TRANSITION TO SPECIAL EDUCATION: THE EXPERIENCES OF PARENTS OF CHILDREN WITH COMMUNICATION DISORDERS ASSOCIATED WITH INTELLECTUAL DISABILITY IN THE PROVINCE OF KWAZULU-NATAL

A RESEARCH PROJECT PRESENTED TO

THE DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

UNIVERSITY OF KWAZULU-NATAL

SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE

DEGREE

MASTER OF COMMUNICATION PATHOLOGY

(SPEECH-LANGUAGE PATHOLOGY)

BY

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DECEMBER 2015

DECLARATION

TRANSITION TO SPECIAL EDUCATION: THE EXPERIENCES OF PARENTS OF

CHILDREN WITH COMMUNICATION DISORDERS ASSOCIATED WITH

INTELLECTUAL DISABILITY IN THE PROVINCE OF KWAZULU-NATAL

I, Sitha Laalje, declare that this dissertation, submitted to the University of KwaZulu-Natal in partial fulfilment of the requirements for the degree Master of Communication Pathology (Speech-Language Pathology), represents my own work and has not been previously submitted to this or any other university.

Signed:_____   Date:_____

ACKNOWLEDGEMENTS

I would like to extend my gratitude to the following individuals who have contributed to the undertaking and completion of this project:

- To all the participants who participated eagerly and willingly without expecting much in return.
- Ms Desiree John and Professor Mershen Pillay for their continued guidance and supervision throughout this project.
- Ms Carrin Martin for a thorough appraisal of the thesis.
- My work colleagues who understood and supported my needs during this period.
- My family for their assistance, encouragement and patience.

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Abstract

Millions of children around the world are affected by childhood disabilities, and are much less likely to participate in schooling than those not affected (Filmer, 2008). This study supports the global initiative to ensure that all children, including those with disabilities, are schooled. The aim of this study was to therefore explore the experiences of parents of children with communication disorders associated with Intellectual Disability (ID), specifically during their children"s transition to special education. An understanding of the nature of the parents" experiences could lead to improved service delivery, which could result in better outcomes for the parent and the child. The researcher adopted a qualitative approach to the study and explored the perspectives of the parents. Focus group and individual interviews were conducted to obtain the data which was transcribed and analysed thematically. The results revealed that at a formal level, parents received inconsistent support from the education structures. Some of their children were removed from school registers, whilst others could not access appropriate education. Assistance was sought from public health facilities and from private psychologists. The parents indicated supportive and non-supportive responses from informal support systems. They also talked about their associated negative and positive emotional experiences during their children"s transition to special education. The study limitations and implications have been discussed. This study made recommendations for stakeholders involved in the transition of affected children to special education. This new knowledge can be translated into action and act as a tool for improving service delivery.

Chapter 1: Introduction

"It is not beyond our power to create a world in which all children have access to a good education. Those who do not believe in this have small imaginations."

(Nelson Mandela, 2007)

1.1 Introduction

Millions of children around the world are affected by childhood disabilities. Approximately 10% of these children have developmental disorders that require access to the health care system and extensive care giving, often into their adult years (Raina et al., 2004). Many of these children are from low-income and middle-income countries, where access to support and care is limited, including schooling and health care (Maulik & Darmstadt, 2007). Children with disabilities are much less likely to be educated than other children (Filmer, 2008). In South Africa in 2011, 104 633 children with disabilities were accommodated in approximately 423 special schools, while a further 110 273 attended ordinary public schools (Department of Social Development, Department of Women Children and People with Disabilities, & United Nations Children's Fund, 2012). However, a large number of children are still unaccounted for and are excluded from the benefits of government-funded education.

One of the goals identified at the World Education Forum in Dakar in 2000 was that all primary school children will participate in a full course of free education by 2015 (United Nations Educational Scientific and Cultural Organization, 2002). Provision of basic education was recognized as being an integral component of the world"s strategy to halve the incidence of poverty within less than a generation. A major global initiative was "Education for All" (Robson & Evans, 2003), which was necessary for three reasons. First, education has been declared a human right, and the denial of education is a violation of human rights. Second, it impacts upon people"s capabilities and thereby contributes to self-development and the development of the country. Third, it has an important role in empowering people in disadvantaged societies, and is also an indispensable means to unlock and protect other human rights (United Nations Educational Scientific and Cultural Organization, 2002). Therefore, the provision of a basic level of education for all must be made

available. It was hoped that this study supported this global initiative in ensuring that all children, including those with disabilities, are schooled.

1.2 Childhood Disability

In 2006, 18 countries participated in the "Multiple Indicator Cluster Survey" programme, an initiative to determine the percentage of children who were screened positive, or who were considered to be at risk for disability, in low-income and middle-income countries (Gottlieb, Maenner, Cappa, & Durkin, 2009a). The study found that more than 10% of children screened positive for disability in 17 of the 18 countries. This incidence places a considerable burden on childhood development and family life, and has implications for resource allocation in affected countries. Research and progress in childhood disability has been limited in low-income and middle-income countries as there is little available data, which is an indispensable part of the development agenda of any country.   According to a Millennium Development Goals Report, we must be able to measure what we treasure and therefore produce sustainable data for the sustainable development of a nation (United Nations, 2015). This data should be used for evidence-based decision-making regarding a country"s own national priorities and development strategies, and to effectively focus their development policies, programmes and interventions. Reliable data also contributes to monitoring the progress and achievement of the Millennium Development Goals, and holds governments and the international community accountable for their actions (United Nations, 2015). It is therefore important to include children"s disabilities in national census and surveys so that they can be counted and prioritized. The two major global initiatives that relate to disability will not be achieved in the absence of relevant data, these being "Education for all" and "Millennium Development Goals" (Robson & Evans, 2003). The first Millennium Development Goal is to eradicate extreme poverty and hunger, and the second is to ensure that all children complete primary education (United Nations, 2002). However, despite the development of statistical systems to produce quality data, reliable statistics for monitoring development remain inadequate in many countries (United Nations, 2014).

Although the number of children enrolled in primary education across all countries more than doubled between 1990 and 2012, there were still 53 million children of primary school age who were not in school, of whom 33 million are in sub-Saharan Africa, with almost 50% of these being unlikely to go to school (United Nations, 2015).   While achieving universal primary education requires both enrolment in, and completion of, the full cycle of primary school education, high dropout rates remain a major impediment.   Between 2000 and 2011, persistent early school leaving slowed progress towards achieving this goal in developing regions. During this period, only three out of five pupils in sub-Saharan Africa were able to complete primary school.   The proportion of pupils who completed the last grade of primary education remained at 73% in developing regions (United Nations, 2015). Boys were at greater risk than girls of leaving school early.   Children who are over-age for their grade are more likely to leave school early due to late entry or repetition.   Other critical factors for early school leaving include travelling or walking long distances from home to school, household poverty and rising opportunity costs of attending school.   Sub-Saharan Africa is home to over half of the world"s out-of-school population and a decline in international foreign aid further threatens basic education in these poor countries (United Nations, 2014).

1.2.1   Education of Children with Disabilities.

It has been estimated that 85% of the world"s disabled children who are under fifteen years of age live in developing countries (Filmer, 2008).   Most of these children do not receive education, are absent in school data sets and do not appear on the national policy agenda.   This was revealed in 14 nationally representative household surveys, which concluded that children not attending school were more likely to screen positive for disability than those attending school.   Disability is a major impediment to accessing education, with these children unlikely to have the same opportunity to start or complete their schooling as the other children in the community (United Nations, 2014). These children often require education that must be adapted to their needs.   However, in many developing countries, such personalized approaches are either deficient or unavailable, which either prevents these children from going to school, or slows their progress.   They should be included and supported in education in order to achieve the Millennium Development Goal of "Education for All" (Filmer, 2008).   These findings were supported by the

World Health Organization"s "Multiple Indicator Cluster Survey" in 2007, which suggested that disability in developing countries is associated with long term poverty, as children with disability are less likely to earn higher incomes (Gottlieb, Maenner, Cappa, & Durkin, 2009b).

A study conducted in a Soweto township in South Africa found that few disabled children attended school (Saloojee, Phohole, Saloojee, & IJsselmuiden, 2007). Furthermore, those with motor impairments were more likely to receive rehabilitation than those with Intellectual Disability (ID). Improved early cognitive and social-emotional development are major determinants of scholastic attainment in developed countries (Pianta & McCoy, 1997). A study in South Africa demonstrated that cognitive ability and achievement at the end of grade one predicted later school progress (Liddell & Rae, 2001). Interventions at this young age can have lasting cognitive and school achievement benefits (Saloojee et al., 2007). This highlights the need for greater efforts to enrol children with disabilities at the earliest grades possible.

