a set of nested Russian dolls, where “each one also simultaneously influences and is influenced by the others.” In other words, “the context of the family fits into that of the neighbourhood; the context of the neighbourhood into the larger contexts of the city, work, and government; and all contexts into the largest context of culture.” What is significant is that any factor affecting the largest context will filter down to the family unit and the individual at the epicentre. Bronfenbrenner (2005, p. 263) believes that social support, or lack thereof, filters down to the family and “determines the confidence or stress that parents bring to their relations with their child.”

Parents of a child with ASD face additional stress factors that parents of neurotypical children do not have to consider. In particular, added financial burdens are placed on these parents in the education of children with special needs. A case in point is the fact that many children with ASD will not be allowed into a mainstream class without a tutor to shadow the child during his school day. The schools willing to allow this sort of shadowing are often private schools which have higher school fees and added to this the parents are then required to pay for a private tutor. Initially, when parents become aware that their child is not developing at the same pace as their peers, they start searching for answers. These parents are also often so desperate to help their children that they will try anything irrespective of the expense in an attempt to help their affected children. This involves numerous assessments by various therapists and psychologists including a plethora of medications some of which are experimental, all of which equate to a very costly enterprise. Only once a diagnosis is made of ASD, can the appropriate interventions begin, and the financial drain on a family can then be quite significant. A support team i.e. physiotherapists, and speech therapists need to be carefully chosen, in order to have the most benefit to the child with ASD. Without the correct support team the effect on the child could be quite detrimental since early intervention strategies are key to helping the child with ASD (Woolfolk, 2007).

A very important facet in the education of the child with ASD is the input from a host of therapists which include speech and language development, occupational therapy, play therapy, and physiotherapy. The cost implications, which can be very high, mean that for many parents, these visits need to be carefully considered. Most Medical Aid Schemes cover some of these costly visits but sadly, not all as stated by the parents: *"but unfortunately medical aid funds ran out and we couldn't continue again because medical aid only paid for so much, we can only pay for so many sessions and you have other responsibilities as well…it is unfair, other parents don't have this" (*Hilda*)*. Wanda also added that *"we were paying so much for a private tutor who used to come to the house to give him private lessons...he made very good progress in a one-on-one situation".*

As early intervention is most effective for children with ASD, most parents go to great lengths to ensure that their children get as much therapy as possible. These therapies form an integral part of the collaborative team necessary for a comprehensive approach to the holistic development of a child with ASD. The worry expressed by the mothers is not being sure whom to trust; and when to trust your own judgement and when to blindly follow the advice of experts. In addition to this, some parents explained that their children were only accepted into a mainstream class if they had their children enrolled in a host of assistive therapies and had a personal tutor (paid for by the parents) who supported the child in the classroom. *He was "allowed" in due to the fact that he had a tutor" (Wanda).*

5.3.5 Theme Five: A journey of personal Growth

Bronfenbrenner (2005, p.108) reworked Kurt Lewin’s (1935) formula of human development and defined it as “the phenomenon of constancy and change in the characteristics of the person over the life course.” In other words “the characteristics of the person at a given time in his or her life are a joint function of the characteristics of the person and of the environment over the course of that person’s life up to that time” (Bronfenbrenner, 2005, p. 108). Using this description, one is able to understand how these parents of children with ASD feel that they are a product of their experiences and the journeys they have been on in the lives of their children.

These parents reported feeling a sense of gratitude from lessons learnt from having a child with ASD. These feelings of gratitude are mainly seen in Hunnisett (2005) where parents recount their journeys with their children with ASD. An overwhelming sense of appreciation is displayed by the parents, often for the smallest achievement that their children achieve. These parents are fully aware that the achievements they celebrate would not even be acknowledged by parents of neurotypical children; but with children experiencing barriers to learning every small victory is a cause for celebration. They accept that their paths have not been easy and have had numerous bumps along the way, but all-in-all; they would not have it any other way. Wanda's sentiment that *"before him, my life seemed much less complicated, but having him has given my life both meaning and direction and for that I am very grateful"* clearly expressed the gratitude. Betty also said *"this is who is he is, what he does to me. I love the little things he does like I wouldn't change him for the world. I love it".* It is not easy for the parents but they appreciate every moment and every little success that their children have.