The Bill of Rights, as contained in the South African Constitution, states that every child has the right to a basic education, including those with disabilities (Republic of South Africa, 1996a). According to the South African Schools Act 84 of 1996, attendance is compulsory for learners from Grades 1 to 9, or between the ages of seven and 15, whichever may come first (Republic of South Africa, 1996b). Similarly, goal two of "Education for All" calls for governments to provide access to free and compulsory primary education. However, while education legislation in South Africa provides for compulsory education, this is not free for all children (Department of Education, 2008a). In reality, many children are turned away from mainstream and special schools because they cannot afford the fees, and stay at home without being educated in a formal school.

1.2.2   South African policies on disability.

Many South African policies focus on disabilities, including the South African constitution (World Health Organization & Department of Psychiatry and Mental Health 2007). This is in line with South Africa becoming a signatory to the United

Nations Convention of the rights of people with disabilities and that of children on 30 March 2007 (Burns, 2011). The White Paper on "Integrated National Disability Strategies" was introduced in 1997. This was aimed at facilitating disability integration into departmental strategies, plans and programmes including the provision of education for children with special educational needs. Gaps still remain with regards to children with disabilities and their families and the efforts of governments to meet their needs (Department of Social Development et al., 2012). Few of the policies that were formulated have been implemented effectively, and the services that are provided are often not accessible to the people for whom they were intended (Adnams, 2010a). Specialized health services, including those for people with ID, are limited and mainly situated in larger towns and cities, which results in those living in rural areas either not being able to access them or accessing them with difficulty. Studies have shown that services are inadequate for children and adults with ID across the country (Adnams, 2010b). Poor policy implementation and service delivery, and the low priority of ID, is resulting in unmet social, health and educational needs.

1.2.3   Personal motivation.

My personal motivation for conducting this research stems from the fact that I have been working as a speech therapist at a special school that admits children who have ID as their primary disability. I have interviewed and advised many parents who were in need of a special school for their children in my capacity as a member of the admissions committee of this institution. They sought assistance for their children who experienced developmental or persistent academic and/ or behavioural difficulties at mainstream schools. The applicants for admission ranged from four to twenty three years of age, and parents relayed a range of stories that arose from various circumstances. Parents often did not know what to do, or where to go for assistance, after being told that their children were not coping within mainstream education. They became emotional and appeared helpless. Accessing appropriate education for their children became a long and difficult process that they and their children endured for years.

Their children were turned away from mainstream and special schools for various reasons, some waited for several years to be placed in a special school, and others were removed from school registers and the parents were asked to find a school elsewhere. Some parents did not know of the existence of special schools or believed that these were unaffordable and therefore kept their children at home. This resulted in their children being denied basic or suitable education. During my interaction and engagement with these parents, they expressed a variety of feelings and experiences, which were managed in a variety of ways. They expressed sad and happy feelings as well as anger, hurt and disappointment. I listened to their stories and commented and advised within my expected role as an admissions officer and health professional (therapist). Furthermore, my response to their revelations was also influenced by my own background, world view, experiences and status as a mother with children. This interaction resulted in my exploration of this topic, with the hope that an understanding of the nature of the parents" experiences could lead to improved service delivery that will enable better outcomes for the parents of children with communication disorders associated with ID.

1.3 Problem Statement

While South Africa has a number of policies that address the needs of children who require admission to special schools, many parents are unaware of how to access them and do not receive consistent support regarding access. This results in many children not attending school or having to wait years for a place in an appropriate educational institution. As a result, many of these children repeat grades are condoned each year at school, go in search of a school, drop out or stay at home as they are refused admission. Very little research has been done in South Africa to explore the experiences of parents of children with communication disorders associated with ID, specifically during their children"s transition to special education. In the absence of this knowledge, the experiences of parents and their children will not be known and their needs may never be understood or met. They may therefore not receive the kind of support and services that they may require. A consequence of this could be that children with disabilities would continue to be denied basic or appropriate education and the Millennium Goal of "Education for all" will never be attained.

1.4   Research Design

Human experience is said to be complex with no specific order or pattern and is based on specific memories (Polkinghorne, 2005). Personal experiences reflect the flow of thought and meaning people bring to their immediate situations. Experience has a vertical depth that can only be captured by reports of experiences made by the people themselves, enabling the richness and fullness of their experience to be tapped (Clandinin & Connelly, 1994).   The parents in this study revealed their experiences that were the reconstructions of the events that they lived, as they interacted with a social environment (Bailey & Tilley, 2002). The researcher adopted a qualitative approach as a means to explore and understand the meaning individuals attached to a social or human problem (Creswell, 2009). Qualitative researchers try to develop a complete picture of the issue under study, by reporting multiple perspectives and identifying the many factors involved in a situation. Qualitative research is not uni-dimensional, but has various theoretical foundations that includes cultural perspectives which were considered during the research process (Pugach, 2001).

The perspectives of the participants were under investigation in this study and this enabled the researcher to understand the participants" social world and the meanings they attached to the study topic (Yates, 2004). The human experiences were described and clarified as it occurred in their lives (Polkinghorne, 2005). A phenomenological perspective was taken, thus enabling them to develop different worldviews, which determined how they interpreted and made meaning of their world, as well as how they understood a specific situation or phenomenon (Yates, 2004). The term "worldview" has been defined as a set of beliefs that guides one"s actions (Guba, 1990). Their worldviews were influenced by their cultures, and their responses to the research questions were influenced by their worldviews.   Life stories emanate from culture and they reflect the culture (McAdams, 2001).

1.5 Research Question

What were the experiences of parents of children with communication disorders associated with ID during their children"s transition to special education in Durban, KwaZulu-Natal?

1.6 Aim of Study

The aim of this study was to explore the experiences of parents of children with communication disorders associated with intellectual disability, during their children"s transition to special education in Durban, KwaZulu-Natal.

The objectives were as follows:

1. To explore the parents" experiences of formal support received during their children"s transition to special education;

2. To explore the parents" experiences of informal support received during their children"s transition to special education;

3. To explore the negative emotional experiences of parents during their children"s transition to special education;

4. To explore the positive emotional experiences of parents during their children"s transition to special education.

1.7 Thesis Outline

This document consists of the following chapters:

Chapter 1: Introduction

This chapter includes a discussion on childhood disabilities, the education of children with disabilities, South African policies on disability, the problem statement, a personal motivation for the study, the research design, the research question and the aims and objectives of the study.

Chapter 2: Literature Review

This chapter provides an overview of the literature relating to legislation governing the education of children with disabilities, barriers preventing children from gaining access to special education, intellectual disability, communication disorders, early childhood education and positive and negative emotional experiences of parents.

Chapter 3: Methodology

This chapter details the research methodology, including the participant selection criteria, sampling, procedure, data collection, data analyses, the research procedure and ethical considerations.

Chapter 4: Results and Discussion

This chapter reports the results of this study, which will be in the form of information-rich descriptions and narratives that relate to each of the four objectives. Verbatim accounts will be included to enhance descriptions, wherever deemed appropriate. The results obtained and the interpretation thereof will be presented concurrently. Interpretations will be made from the data obtained and supported by current literature.

Chapter 5: Conclusion

This chapter addresses to what extent the aim of the study was met, indicates the study limitations and recommendations; as well as the theoretical, clinical and research implications of the study.

1.8 Summary

More than 100 million children in the world are still deprived of access to primary education. One of the goals identified at the World Education Forum was that all children will participate in a full course of free education by 2015 (United Nations Educational Scientific and Cultural Organization, 2002). It has been estimated that 85% of the world‟s disabled children who are under fifteen years of age, live in developing countries (Filmer, 2008). Most of these children do not receive education, are absent in school data sets and do not appear on the national policy agenda. The Bill of Rights, as contained in the South African Constitution, states that every child has the right to a basic education, including those with disabilities (Republic of South Africa, 1996a). Many South African policies focus on disabilities, including ID (World Health Organization & Department of Psychiatry and Mental Health 2007). Few of these policies have been effectively implemented and the services that are provided are often not accessible to the people for whom they were intended (Adnams, 2010a). The aim of this study was to therefore explore the experiences of parents of children with communication disorders associated with

ID during their children‟s transition to special education. An understanding of the nature of the parent experiences could lead to improvements in service delivery, which could result in better outcomes for the parent and the child with a communication disorder associated with ID. It is hoped that this study would provide insight into the parents‟ experiences.

Chapter 2: Literature Review

2.1 Introduction

This chapter begins with a discussion of international and South African legislation governing the education of children with disabilities, which will inform or indicate the extent to which the rights of disabled people are protected by law. Barriers to accessing education have been included, as some children are prevented from gaining access to special education. The reader has been orientated to the concept of intellectual disability as such children may require special education from an early age (Bergen, 2008). Early Childhood Development programmes were deemed important as it can facilitate the early identification of ID and children"s transition to special education (Velez et al., 2014). The level of success during the transition to school, or when transferring between phases of education, can be a significant factor in determining children"s future progress and development (Docket & Perry, 2007). Furthermore, transition to special education can be an emotional experience for the parents of the affected children. The chapter reviews the negative and positive effects of a child"s disability on the family (Hastings, Beck, & Hill, 2005). Finally, delivering effective services to people from various cultures requires an understanding of how their cultures influence their views on disability and their resulting practices (Stone, 2005). This information will assist professionals in providing effective services to people across cultures.

2.2 Children with Communication Disorders Associated with Intellectual Disability

Intellectual disability is one of many developmental disorders in children, but the most prevalent neurological disorder globally (Bergen, 2008). According to Vinson (2012), a child with ID should demonstrate marked deficits relative to his/her chronological age in the areas of intellectual functioning, personal independence, self-care and social responsibility, with the age of onset being before 18 years. The term "Mental Retardation" has been used interchangeably with the term "Intellectual Disability" in the literature, with both terms referring to the same population of individuals (Luckasson, Borthwick-duffy, Coulter, Craig, & Reeve, 2007). In the United Kingdom, ID is referred to as a learning disorder. In South Africa, a child with

ID is referred to as having a barrier to learning (Department of Education, 2001). The term "Intellectual Disability" will be used for the purposes of this study.

Intellectual disability is very prevalent in under-resourced schools in South Africa because of many risk factors (Prinsloo, 2001). The intellectual and social learning problems of children with ID are difficult to manage in the regular classes, and they are accommodated in special schools or schools for learners with special needs (Department of Education, 2001). The prevalence of ID varies amongst countries. Surveys in high income countries show three to five affected individuals per one thousand with severe ID (Intelligence quotient below 55). Estimates from developing countries, however, have revealed prevalence rates from five to twenty two per one thousand (Bergen, 2008). Various risk factors are associated with the onset of ID during the prenatal and developmental period in South Africa. Poverty, malnutrition, inadequate medical facilities, pre-natal infections and infections during early childhood are some of the risk factors that cause a high incidence of disability among children in developing countries. Malnutrition and infections cause stunting of a child"s cognitive and physical development. The number of stunted children has increased by one third in sub-Saharan Africa (United Nations, 2015). Tests of intellectual functioning are used to determine mental ability and to measure intelligence (Hourcade, 2002). Intellectual disability was classified into four levels of severity (mild, moderate, severe and profound), which were based mainly on intelligence quotient scores. The level of support that is required by individuals with ID increases as the severity of the disability increases. Individuals who are classified as severe to profoundly affected require complete care and supervision even as adults (Hourcade, 2002).

Children with ID have difficulties with communication (Vinson, 2012). Communication disorders are disorders of speech (articulation, voice, resonance, and fluency), myofunctional (swallow) patterns, language, cognition, communication, hearing and balance (American Speech-Language-Hearing Association (ASHA), 1993). The definition includes disorders of reading and writing, as well as manual and other communication systems. Communication disorders occur in approximately 10 to15% of young children (Bacon & Wilcox, 2011). Children with ID usually demonstrate global developmental delay and have difficulties with all aspects

of communication (speech, language, cognitive and myofunctional patterns). Early identification and timely intervention of communication disorders, can improve the outcome for the child (Sachse & Suchodoletz, 2008). This is followed by diagnosing specific speech and/or language disorders and identifying possible etiological factors related to the presenting communication difficulties (Vinson, 2012).

Communication disorders can vary in severity and are more pronounced with an increase in the severity of the ID. They are traditionally divided into three categories

- The mildly affected child with ID has delayed social and communication skills that can go unnoticed until the child begins school or later. Academic skills may not progress further than the sixth grade level and special education is required thereafter. These children are especially disadvantaged as they are only identified or diagnosed after learning problems and persistent academic underachievement become apparent, by which stage they have often failed subjects and repeated grades (Prinsloo, 2001);

- The moderately affected child may have a delay in learning to talk and therefore progress up to the fourth grade level, after which special education is needed;

- The severe to profoundly affected child may learn to talk at a basic level or minimally and may require an alternate means of communication, which will be facilitated by the speech-language therapist. This type of child will not develop functional academic skills and will need complete care and supervision, even as an adult (Vinson, 2012).

Children with communication disorders associated with ID may experience challenges throughout their lifespan. They may experience difficulty with acquiring literacy skills, which can affect their understanding of the various academic subjects throughout the school years. It can result in academic underachievement or failure, with this subset of the population not being able to participate fully as productive members of the community and society (Roth, 2011). Furthermore, children with communication disorders are at higher risk of emotional and behavioural disorders compared to the community at large (Bishop & Leonard, 2000). Problems relating to

socialization and decreased peer interaction can arise with socially inappropriate behaviours, such as aggression or emotional outbursts occurring. These children have a variety of educational needs that must be accommodated within a country"s system of education.

Children with ID may be at a greater risk for early school difficulties, partly due to their deficits in cognitive ability and adaptive behaviours, which can result in parents being frequently summoned to school because of their child"s behaviour. These children are at risk for many negative outcomes, such as academic difficulties, emotional, behavioural and mental health problems (Pfeiffer & Baker, 1994). Epidemiological studies indicate that individuals with ID are three times more likely to have a severe behaviour disorder or mental health problem than their typically developing counterparts (Baker, McIntyre, Crnic, Edelbrock, & Louw, 2003). Transition in five and six year old children, with and without ID, was examined (McIntyre, Blacher, & Baker, 2006). The results indicated that children with ID had significantly more teacher reported problem behaviour than typically developing children. It was concluded that children with ID had less positive experiences than their peers during their transition to school and this can affect their school outcomes.

2.3   International Legislation Governing the Education of Children with Disabilities

In many industrialized and some developing countries, laws have been passed defining the educational rights of children with disabilities and the procedures to be followed in assessing and meeting their needs. Children with disabilities are vulnerable and laws and policies are intended to promote full participation and integration of these children into society (Pivik, McComas, & Laflamme, 2002). These laws also ensure disabled children"s rights to education (McConkey & Bradley, 2010). Laws in the United States of America, Canada, England and other countries promote inclusive education, which provide for disabled children to be educated in regular educational settings with their non-disabled peers (Papadopoulou, Kokarida, Papanikolaou, & Patsiaouras, 2004). However, children with severe disabilities in these countries are accommodated in special settings. In the United States, "Part C" of the "Individuals with Disabilities Education Act of 1990" was aimed at planning, developing and implementing programmes that address the

needs of affected individuals and their families (Bayhan & Firat Sipal, 2011). In 2005, Turkey passed "The Public Law for Individuals with Disabilities", it"s purpose being to provide social rights for individuals with disabilities and to inform society about disabilities (Bayhan & Firat Sipal, 2011). These laws ensured that the rights of disabled people are protected and that they are not marginalized in society. Similarly, laws and policies have also been developed to protect the interests of disabled people in South Africa. This legislation will be discussed further below.

2.4. An Inclusive Education System in South Africa

A new and unified education and training system was implemented in South Africa in 2001 to redress past imbalances and to progressively raise the quality of education and training (Department of Education, 2001). The Department of Education compiled the White Paper Six, which is a policy document that addresses special education and the education of learners with disabilities (Department of Education, 2001). It outlined the government"s intention to include special needs education as an integrated component of the general education system. The full range of learning needs was accommodated, including those learners with barriers to learning and development (such as ID). Intrinsic and extrinsic barriers to learning were acknowledged, with ID and other developmental disabilities being identified as an intrinsic barrier. Extrinsic barriers can be systemic or environmental, and can be altered to enhance learning.   An inclusive education system would minimize the intrinsic and extrinsic barriers to learning. The role of educators in identifying and addressing barriers to learning was highlighted by the Department of Education (Department of Education, 2001). Educators were expected to provide appropriate support to children, be trained to identify barriers and address specific needs in the classroom, and to refer learners for further assistance when deemed necessary. The following three levels of support were proposed in schools in South Africa

- Low-level support for children requiring some support in ordinary (mainstream) schools;
- Moderate-level support for children with barriers to learning in full service schools;
- High-level professional support for learners with high levels of need, such as those with ID in special schools.