The parents also agreed that Autism is a *journey* which they were on with their children and that it involved being able to look back reflectively on how far they had *travelled*. These are some of the comments that reflect this sense of gratitude for lessons learnt along the way. Nellie wrote *"this journey is not just one of suffering there is always laughter...it is a journey of courage, of celebrating small victories and facing your challenges. It is a journey of the unknown. A journey of fear...It is a journey of hope...more victories...okay to not have a good day...counting every small victory…"*

Through the experience of working with their children, these parents not only think that they have changed but they also found that they viewed and dealt with other people differently. Nellie felt that living with Autism taught her *"to live life at a slower pace to actually stop and look";* and Hilda said that *"I look differently at people and at children and at people dealing with different challenges and even with neurotypical people*". This sentiment was further echoed by Wanda who said, *“I also think I was a very intolerant person before and I think I actually dealt with children with disabilities in a lot less tolerant way than what I do now. I think Mark has definitely broadened my horizons"*. Nellie felt "*blessed to have been chosen for their journey, for being part of a bigger plan, for being able to make a difference and most of all....for being changed";* and Hilda added that *"It has stretched me in ways I never could imagine*".

The attitudes of other children and their parents have also had an impact on the child and the members of his/her family. Generally, the impression is that most people do not care enough to get involved and because it does not affect them directly, they have no interest in finding out more about Autism. Society in general has a fear of the unknown and currently many people know very little about Autism, *"…if you're not faced with it, you don't care…"(Nellie)* and Wands said *".... she (the class teacher) later admitted to me that she had been very afraid of Mark because her previous experience of ASD..."* This sentiment is echoed by Kluth (2009, p. 2) who is of the opinion that even though we have been inundated with information about autism in the media, movies and research this so-called label and diagnosis is still so new that our "ignorance still surpasses our knowledge”. Betty sums it up nicely when she says *"...it’s amazing how often people think autism just means that your child can't talk.”*

Participants in this study also stated that whilst raising a child with ASD is never easy, they felt that they were in essence chosen for this and bearing this in mind they would never want to change their children but that their purpose was to make their children's journey as smooth as possible. This meant being involved in the day-to-day schooling of their children as well protecting them from society, if necessary. The following quotes provide evidence of how aware these parents are of how difficult the journey could be, but that they were prepared for it by finding solace in the knowledge that their children got up and continued to fight every day. Betty says “j*ust getting him to start talking is amazing",* while Nellie points out that *"the life of an autist is a very challenging one. No one day is simple without challenges...the processing disabilities, the challenges with comprehension and expression and scholastic issues".* Continuing this discussion Wanda highlighted that *"he has made my life richer...he has given me a purpose, the reason why I study is because of him",* while Hilda stated that *"for me it is normal…”*

It is not surprising therefore that *living each day as it comes* has become the mantra of parents of children with ASD. Not having the luxury of knowing what milestones their children should reach, means that long term plans are not something they are able to make as exemplified by Hilda *"We are trying to squeeze them into the world and we don't even understand them*.” Although these parents are extremely positive about their children and the progress they are able to make, they do sometimes find it hard listening to other parents talking about their neurotypical children and the progress that they are making. *"I hear these people continuously talking about their children and their grandchildren being just about super human it makes me sick inside. Because we work so hard at just something that should be so simple and then there is no big reward…"* (Hilda).

5.4 CONCLUSION

This chapter presented an analysis of the data produced through memory work, drawings and focus group discussions. The analysis revealed five themes that responded to the key research question. The first theme discussed parents having to deal with the personal vulnerabilities of their children presenting with ASD, while the second theme pointed to parents having to deal with exclusive communities and schools. The third theme touched on the education system and the challenges parents face in it, while the fourth theme highlighted the financial stress that parents face in educating children presenting with ASD. The fifth theme was about how having to deal with all the challenges parents face in educating their children who present with ASD is a journey of personal growth.

In the following chapter, I present a summary of the study findings and conclusions. Then I also make recommendations on how to ease the journey of parents and children presenting with ASD in the education system in South Africa. Finally I make recommendations for further research.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

This chapter draws the study to a close by offering a summary of the findings in response to the research question: **What are the experiences of parents regarding the education of their children presenting with autistic spectrum disorders?** The data from the qualitative and interpretive study, using a phenomenological research strategy, and generating data through use of drawings, memory work and focus group interviews, was rich and interesting, and enabled the construction of five themes. Bronfenbrenner's ecosystems perspective was used as a theoretical lens to frame the study.

The purpose of this chapter therefore is to summarize the findings; draw conclusions from the findings; mention what the limitations of the study are; and offer recommendations for further research.

6.2 SUMMARY OF THE FINDINGS

The data was generated with four parents, all women, who have children presenting with ASD. The parents who participated in the study shared their experiences regarding the education of their children who are on the autistic spectrum.

6.2.1 Dealing with personal vulnerabilities of children presenting with ASD

Each child is unique and presents a different clinical diagnosis. For this reason these children are frequently rejected or misunderstood by peers. Parents therefore assume a protective role in order to protect their children in these circumstances. They feel a strong need to protect and at all costs prevent them from getting hurt, either physically or emotionally. This role of protector was one which also caused the mothers anxiety because although they wanted to protect their children they also were cognisant of the fact that they were frequently jumping in and attempting to prevent failure before it even happened.

6.2.2 Dealing with exclusive communities and schools

Parents of children with ASD often experience a sense of isolation and rejection from society, schools, parents of the other learners and the learners themselves. There is a strong feeling amongst the parents of children with ASD that the only people who truly understand what they are going through are other parents of children with ASD. For this reason not only do these parents feel isolated but to some extent they isolate themselves. Despite this, the overwhelming feeling amongst these parents is a need for their children to be accepted and to be given the same educational opportunities as other children.

6.2.3 An unprepared education system

Learners with ASD do not follow *typical* educational paths and can therefore not merely be placed into a conventional schooling environment. The parents of learners with ASD expressed feelings of great distress at the lack of teacher training, an unwillingness to learn about the child with ASD and a seemingly inflexible curriculum. They also expressed despair at the fact that there never seemed to be a comfortable place for their children. The school environment was either completely intolerant or so tolerant that they were not being told of incidents at school which they felt they needed to know about.

6.2.4 Financial stress

Parents of children with ASD face additional financial stresses in the form of assessments with specialist therapists and psychologists, as well as the therapies which these specialists then recommend. In addition to this are all the private therapy sessions which are necessary in order for the child to be given the most input possible in order to have the greatest chance of any degree of educational success. Added to this is the need for parents to get additional tutors for their children. All these demands create a huge burden for parents who want to educate their children presenting with ASD.

6.2.5 Journeys of personal Growth

These parents to a great degree feel that their lives and they themselves are defined by their children. They feel a sense of gratitude to have been chosen to walk this path with their children and feel that although the path has not been easy they have grown with their children. They seemed to feel that by being exposed to their children they have in fact become better people. They argue that before they had their children, they viewed themselves as having been fairly intolerant towards people with disabilities but now they looked at people in a completely different manner.

6.3 CONCLUSIONS

Barriers to learning are a reality in our world today, and South Africa in particular. This is why efforts were made to ensure inclusion of all learners irrespective of their being or ability (DoE, 2001). The WP6 requires that schools become inclusive and create spaces in which all barriers to learning are removed in order that no child can be left behind in the education system (Karten, 2010). However, this study has shown that children presenting with ASD are not being fully included within the South African education system. Parents of children presenting with ASD highlight their experiences of educating such children as extremely challenging. They point out that communities and schools are not inclusive of such children, and that the education system is not prepared for children presenting with ASD; hence this leads to greater financial challenges as they have to employ tutors for their children. Due to the unpreparedness of schools and communities regarding autism, parents fulfil multiple roles in the lives of their children in order to ease them into the schooling system. While this is a cherished process for the parents it also drains them physically emotionally and financially.

The parents thus argue that in order to bring about change in schools parents need to be more involved but this also means that the schools need to allow parents to be involved in the education of their children. There needs to be open lines of communication between parents and teachers, with neither party feeling threatened by honest communication.