The Institutional Level Support Team (ILST), comprising staff at the school, should be responsible for addressing specific barriers to learning through collective problem-solving. The District Based Support Team, which should be developed by the provincial and national education departments, should provide ongoing support to the Institution Level Support Teams in these schools. The intention is to expand access and provide education to those learners who are not in the school system. A further aim is to develop the competencies of teachers to address barriers to learning and to accommodate a wide range of learning needs (Department of Education, 2001). Figure 2.1 below depicts the national education structures for all children in the education system with respect to the provision of support at the various levels in the Department of Education.

National Education in collaboration with Provincial Education and all other stakeholders

District Based Support Team (DBST)

Special Schools: High level support with ILST

Full-service Schools: Moderate support with ILST

Ordinary schools: Low level support with ILST
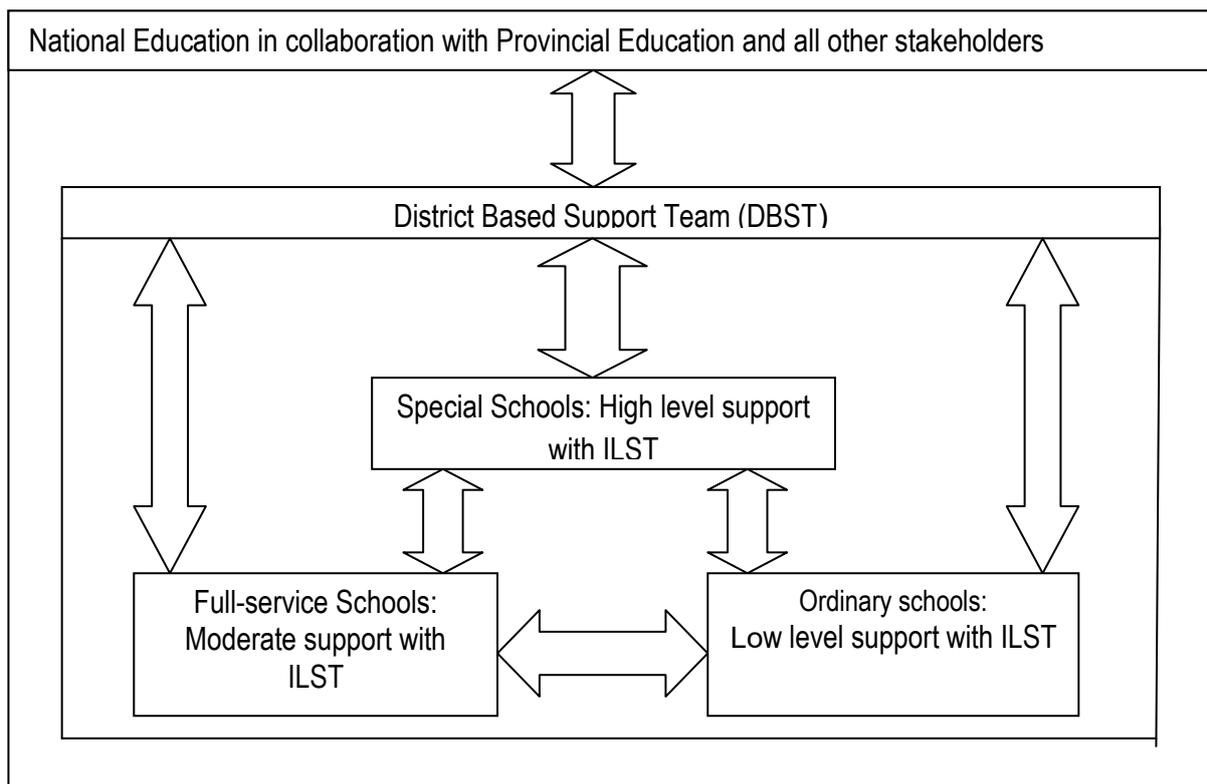
Figure 2.1. Education structures with levels of support.

The district education staff plays an important role in ensuring that the education needs of the children they serve are understood and addressed, and that the national learning goals are achieved. The District Based Support Team should provide class-based, institutional, administrative, psychosocial, environmental and health support to schools (Department of Education, 2014b). Each district is required to have this team that consists of integrated professional support staff (DoE, 2008). The core support providers should include psychologists, therapists, remedial teachers, special needs specialists and other health professionals. Their key role is to assist educational institutions to identify and address barriers to learning, to evaluate programmes and to promote effective teaching and learning.

According to the National Education Policy Act 27 of 1996, the rights and wishes of children with special educational needs must be considered upon admission to an ordinary public school (Department of Education, 2003). This Act requires ordinary public schools to admit children with special educational needs, where this is reasonably practical. According to White Paper Six, schools are encouraged to accommodate such children and to make their facilities accessible to them. Children who cannot cope in mainstream education should be referred to the Institutional Level Support Team in the school (Department of Education, 2008b). If this team fails to address the problem, the school may refer the child to the District Based Support Team after completing the appropriate referral documents. If the child cannot be accommodated in a particular educational setting, the principal of the school should refer the child to the head of department for re-admission to another suitable public school. This process should be undertaken as a matter of urgency to ensure that the child is not prejudiced in receiving appropriate education.

2.5 Transition to Special Education

The word "transition" in the context of child development refers to the process of change that is experienced when children and their families move from one setting to another in terms of location, learning environment, caregivers/teachers, curriculum and individual development, as well as from one mental state to another (Docket & Perry, 2007). The transition process starts when parents begin to think about and make decisions related to schooling, and concludes when they feel secure and accepted within the school environment. Transition to a new school occurs over a

period of time as children engage in a range of experiences that promote their learning, development and wellbeing. Transitional activities enable young children to ease their anxieties about leaving a familiar environment for an unfamiliar one (United Nations Educational Scientific and Cultural Organization, 2012). Adjusting to change can be a challenge for young children and can affect their ability to achieve in primary education. The United States federal law mandates transition to kindergarten programmes for those children identified with special needs. However, the support services are not clearly specified and the programmes are not uniformly provided (Troup & Malone, 2002).

The level of success during the transition to their first school or transfer between schools, both socially and academically, can be a significant factor in determining children"s future progress and development (Docket & Perry, 2007). A successful start to school is linked to later positive educational and social outcomes (Fabian & Dunlop, 2002). One of the enabling factors that assist children during transition is the availability of a range of services, parental support, peer group activities, home support, family involvement, parent-teacher partnerships and Early Childhood Development programmes. Lack of smooth transition and school readiness activities can result in high drop-out and grade repetition rates in primary schools, as observed in a review of the South Asian and Pacific countries (United Nations Educational Scientific and Cultural Organization, 2012). Therefore families, schools and communities should collaborate to ensure that the successive transition from one educational setting to the next is positive, and results in successful experiences for young children and their families (Akhter, Sarkar, Kibria, & Das, 2012). However, school transitions may not necessarily be positive, with parents encountering many difficulties during the process of transition from home or preschool to the regular classroom (Janus, 2004b).

2.6 Factors Affecting Children's Transition to Special Education
2.6.1 Poverty.

Poverty has been found to affect access to education, with sub-Saharan Africa having the highest global rates of absolute poverty for children (Shonkoff, Richter, van der Graag, & Bhutta, 2012). More than 40% of the population in sub-Saharan Africa still lives in extreme poverty in 2015, with children with special health care

needs, being significantly more likely to live with poor families than children in general (United Nations, 2015). A study was conducted on the impact of information on the perceived need for and access to specialized services for children with special health care needs (Porterfield & McBride, 2007). Access to these services appeared to be driven by income and educational status of the parents, as well as by the severity and nature of the special needs of the child. Those with a higher education level and higher income may have greater access to information than their less educated and lower income counterparts. Poverty and lack of education may reduce a parent"s access to information and intervention services for their child. Less educated and lower income parents had a lower perceived need for specialized health care services or did not know what services were available (Porterfield & McBride, 2007). If parents do not think that their children need a care service they will not seek that service. They also appeared to be less interested in their children"s education, and tend to avoid engaging with the school, which can delay or prevent access to special education. A study recommended that teachers involve parents from poor socioeconomic backgrounds in school related activities, as they are generally less educated and lack the necessary knowledge, skills and resources to assist their children (Moletsane, 2004). Intervention in the form of information at the level of the family is recommended.