6.4 LIMITATIONS OF THE STUDY

Having made the above conclusions I cannot however ignore the limitations of this study and the unresolved issues within it. Being a parent of a child with ASD, I undertook this study with other parents of children with ASD in order to get in-depth information about their experiences. My study, therefore, is a small-scale study that cannot be generalized to the broader Port Elizabeth or South African population. It does however raise significant issues and ideas that could be explored further in different contexts and perhaps on a larger scale and with a larger sample group. The participants in this study were only women and thus their experiences may not reflect how fathers could experience the education of their children who present with ASD.

6.5 RECOMMENDATIONS FOR INCLUSIVE SCHOOLS

- School principals need to ensure that teachers attend any workshops which deal with supportive strategies for inclusion of learners with special educational needs

- Principals need to encourage parents to get more involved in the education of their children with SEN and encourage better collaboration between parents and schools

- Department of Education needs to liaise with Department of Health in order to provide relevant information regarding special education needs, in the form of documents and resources for teachers

6.6 RECOMENDATIONS FOR FURTHER RESEARCH

Against the background of this exploration future research in the following areas is suggested:

- Exploration of the type of pre-service and in-service training for teachers to establish a training model that can produce teachers who have a good working understanding of autism and are aware of intervention strategies which have been proven to work.

- Exploring the perceptions of parents of children with ASD from a male (father) perspective
- Exploring teacher's views, opinions and experiences on the inclusion of autistic children into their classes.

6.7 CONCLUSION

This chapter draws the study to a close. Having identified a gap in the literature regarding how parents experience educating their children who present with ASD, the study has contributed to understanding the dilemma of parents, who try their best, but who are not necessarily supported to do so. The study therefore points to the importance of all school teachers being equipped with necessary skills by the DoE, enabling them to fulfill an important role of including children who have barriers to learning in their schools and communities. The study also highlights the role of higher education institutions in ensuring that all students are empowered with the necessary skills to address the vulnerabilities of children presenting with ASD and other special educational needs. Autism is clearly not a private issue, but of public concern, a concern which needs to be enthusiastically and vigorously taken up by whole communities.

“Unless someone like you care a whole awful lot. Nothing is going to get better. It’s not” Dr Seuss

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Addendum 1: Participant Instructions

Faculty of Education

NMMU

Tel: +27 (0)41 504-3767 Fax: +27 (0)41-504-9767

E-mail Faculty Chairperson: paul.webb@nmmu.ac.za

15 July 2013

Ref: H13-EDU-ERE-024

Contact person: Mrs Wanita McGrath

Dear Participant

You are being asked to participate in a research study. We will provide you with the necessary information to assist you to understand the study and explain what would be expected of you (participant). These guidelines would include the risks, benefits, and your rights as a study subject. Please feel free to ask the researcher to clarify anything that is not clear to you.

To participate, it will be required of you to provide a written consent that will include your signature, date and initials to verify that you understand and agree to the conditions.

You have the right to query concerns regarding the study at any time. Immediately report any new problems during the study, to the researcher. Telephone numbers of the researcher are provided. Please feel free to call these numbers.

Furthermore, it is important that you are aware of the fact that the ethical integrity of the study has been approved by the Research Ethics Committee (Human) of the university. The REC-H consists of a group of independent experts that has the responsibility to ensure that the rights and welfare of participants in research are protected and that studies are conducted in an ethical manner. Studies cannot be conducted without REC-H's approval. Queries with regard to your rights as a research subject can be directed to the Research Ethics Committee (Human), Department of Research Capacity Development, PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031.

If no one could assist you, you may write to: The Chairperson of the Research, Technology and Innovation Committee, PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031.

Participation in research is completely voluntary. You are not obliged to take part in any research. If you choose not to participate in medically related research, your present and/or future medical care will not be affected in any way and you will incur no penalty and/or loss of benefits to which you may otherwise be entitled.

If you do partake, you have the right to withdraw at any given time, during the study without penalty or loss of benefits. However, if you do withdraw from the study, you should return for a final discussion or examination in order to terminate the research in an orderly manner.

If you fail to follow instructions, or if your medical condition changes in such a way that the researcher believes that it is not in your best interest to continue in this study, or for administrative reasons, your participation maybe discontinued. The study may be terminated at any time by the researcher, the sponsor or the Research Ethics Committee (Human).

Although your identity will at all times remain confidential, the results of the research study may be presented at scientific conferences or in specialist publications.

This informed consent statement has been prepared in compliance with current statutory guidelines.

Yours sincerely

____

Mrs Wanita McGrath

RESEARCHER

15 July 2013

____

Dr M. Khau

Supervisor

15 July 2013

I ____________________________ state that I freely and voluntarily will participate in activities related to your Focus group research. I understand that all data collected will be strictly confidential and used only for research purposes.

Signature of participant: ____

Full name in print: ____

Date: ______________________________

Addendum 2: Written information to be given to participants.

Thank you for your willingness to participate in this study. I would like to stress that your participation is completely voluntary. I will be providing you a detailed description of the requirements which I will need you to read and then initial to show that you understand what your participation entails. Since your participation is voluntary you may also withdraw at any point.

Participation in this study will require you to attend a minimum of 2 focus group sessions. These sessions will be recorded using an audio recording device, which will later be transposed into written text to be used in the study. At no time will your names be used in this study in order to protect your, as well the groups anonymity. All information will therefore be treated with the greatest confidence.

In order to generate the data needed to complete the study, you will be given a diary in which to record your memories of the experiences you have had in the education of your child with ASD. In other words these will be any memories you choose to share, there is no ‘right nor wrong’ entry.

The second activity will require you to depict yourself by means of a drawing. This drawing will be a representation of how you see yourself in the life of your child presenting with ASD. Once again there is no right or wrong drawing. I would ask that you accompany your drawing with a written explanation which would give further insight into your depiction.

These sessions will be held at my home and if at any stage you require transportation to and from these meetings, I will gladly necessitate this for you.

Due to the sensitivity of the phenomenon I have made arrangements with FAMSA to provide counselling services should the need arise.

I would also like to stress that you will not be required purchase any additional supplies in order to complete this study, all costs for materials will be borne by me. On completion of the study you are also more than welcome to read the dissertation.

Thank you once again for your willingness to participate in this study. Should you need any additional information, I will happily supply this for you.

Kind regards

____

Wanita McGrath

0832302703 **<u>or</u>** 041 366 1369

____

Dr M. Khau

Supervisor

Addendum 3: Information and Informed consent form

NELSON MANDELA METROPOLITAN UNIVERSITY

INFORMATION AND INFORMED CONSENT FORM

RESEARCHER'S DETAILS	
Title of the research project	**EDUCATING CHILDREN PRESENTING WITH AUTISTIC SPECTRUM DISORDER: EXPLORING PARENTS' EXPERIENCES**
Reference number	
Principal investigator	**WANITA MCGRATH**
Address	**6 MICHAELANGELO AVENUE, PARI PARK**
Postal Code	**6070**
Contact telephone number (private numbers not advisable)	**0832302703**

A.1 HEREBY CONFIRM AS FOLLOWS:		**Initial**
I, the participant, was invited to participate in the above-mentioned research project		
that is being undertaken by	Wanita McGrath	
from	Faculty of Education	
of the Nelson Mandela Metropolitan University.		

THE FOLLOWING ASPECTS HAVE BEEN EXPLAINED TO ME,	**Initial**

THE PARTICIPANT:					
2.1	**Aim:**	The investigator is studying: **EDUCATING CHILDREN PRESENTING WITH AUTISTIC SPECTRUM DISORDER: EXPLORING PARENTS' EXPERIENCES** The information will be used for research purposes.			
2.2	**Procedures:**	I understand that I will participate in this study which will use Memory work, Drawings and Focus groups. I will be expected to produce memory accounts and drawings as part of my participation.			
2.3	**Risks:**	I understand that, in the event that I feel that I need to discuss any feelings, which may have arisen as a result of my participation in this research, I will be assisted in finding an appropriate person to speak to.			
2.4	**Possible benefits:**	As a result of my participation in this study I will gain a deeper understanding of ASD and will, through my participation add to the body of knowledge.			
2.5	**Confidentiality:**	My identity will not be revealed in any discussion, description or scientific publications by the investigators.			
2.6	**Access to findings:**	Any new information or benefit that develops during the course of the study will be shared in the form of academic writings and I will get copies of any publications produced.			
2.6	**Voluntary participation / refusal / discontinuation:**	My participation is voluntary	YES	NO	
		My decision whether or not to participate will in no way affect my present or future care / employment / lifestyle	TRUE	FALSE	