2.6.2   Support structures and services for children with disabilities.

The success of transition to school for a child with disabilities is largely dependent on the availability of support structures at the school. Parents often complain about the lack of specialised teaching staff or programmes in these schools. A community study by Moletsane (2004) showed that one third of the parents was not satisfied with the services their children received during the transition. In another study it was found that most of the disabled children received some school based services but only three received all the required services and supports (Valeo, 2003). Disabled children and their families require services that are accessed from a variety of service providers, such as health, education, social services, housing and benefit agencies (Gordon, Parker, & Loughran, 1996).

Research has indicated high levels of unmet needs in these areas in parents of disabled children which can delay access to special education (Sloper, 1999). These unmet needs included information and advice about services, the child"s condition and how to help the child, financial and material support, housing, and transport. Beresford (1995) reported that many parents have great difficulties in finding out about available services, who to approach for help and services relevant to their needs and situation. A persistent feature of the parents" accounts was their concerns regarding the bureaucracy in dealing with the service systems, with the lack of co-ordination between the services being a major challenge (Goddard, Lehr, & Lapadat, 2000). There was a lack of communication between the services used by the children prior to going to school and the school system, this being one of the major barriers to successful transition for children with disabilities (Janus, Kopechanski, Cameron, & Hughes, 2008). Lack of continuity between kindergarten and primary school was anxiety provoking (Einarsdottir, 2003). It must be noted that this study was conducted in an urban centre where support systems, procedures and policies were available for parents of young children with disabilities. The dissatisfaction was attributed to the poor implementation of policies and strategies that had been developed to provide support (Janus, Cameron, Lefort, & Kopechanski, 2007). The importance of integrating or linking services to improve the efficacy of service delivery has also been emphasized, and that they are free or at low-cost. In South Africa, there appears to be a lack of research conducted on the services used by children going to school and those of the school system. This could possibly be due to fragmented services that are provided.

2.6.3   Inadequate psychological assessment services.

Progress in mental health service development has been slow in most low-income and middle-income countries (Saraceno et al., 2007). There appears to be a great need for additional psychological services at a primary level in South Africa (Petersen, 2004a). Psychological assessment services involve administering psychometric tests by registered psychometrists or psychologists. The psychological assessment service provides a mechanism to assist children with ID and scholastic problems, and to place them appropriately in special schools. South Africa has a ratio of 0,32 psychologists per 100 000 people (World Health Organization & Department of Psychiatry and Mental Health 2007). People in better resourced

countries, such as the United States of America, have a ratio of 33,9 psychologists per 100 000 people (Hamp, Stamm, Christidis, & Nigrinis, 2014). In a study conducted in Israel the parents were asked about the main services they sought, with most (93, 5%) reporting that they used psychological services either for their affected child, themselves or for the siblings. These services were for psychological testing, guidance or for emotional support. Other services sought were educational (80,6%), medical (71%) and paramedical services, including therapy (51,6%) (Heiman, 2002). Intellectual disability with scholastic difficulties was identified most frequently by a psychological referral service in the late 1990"s in South Africa (Petersen, 2004b). This implied that many children with ID were found in South African schools. Most of the referrals were made to special schools by teachers in the public mainstream education system. It has been recommended that the availability of mental health care be increased in low-income and middle income countries (World Health Organization, 2001).

Despite being unable to cope with the curriculum, many children with ID are found in mainstream schools in South Africa (Pillay & Lochart, 1997). This is attributed to the lack of special services within the educational system that can provide the relevant assessments to identify such children. Psychological services were almost non-existent in rural areas in KwaZulu-Natal. One district was reported to have two psychologists, one social worker and one speech therapist as specialist field workers serving 563 schools, with requests for assistance by schools being placed on a waiting list (Department of Education, 2008b). Consequently, there may be a delay in identifying and placing learners with ID in appropriate educational settings. Such learners may therefore be denied access to early intervention, appropriate education and other services for long periods. A further recommendation was that mental health services should consider ID and other scholastic difficulties in addition to more serious mental illnesses (Pillay & Lochart, 1997). Other kinds of services are also important to children with ID.

2.6.4   Insufficient teacher knowledge.

Insufficient teacher knowledge in the field of special needs and education can delay children"s access to special education. Generally, teachers may have little knowledge and fewer skills to support children with specific educational needs in

large classrooms in mainstream schools (Prinsloo, 2001). Teachers may be unaware of the causes and nature of the child"s scholastic difficulties, and may be antagonistic to such children. Many teachers may not be prepared for the challenges they face with these children and may be of the opinion that they should be placed in special schools (Arbeiter & Hartley, 2002). Their training may not meet the needs of the inclusive classroom, and they may need preparation and guidance in the ways of teaching (Pivik et al., 2002). It is the responsibility of the education system to ensure that teachers in mainstream schools are trained and given the necessary resources to undertake their tasks. Teachers should be supported and monitored so that they can identify developmental delays and refer the children for further evaluation (Velez et al., 2014). Teacher training must be reviewed so that teachers can determine the learning needs of individual children and adapt their learning programmes, teaching techniques and materials accordingly (Prinsloo, 2001).

Pre-service teacher training programmes are slowly being adapted to include special needs knowledge (McConkey & Bradley, 2010). In 2014, the South African government launched a project called „Operation Phakisa", which was aimed at implementing its policies and programmes better, faster and more effectively (Department of Planning Monitoring and Evaluation, 2014). This involved setting up clear targets, follow-up procedures, on-going monitoring and making the results public. In 2015, the government added education to this initiative, with the aim of enhancing the standard of basic education in the country, with teacher training having been prioritized. The South African government has acknowledged that countries that do not invest in education will always be left behind (Matshediso, 2015). The central rationale for investing in education, including education quality, lies in it"s important contribution to economic growth of a country (Tikly & Barret, 2009).

Teachers can also benefit from collaborating with therapists and psychologists, who can guide teachers in implementing appropriate teaching approaches (McConkey, 2007). An accurate assessment of a child"s learning difficulties needs the skills of specialists, such as speech-language therapists, occupational therapists and psychologists. Psychologists have the skill to assess children who are

experiencing difficulties in learning and make appropriate referrals regarding suitable school placement.

2.6.5   Teachers' attitudes towards children with disabilities.

Teachers" attitudes can affect the nature of children"s transition to their new school.   A study evaluated teachers" attitudes towards their disabled and non-disabled students (Cook, Cameron, & Tankersley, 2007). It was found that teachers rated themselves as significantly more concerned and indifferent towards those students with disabilities in the class, compared to those without. Those with disabilities were also rejected. Emotional bullying in the form of name calling, pointing, being labelled with derogatory terms, condescending attitudes and generally being treated differently from other children have been reported. Students reported this as being most hurtful (Pivik et al., 2002). It was felt that the educators" perceived lack of experience and knowledge regarding the instruction of students with disabilities may explain the higher indifference rating towards them.   The unsupportive teacher responses indicated the need for increased knowledge, sensitivity and empathic understanding of childhood disability.

2.6.6   Quality of Early Childhood Development programmes.

Many children, especially those with disabilities who have minimal opportunities, cannot access Early Childhood Development programmes due to various barriers (Betts & Lata, 2009).   Early child development services or programmes can include a broad range of services that promote or support the development of young children in preparation for formal schooling (Ricter et al., 2012). Current best practices encourage health care providers to promote early childhood development, and use systems for early identification and management of associated delays and disabilities, which can be included in early childhood development programmes (Velez et al., 2014). In addition to awareness, training is necessary to translate this into accurate problem identification (Britto, Yoshikaw, & Boller, 2011; Ertem, Pekcici, Gok, Ozcebe, & Beyazova, 2009). Early intervention is particularly important for children with ID, as it is related to optimal cognitive development. Children with ID who receive early intervention in the first year of life experienced more accurate patterns of cognitive and social development (Dale, 1996).