3. THE INFORMATION ABOVE WAS EXPLAINED TO ME/THE PARTICIPANT BY:	**Initial**

Wanita McGrath									
in	**Afrikaans**		**English**		**Xhosa**		**Other**		
and I am in command of this language, **or** it was satisfactorily translated to me by									
Wanita McGrath									
I was given the opportunity to ask questions and all these questions were answered satisfactorily.									

4.	No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.	

5.	Participation in this study will not result in any additional cost to myself.	

A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT:

Signed/confirmed at on 20	
Signature or right thumb print of participant	Signature of witness: Full name of witness:

A. STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I,	WANITA MCGRATH	declare that:

1.	I have explained the information given in this document to								
2.	He / she was encouraged and given ample time to ask me any questions;								
3.	This conversation was conducted in	**Afrikaans**		**English**		**Xhosa**		**Other**	
	And no translator was used <u>OR</u> this conversation was translated into								
	(language)			by	WANITA MCGRATH				
4.	I have detached Section D and handed it to the participant				**YES**			**NO**	
Signed/confirmed at				on				20	
Signature of interviewer				Signature of witness: Full name of witness:					

B. DECLARATION BY TRANSLATOR (WHEN APPLICABLE)

I,	(full names)		
ID number			
Qualifications and/or			
Current employment			
confirm that I:			
1.	Translated the contents of this document from English into	(language)	
2.	Also translated questions posed by	(name of participant)	as well as the answers given by the investigator/representative;
3.	Conveyed a factually correct version of what was related to me.		
Signed/confirmed at	on	20	
I hereby declare that all information acquired by me for the purposes of this study will be kept confidential.			

Signature of translator	Signature of witness:
	Full name of witness:

C. IMPORTANT MESSAGE TO PATIENT/REPRESENTATIVE OF PARTICIPANT

Dear participant/representative of the participant

Thank you for your/the participant's participation in this study. Should, at any time during the study:

- an emergency arise as a result of the research, or
- you require any further information with regard to the study, or
- the following occur

(indicate any circumstances which should be reported to the investigator)

Kindly contact	
at telephone number	(it must be a number where help will be available on a 24 hour basis, if the research project warrants it)

Addendum 4: Approval from NMMU Ethics Committee

Nelson Mandela
Metropolitan
University
for tomorrow

FACULTY OF EDUCATION
Tel . +27 (0)41 504 2125
Fax. +27 (0)41 504 9383

8 August 2013
Ms W McGrath / Dr M Khau
Education Faculty
NMMU

Dear Ms McGrath / Dr Khau

EDUCATING CHILDREN PRESENTING WITH AUTISTIC SPECTRUM DISORDER: EXPLORING PARENTS' EXPERIENCES

Your above-entitled application for ethics approval was approved by the Faculty Research, Technology and Innovation Committee of Education (ERTIC) meeting on 6 August 2013.

We take pleasure in informing you that the application was approved by the Committee.

The ethics clearance reference number is **H13-EDU-ERE-024**.

We wish you well with the project. Please inform your co-investigators of the outcome, and convey our best wishes.

Yours sincerely

Ms J Elliott-Gentry
Secretary: ERTIC

Addendum 5: Transcriptions of Memory Work (small sample)

Nelly: For me the monumentous moment was at eighteen months we were wondering about Annie' because she was quiet and she was playing on her own. We were actually having dinner with family and my sister in law was commenting on her being awkward with people and not talking much. We said but you can't compare Annie' with her cousin, because he was talking at eleven months, so let's not go there. Let's give it six more months, and that's what we left it at then. Then she started going to playschool and she was there for a while, then the one-day the teacher called me in and said she wanted to chat to me. She asked me if I also noticed that she does also not react to her name at home. We did but we thought she was just ignoring us. So I asked if there was anything else and she said, “She likes to play alone in the corner; she doesn't like me reading to group.” So I said I would look into it and have her ears tested. But when I turned around from that teacher I thought “What are my child's symptoms?” I didn't even know what autism was all about. I went home to my good friend Google and all the symptoms I typed in brought up red flags. And I thought oh my goodness. I then told my husband.

Wanda: What was his reaction?

Nelly: That's where we are pro-active. We looked at her problems and then looked at how we could fix it and if we can’t fix it, how will we deal with it? We went into auto pilot - first audiologist, then paediatrician, every possible blood test you could think of, MRI, EEG, we did everything, psychologist, speech therapist, occupational therapist.

Wanda: I resigned from my job, spent two years at home with him.

Nelly: For us her clinical picture was very grey, some areas were a definite yes and some were sort of can't be. Nobody wants to give you a definite answer: yes you have an autist.

Wanda: You actually wish someone would just have the balls to come right out and say to you; I think he may be on the spectrum.

Nelly: No they keep saying things like there must be something going on and as a parent, you walk around thinking “Am I imagining it? Is there something wrong with me, this child is not normal, but everywhere you go people are saying it may be this or that. So for me, that day when I got my diagnosis was the best day ever. I was celebrating. Because for the first time in a year, I was not dealing in an intervention because she might be autistic - I had an autist and that was that. It wasn't just me thinking there was something wrong anymore, there is something wrong. You’re actually dealing with it now. You're not just wondering what the heck is going on and especially when we went to the specialist. It was a no-brainer - you have an ASD situation here. He sat us down and worked with her for a bit and said “Okay let me explain the ASD to you.” We were like “Wait a minute. Are you saying she is? So for me the autism diagnosis wasn't the end of my world, whereas for most people it is like how will we go on from here? We were like, “Yay we can go on from here.” But I know that a lot of people experience this differently. The other day the OT said to me that she would very much like me to meet one of her other autistic children's moms because she had been struggling for six months to come to terms with the fact that her child is autistic. Just to wrap her head around it and embrace it, whereas for us it’s our child. I love her for who she is.

Wanda: Absolutely, I adore my son!

Nelly: We look at how she deals with life, by taking it day by day. But not all people are able to get it, wrap their head around it, although I don't think that you will ever truly wrap your head around autism.

Wanda: But you can come to accept it. This is my child. This is his diagnosis and I can deal with it. Other people must also deal with it. I actually introduce my son and I tell them before this is what to expect. This is who he is; you just wish that the teachers at school could be the same. I look at some of my staff at school at school and there are kids who definitely are somewhere on the autism spectrum - they are pretty high functioning because they can survive at a mainstream school. I say survive because they are hanging in there by their nails but the teachers are so intolerant of them. These are my friends I am talking about, they are intolerant, they don't get them and they don't understand why these kids are struggling. You look at them and you wonder if it would even help if I explained it to you. I don't know if it even would. I have tried.

Nelly: It's a thing of if you're not faced with it, you don't care.

Wanda: They have two normal neurotypical kids at home.

Nelly: For me I wondered about autism at school, but I didn't read up about it and to find out what it was about.

Wanda: I saw the movie about the boy knocking his head up against a wall...

Nelly: But then when you're faced with a child who has it you have to face it. If you don't have it you don't bother facing it and if you're not a compassionate person by nature, why bother? And I think that, that's the problem with teachers these days, for a lot of them being a teacher is not a calling anymore.

Wanda: No its a job

Nelly: You don't have that compassion, I am just doing my job. That's where one of the problems comes in. They also aren't aware of it, they aren't aware of autism and dealing with it. As simple or difficult as it is they are simply not made aware of it. So for me tolerance might be our biggest problem. For example the teacher Annie' is with now is an angel, I think she fell right from the sky and became my child's teacher. She is absolutely amazing but she is tolerant and because she is tolerant I will never know that my child is struggling. If Annie' screams at friends she will tolerate it. If Annie' is having a bad day, she is tolerated. Whereas I actually want her to complain. I want her to say “Listen, your child screamed my head off today at least five times.” But I will never hear that because she is tolerated. So sometimes, intolerance is a good thing. It would be great if people were intolerant but were speaking about it and willing to learn from it.