More than half of the world‟s governments have Early Childhood Development policies that are intended to produce desired outcomes but are not necessarily achieving these (Shonkoff et al., 2012). It has been proposed that Early Childhood Development programmes must emphasize the features of access and quality in order to effect sustainable and meaningful changes for the people whom it is intended (Britto et al., 2011). It was agreed that early childhood care and education would be expanded by 2015 (Khumalo & Hodgson, 2015). The Department of Basic Education in South Africa has introduced the policy on Screening, Identification, Assessment and Support, which is a framework for standardizing the procedures to identify, assess and provide programmes to all children who require additional support to enhance their participation and inclusion in school, from grade R to grade 12 (Department of Education, 2014a).   Although several policies on educating children are in place in South Africa, there has been no specific strategy on providing and accessing services for those with disabilities (Storbeck & Moodley 2011). No screening programmes have been developed and implemented to identify disorders, from birth to three years, or management programmes once a disability has been identified in early childhood.   Good Early Childhood Development programs can facilitate a child‟s transition to special education, should this need arise.

2.7 The Emotional Experiences of Parents of Children with Intellectual Disability

2.7.1   Negative emotional experiences.

Increased stress has been a widely reported effect of having a child with a disability.   Parents of children with disabilities have reported feelings of hopelessness, social isolation of the family in the community, and child behaviour problems (Woolfson, 2004). Warfield et al (1999) found that parents of children with ID report greater levels of child related stress than parents of typically developing children. Sloper and Turner (1993) reported high levels of distress in approximately 70% of mothers and 45% of fathers of severely disabled children.   In a study conducted by Veison (1999), it was found that parents, mainly mothers of disabled children, have markedly more emotional states and depressive symptoms. Olsson and Hwang (2001) found that mothers of children with disabilities are at a greater

risk of suffering from psychological distress and depression. A possible reason for this is that the mothers take on a larger part of the care and practical day-to-day work that a child with a disability requires (Marcenko & Meyers, 1991). The high number of single parent households in South Africa has resulted in the care of children with ID becoming the responsibility of single women, or their siblings, relatives or grandparents (Kalipeni, 2008). Many factors have been reported to contribute to parental stress of having a child with a disability (Pahl & Quine, 1985), some of which are outlined in Table 2.1.

Table 2.1.	
Factors contributing to parental stress	
1.	Behavioural problems of the child.
2.	Daily care demands related to the child.
3.	Adverse effects on siblings and relationships.
4.	Marital conflicts associated with raising the child.
5.	Adverse social consequences such as social isolation from family and friends.
6.	Concerns about the future of the child.
7.	Loss of leisure time.
8.	Unrealistic expectations of parents.
9.	Problems encountered with services.

Pahl and Quine (1985) found that the highest levels of stress in a parent were due to having a child with behavioural problems. Emerson (2003) reported that children with ID have an increased risk for behavioural and psychiatric disorders, and this poses a challenge to their caregivers, resulting in an increased care-giving burden. Children with severe ID present with more behavioural problems (Tonge, 1999). Samerof (1998) proposed that maladaptive child behaviour and parenting stress can interact with each other to produce heightened effects. This may place pressure on families to seek social support to help them to manage the child"s behaviour problems (Sharpley, Bitsika, & Efremidis, 1997). Studies have reported a strong relationship between language and behaviour problems, with the former showing a higher incidence of the latter, and conversely, children diagnosed with

behaviour problems showing a higher incidence of language disorders (Barker et al., 2009). Language deficits may contribute to behavioural problems by interfering with the understanding and expression of requests and needs to others, thereby affecting the child"s emotional and behavioural regulation. However, it has not been established whether difficulties in language result in behaviour problems, if behaviour problems result in language disorders, or whether the two are independent outcomes of a more general developmental process (Brownlie et al., 2004). Families also have to manage other aspects of the child on a daily basis.

Daily care demands can be stressful for the family with a loss of leisure time due to responsibilities related to caring for the child (Gupta & Singhal, 2005). Adverse social consequences, such as social isolation or negative reactions from others, can serve as a source of stress. Russel (2003) reported that unrealistic expectations of parents can result in disappointment, poor relationships and resultant stress. There are concerns about the future of the child when the parents are no longer able to care for him or her. The disability can also have adverse effects on siblings and relationships among the family members. Marital conflicts, associated with raising the child can arise, with divorce being significantly more common among the parents of disabled or sickly children than among those of healthy children (Mauldon, 1992). The sources of stress for the parents must be acknowledged in order to provide appropriate services for them.

Parents of children with disabilities may experience a complex and stressful life situation that can have negative consequences if the health care and social service systems do not acknowledge these issues and assist such families (Raina et al., 2004). Middleton (1995) concluded that a lack of parent support and high levels of parental distress will affect the child"s well-being and development. Reducing stress can therefore have better outcomes for child behaviour. McConachie (1994) claims that knowledge about sources of stress in parents informs service delivery and development. Information from well-designed evaluations of interventions and services promotes the development of appropriate service delivery models. Early intervention services for the child and the family may relieve the parent of some stressors, and the difficulties associated with raising a child with special needs may be managed more effectively (Adkinson & Griffith, 1999). Creating a robust

foundation for healthy development in the early years of life is an important pre-requisite for individual well-being, economic productivity and happy societies around the world (Shonkoff et al., 2012). This will be informed by an understanding of how parents of children with disabilities cope with stress and how they can be assisted in this regard.

Taanila, *et al*. (2002), claim that by recognizing the coping strategies, as well as risk indicators of poor coping, used by parents, professionals and service providers can offer suitable services to support the family during this stressful period. In order to cope, the family uses its resources and strategies, which refers to active processes and behaviours to help it to manage and adapt to a stressful situation (Taanila et al., 2002). Research has found that the most important coping strategies used by the parents were accessing information, accepting the disability, accessing social support and good family cooperation. The parents, who coped well, indicated that they had been well informed about their child"s diagnosis and treatment, and had actively sought ways to cope in the stressful situation. Furthermore, Sloper and Turner (1991) indicated that parents who use active problem solving coping strategies to deal with stressors show less distress than those who use passive strategies related to avoidance or self blame. A further coping strategy used by parents was trying to find meaning in negative events. This strategy has been found to yield positive emotions that help to cope with stress. Benefit-finding in the midst of stressful situations assists in finding meaning in life challenges, thereby helping people to move forward in their lives (Folkman & Moskowitz, 2000). Professionals can assist parents in identifying positive emotions by understanding models of stress and coping.

A number of models of stress and coping have been proposed, with Lazarus and Folkman (1984) having developed a cognitive model. This model acknowledges that people differ in their appraisals of similar events, and that not all parents will view the child"s disability as a source of stress. Goddard, Lehr and Lapadat (2000) explored a deconstructed view of disability, with parents of children with ID telling their own stories and thereby challenging stereotypes on disability. They outlined both the positive and negative experiences, with some parents reporting that these differed greatly from that of their professionals. According to Goddard et al. (2000),

much of what the parents said did not match the traditional negative view of disability, with some parents reporting positive experiences. Research shows that stress does not have to be an expected consequence in a family with a child with a disability (Gupta & Singhal, 2005).

2.7.2 Positive emotional experiences.

Turnbull (1986) conducted one of the first studies on the reported positive experiences of parents of children with disabilities. They found that parents of children with disabilities acknowledged the positive contributions made by their children. Several studies have indicated that many families have been successful in acquiring positive perceptions when raising a child with a disability. Hastings and Taunt (2002) reported that family members generally experienced a feeling of satisfaction at being able to care for a disabled child. In a study by Scorgie and Sobsey (2000), some of the parents associated positive life-changes, specifically with raising a child with a disability, an experience that may not occur with parenting a non-disabled child. Their lives became more meaningful and were enriched as a result of their experiences with their children.

Despite the various constraints associated with caring for a child with complex needs, most mothers perceive valuable benefits in a child with a disability (Green, 2007). In a study conducted by Hastings et al. (2005), parents were pleased to be asked for the first time about the positive aspects of raising a child with a disability. The authors indicated that very few studies focus on the positive impact of children with disability on family members, as most studies are not designed to elicit positive perceptions, but have a leaning towards addressing or expecting problems. Gupta and Singhal (2005) added that there should be a shift away from the negative view of disability to a focus on the positive outcomes. It is therefore important for researchers to examine their instruments when eliciting responses from parents, to ensure that they are given the space and opportunity to provide positive responses.