Heidi: I think the boundaries of tolerance and intolerance, I think that's what you are saying, there need to be boundaries. Like this I think I need to tell the parents about. They should think of what the parents need to hear.

Wanda: Yes, this is necessary and this is not necessary. They are dealing with so much already. This just needs to be written down and at some stage maybe I can just mention it at another stage, but you don't need to bombard the parents with all this information. Otherwise, it is a constant barrage of negativity.

Nelly: Just like the decision to send my child to a mainstream school was not an easy one, I felt like I was throwing my child to the wolves. It was my worst day ever and the month running up to that day were the worst ever. Wondering if she is going to be okay? How is she going to cope on that first day? How she is going to cope in class and if she is actually going to have interaction with her friends? How is she going to deal her teacher and how is it going to work? It's a big thing - it was a huge step. But it went well, we were lucky enough that it went well for us. When we went to the school we said “Look, this is what we have. We have a very, very high functioning autist. You won't know there is something wrong unless we tell you there is something wrong but life to her is challenging. She doesn’t understand you speaking to her, you might ask her a question and she won’t answer you, not because she doesn't get it. I need to be able to tell that to her teacher.” He wanted us not to tell the teacher but we said that, that was not going to happen. We said we were glad that he wanted to give her a fighting chance but I need to be able to help my child. Whoever she gets to needs to know what she is dealing with.

Wanda: Give the teacher a chance to read up a bit and find suitable activities for her, look at support groups on line, where the teacher can actually get help to help your child.

Nelly: So I then gave them all the reports from all the specialists, the teacher needs to read them and once she has done it I need to see her. After a while once I saw the teacher she commented that what she saw in the reports and what she saw where not the same thing. So I said “What you are seeing is the result of a year of intensive intervention. If we didn't have that you would have seen exactly the same or worse. I needed you to know that I am not just throwing my child at you. We are involved and it's important to us that she does well, being able to do, so I need communication from you. I need to know if she is not coping, I need to know if you think she needs help with something.” Now I am experiencing tolerance with this teacher but it might not be the case with the next teacher. She might not be that tolerant.

Wanda: Yes, we had that in grade one but not in grade 2.

Nelly: My son’s grade one teacher was a piece of gold. She was absolutely amazing. She understood that my child needs to move to learn, he needs to talk while you talk to actually take in what you are saying. That's the way he processes, she got that. But now the grade 2 teacher has no tolerance. Within the first month we got a letter and he isn't even on the spectrum. But even though I hate the fact that she is so intolerant of my child and that she doesn't understand him at least I know when there is something that needs to be dealt with. So with Annie's teacher she is so tolerant of everything I would never ever know, okay we need to deal with it. So when it comes to the next teacher I won't know, and that's scary not being able to know.

Wanda: Perhaps you could have a handover, a massive handover. You spoke about handovers, Hilda?

Hilda: Yes, I was very fortunate that Red had three teachers, his grade two and three and then three and four and five and then six, teachers all stayed the same which was fantastic. That is the way that autists should be taught, that you don’t keep changing because the classes are so small. Matter of fact, having mixed grade in class means that they are continuously learning. With him only having three teachers I was able to give them almost every book on a parent’s journey. Now with the last one, his teacher John said “Please don't stop giving me these books. I find them fascinating. I didn't know these kids and they are fascinating and I am going to study in this direction.” He thinks these children are beautiful, he didn't know. He said “I have taught for so many years and now Red as taught me.” That has been the wonderful journey and it’s come to an end but he has told us “Please be in my life. You can't just step out. Please tell me what's happening to Red.” So we are keeping in contact and two weeks ago Red asked if we could please go back to his primary school because he wants to go back and see all the people. Do you know what he did? I told him to remember that we are not part of the school, we have to ask permission. He went into the class and found all the computers that they had put in and was asking Mr X have we still got this? Yes Red. Mr X this is mine. Yes Red but

I would like to keep that if you don't mind, because every time I look at it, it brings back good memories. So it means something to him too on some level.