Positive perceptions play an important role in the coping process, as they result in a better quality of life for the entire family and improve the child"s prognosis (Gupta & Singhal, 2005). Maintaining and enhancing positive emotions can be beneficial when coping with and recovering from stress, as it ameliorates the impact of a child"s

disability on family members. Positive emotions can be transforming and aids in recovery from stress (Tugade, 2011). People who experience positive feelings are more flexible and integrative, and accept a wider array of behavioural options (Isen, 2000). In addition, parents who perceived their child with a disability as having a positive impact on the family were less stressed even when the child had behaviour problems (Blacher, Baker, & MacLean, 2007). Further studies show that positive emotions make people more resilient (which is a valuable personal resource) and able to cope with occasional adversity, be more receptive to ideas, more creative and more action orientated (Fredrickson, 2006). These traits are important and useful to the parent who is raising a child with a disability and indicates that they are motivated to seek out services to assist them and the child. Their actions are goal directed and include efforts directed at acquiring resources to assist with managing their child.

2.8 Supporting Families of Children with Disabilities

A multidimensional model of human functioning was proposed by Wehmeyer et al. (2008). Several dimensions have been considered to be important to human functioning and more especially to that of people with ID. These are intellectual ability, adaptive behaviour, participation, health and context. Contextual factors include support which refers to resources and strategies that that are aimed at improving the well-being of a person and to improve individual functioning. Human functioning is facilitated by a good agreement between individuals and the types of support that can be obtained from their environments. The profile and intensity of supports must be determined, with services being considered to be one kind of support. Intellectual disability should be viewed within a multidimensional perspective and society should respond with interventions which emphasize the role of support to improve the functioning of such individuals (Wehmeyer et al., 2008). Various types of support for parents have been identified which can be integrated into programmes in various ways, as indicated in Table 2.2.

Table 2.2.

Types of support

Types of support	Description of support
1. Physical support	This refers to the health or daily living skills of the disabled person (Kyzar, Turnbull, & Summers, 2012).
2. Material support	This refers to assistance related to improving access to adequate financial resources and completing necessary tasks (Kyzar et al., 2012).
3. Informational support	This refers to improving knowledge that leads to improved decision making (Kyzar et al., 2012). Guralnick (1998) claims that informational and resource needs should be continually addressed to parents from early childhood years to adulthood. If these components are present and can be properly accessed, they can mitigate many of the stressors associated with having a child with ID.
4. Socio-emotional support	This kind of support to parents has been shown to alleviate stress, create positive feelings and includes resource and information sharing as well as emotional and psychological (Heiman, 2002). This can also extend to formal services received from professional-based organizations as well as services from more informal organizations such as social clubs, churches and support groups (Kausar, Jevne, & Sobsey, 2003).
5. Formal support	This has been defined as assistance that is social, psychological, physical or financial, and is provided either free or in exchange for a fee through an organization (McGill, Papachristoforou, & Cooper, 2005).
6. Informal support	This is defined as a network that may include family friends, neighbours and other parents of children with disabilities (Dyson, 1997; Raina et al., 2004). Informal support was found to be a more effective stress buffer than formal support. The most useful source of informal support for mothers was parent support groups where they felt free to talk about their concerns (Boyd, 2002).

The above forms of support can be integrated into programmes in various ways. Key worker programmes for families of children with disabilities have been advocated but not widely implemented, the aim of this type of programme being to facilitate information provision, emotional support and co-ordination among support providers. A hospital-based key worker service was implemented in a paediatric ophthalmology department in the United Kingdom (Rahi, Manaras, Tuomainen, & Hundt, 2004). Initial ophthalmic assessments were conducted; parents were advised about visual stimulation and were provided with information about educational and

social services. Questionnaires were completed by parents to determine the effects of the services provided. This key worker service provided important information to the parents, emotional and social support and access to health and educational services. It was recommended that implementation of similar services for families with children with other disabilities could be just as valuable. This indicates that there are ways to provide appropriate and relevant support to families of children with disabilities.

The way in which professionals support children with disabilities and their families is very important as it can either enhance or impede their outcomes. Currently, Family Systems Theory forms the basis of many models of service delivery and highlights the interrelatedness of family members and the importance of acknowledging the needs of all family members, not just those of the family member with a disability (Murray, 2000). Disability service systems should attempt to support families by helping the family system to function better and to improve various aspects of their family life (Samuel, Rillota, & Brown, 2012). Four important beliefs drive the implementation of family-centred services, namely:

- the family and not the professional is the constant in the child"s life, and must therefore be given high priority;
- the family is in the best position to determine the needs and well-being of the child.
- the child is best helped by helping the family, which may extend to understanding the family"s community and providing information that addresses their needs;
- family choice and decision making in services, provision, showing respect, affirming their strengths and enhancing the control over the services they receive, as well as partnerships and collaborations with families are emphasized (Dunst, 2002).

The Family Systems Theory of service provision allows for individual choice making, thereby giving them a sense of control over their lives. The choices made, however, may not always be perceived by others to be in the best interests of the individual, from which ethical and professional challenges can arise (Brown & Brown,

2009). In a review of the family-centred literature, although small, many studies consistently show that the use of help-giving practices is closely related to parent satisfaction with the professional support they receive. The manner in which services are provided by professionals to families is crucial to the family-centred approach, and the research has consistently considered service delivery needs (Dempsey & Keen, 2008). In this regard, specifically in South Africa, the cultural context of the family is an important consideration when services are being provided to affected families.

Cultural competence, with respect to meeting the needs of those being served, is important when delivering services to people with disabilities. The match between cultural needs and services is an important indicator of the quality of care that is provided to the children and their families (Britto et al., 2011). As a culturally diverse country, the contextual factors of race, culture and language are relevant to this study, where the culture of those providing services may be different to those receiving them. Delivering effective services to people from various cultures requires an understanding of the ways in which their culture influences their views of disability and how those affect their associated practices. Practitioners need to be aware of the fact that the culturally determined ways in which disability and rehabilitation are conceptualized by people will affect the manner in which rehabilitation professionals are received as well as the extent to which they will be able to serve their patients (Stone, 2005). In the absence of any cultural understanding regarding childhood disabilities in particular, assumptions will be made about relevant issues pertaining to the affected families and their children, which may not result in the desired outcomes.

2.9 Summary

Children with communication disorders associated with ID have many special educational needs that should be accommodated within a country"s system of education. In many industrialized and some developing countries, laws have been passed to ensure disabled children"s" rights to education and define such rights of children with disabilities (McConkey & Bradley, 2010). A new and unified education and training system was implemented in South Africa in 2001, which outlined the government"s intention to include special needs education as an integrated

component of the general education system (McConkey & Bradley, 2010). Intellectual disability is one of many developmental disorders in children and the most prevalent neurological disorder globally (Bergen, 2008). Most of these children have special educational needs and must be accommodated in the education system. However, many factors may hinder a child"s transition to special education, such as poverty, lack of services and insufficient teacher knowledge in the field of special education. This can be addressed by providing Early Childhood Development programmes, which can also facilitate the smooth transition to special education for many children. Delivering effective services requires an understanding of the ways in which culture influences their views, understanding of and practices towards disability. Parents of children with ID have reported both negative and positive experiences during their children"s transition to special education.

Chapter 3: Methodology

3.1 Introduction

This chapter outlines the methods used to achieve the study aim including procedures pertaining to the selection of participants, collection of data and the analyses of this data. Reliability, validity and trustworthiness of the research process as it relates to qualitative research have been discussed and ethical considerations have also been raised. The American Heritage Dictionary of the English Language defines the word "parent" as "one who begets, gives birth to or raises a child" (Editors, 2006). This definition includes being a guardian or a protector. This definition will be used in this study irrespective of whether this person is the child"s biological mother or father or not. The terms "teacher" and "educator" have been used interchangeably in the literature. The term "teacher" was selected for use in this study, as the parents were more familiar with this term. The terms "learner", "student" and "children" were used interchangeably. The term "children" was selected for use as the parents were more familiar with this term.

3.2. Aim and Objectives

The aim of the study was to explore the experiences of parents of children with communication disorders associated with ID, during their children"s transition to special education. The study had the following objectives:

1. To explore the parents" experiences of formal support received during their children"s transition to special education;

2. To explore the parents" experiences of informal support received during their children"s transition to special education;

3. To explore the parents" negative emotional experiences during their children"s transition to special education;

4. To explore the parents" positive emotional experiences during their children"s transition to special education.

3.3. Research Approach

The researcher adopted a qualitative phenomenological approach to the study to explore the participants" perspectives (Yates, 2004). An attempt was made to understand the parents" social world and the meanings they attached to the topic under study. Their experiences were described as they occurred in their lives (Polkinghorne, 2005). The researcher sought to understand the lived experiences of the participants about the research topic (Cresswell, Hanson, Clark Plane, & Morales, 2007). The phenomenological perspective acknowledged that the parents developed different worldviews which determined how they interpreted and made meaning of their lives (Yates, 2004). The term worldview has been defined as a set of beliefs which guides one"s actions (Guba, 1990). In this study the parents attempted to interpret and make meaning of their experiences as their children set out to transition from one learning environment to another.

3.4   Participants
3.4.1   Study population.

The target population consisted of the parents of the 120 children with communication disorders associated with ID who were admitted to a school for learners with special educational needs in Durban, KwaZulu-Natal Province. The main criterion for admission to this school is that the child must have an intellectual disability. As a government-funded school, the parents came from a range of socio-economic backgrounds. Their levels of education and income varied and their cultural backgrounds reflected the diversity of ethnicities in the province. As a day school, the children needed to reside within close proximity to the school so that they could be transported each day. The parents were expected to pay school fees, if they could afford it, and purchase school and sports uniforms and some stationery.

3.4.2   Sampling technique.

Sampling refers to the process of selecting individuals to participate in a research study (Gravetter & Forzano, 2012). Purposive and convenience sampling techniques were used to select participants for this research. Purposive sampling involved choosing people (parents of the children at the school) from whom the researcher could learn about the experience under study (McBurney & White, 2007). The parents of a group of children who were admitted to the school were,

conveniently available and willing to participate in the study (Onwuegbuzie & Collins, 2007). The participants in this study had children who have communication disorders associated with ID and who had experiences related to accessing special education. Convenience sampling allowed for easy access of the participants as they were the parents of the children admitted to the school at which the researcher is employed. These participants represented a theoretical "population" as they were spokespersons for all the parents regarding the topic of inquiry (Wilson & MacLean, 2011).

3.4.3 Inclusion and exclusion criteria.

The following inclusion criteria applied to the study participants

- Parents of a child with confirmed diagnoses of a communication disorder associated with intellectual disability. Individuals with the relevant experiences can provide descriptions of those experiences (Polkinghorne, 2005);
- Parents of a child who was admitted to the school in the years 2012, 2013 or 2014. Parents of children, who had recently been admitted to the school, would have been able to recall and describe their experiences better;
- Parents of children between 6 and 13 years of age. The parents of children within this age range could have had experiences that were similar;
- Parents who spoke either English or isiZulu as a first language. IsiZulu, followed by English, are the two most common languages spoken in KwaZulu-Natal (Mesthrie, 2008).

The following exclusion criteria were applied to the study

- Parents who did not agree to participate in the study, according to the outcome of the request for parent participation in the study;
- Parents of a child whose ID was not accompanied by associated disorders such as Autistic Spectrum Disorder; as such disorders constitute different diagnostic conditions (Bacon & Wilcox, 2011). This could have resulted in dissimilar experiences concerning transition to special education.

3.4.4.   Recruitment strategy.

Approval for the study was obtained from the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee. Request for consent was obtained from the KwaZulu-Natal Department of Education (Appendix A) and the School Management Team and the School Governing Body (Appendix B). A list of likely participants was compiled, by applying the inclusion and exclusion criteria for selection. The "Request for Parent Participation" in the study (Appendix C) letter was forwarded to all of the likely participants. The "Letter of Information" (Appendix D) was then forwarded to all the participants who responded with interest by supplying their contact telephone numbers. Parents who agreed to participate in the study completed the "Letter of Informed Consent" (Appendix E). Participants were randomly assigned to the pilot and the main studies, and appointments for the focus group discussion and the individual interviews were scheduled.

3.4.5.   Sample size.

The desired sample size was calculated in consultation with a statistician, given that this was a phenomenological study, where the in-depth exploration required limiting the number of participants. A desired sample size of thirteen was therefore used to develop the study methods. Following the request to parents to participate, replies were received from 23 parents, of whom 19 were included. The sample therefore consisted of six for the pilot study and 13 parents for the main study. Random assignment of the participants was conducted, to either the individual interview or the focus group. This negated the possibility of researcher bias and also ensured that any kind of possible influence was evenly distributed between the two groups (Shenton, 2004). Two focus groups of four parents each and five individual interviews were conducted. Smaller focus groups of between four to eight participants often provide an environment where all participants can play an active role in the discussion (Smithson, 2008). The five individual interviews enabled the researcher to identify patterns or trends in the data (King & Horrocks, 2010).

3.4.6   Study participants.

Ten of the 13 participants in the study were the biological parents of their children. Two of the participants were aunts who assumed guardianship of the children after their biological parents deceased. One participant was the elder sister who assumed guardianship of her brother in spite of their mother being alive. Eight of them spoke in English and five in isiZulu.   Although isiZulu was their first language, three of the eight participants chose to speak in English.   All of the participants were female. The children"s ages ranged from seven to thirteen years. Twelve of them were transferred from mainstream schools to the special school. One child was referred to the special school by the crèche. All of these children could not cope in mainstream education and ten of them repeated a grade in the foundation phase of their schooling.   Their children were referred to the special school by the District Education Officials, by state health departments or by private psychologists. A description of the participants in the main study is provided in the table below:

Table 3.1.					
Description of participants in main study					
Participant number	**Sex**	**Relationship to child**	**First Language**	**Interview Language**	**Age of parent's child**
Focus group 1					
1	Female	Mother	isiZulu	isiZulu	12 years
2	Female	Mother	isiZulu	isiZulu	13 years
3	Female	Sister	isiZulu	isiZulu	7 years
4	Female	Mother	isiZulu	isiZulu	8 years
Focus group 2					
1	Female	Mother	isiZulu	isiZulu	10 years
2	Female	Aunt	isiZulu	English	10 years
3	Female	Aunt	isiZulu	English	8 years
4	Female	Mother	isiZulu	English	12 years
Individual interviews					
1.	Female	Mother	English	English	13 years
2.	Female	Mother	English	English	11 years
3.	Female	Mother	English	English	12 years
4.	Female	Mother	English	English	8 years
5.	Female	Mother	English	English	10 years

3.5 Data Collection

3.5.1 Data collection methods.

Focus group discussions and individual interviews were conducted to gather the data for this study. The focus group discussions were conducted first, followed by the individual interviews. The focus group discussions provided an initial overview of ideas and this was subsequently followed by individual interviews. In this way collective discourse was compared with individual opinion and experience (Gibson & Brown, 2009). Salkind (2006) identified certain functions of focus group discussions which facilitated the collection of the data for this study. The focus group discussions served to gather information on the topic under study. It facilitated a lively discussion which was recorded so that the content of the discussion could be analysed later. It encouraged group interaction on the central discussion questions and this helped to bring various viewpoints together in a way that individual interviews may not have been able to. It provided insight into the operation of the group social processes in the expression of their knowledge. The groups also helped to determine how the members reached decisions about the information which was important to them.

An interview occurs when an interviewer (researcher/interpreter) obtains information through direct interchange with a participant who is expected to possess the information or knowledge that is sought (DePoy & Gilson, 2008). The interviews provided an enriching experience for the researcher where personal contact with the participant created opportunities to enter the participant"s lived world and to gain new insights (Kvale, 1996). The interviews yielded much useful information about the participants" beliefs, feelings and perspectives pertaining to the research topic. The researcher was able to clarify ambiguous answers with the participant. Follow-up information was sought from the participant. The individual interviews also enabled participants to discuss issues that they may not have been willing to discuss in a group situation. The interviews could have had disadvantages. Individual interviews may have been time consuming. The researcher may have asked questions that did not elicit the desired responses. Some participants may have felt intimidated by being alone with the interviewer and this could have negatively affected their responses. Participant responses could have also been misconstrued or untruthful (Greeff, 2011).

3.5.2 Data collection instruments.

The focus group discussions and the individual interviews were guided by the same schedule of questions (Appendix G). There were three main open-ended questions that enabled the researcher to understand and capture the points of view of the participants without predetermining their views through rigid questions (Yates, 2004). The main questions had corresponding probe questions that were used to deepen, and increase the richness and depth of responses. They also provided cues to the parent about the kinds of responses that were desired but were not necessarily prescribed. The three main questions with motivations have been illustrated in the table below:

Table 3.2.
Focus Group and Individual Interview Questions with Motivations

Main Question	Motivation
1. Let's talk about how you found this school for your child?	To obtain information about the parents' experiences relating to formal and informal support (Boyd, 2002; Dyson, 1997; McGill et al., 2005; Raina et al., 2004). This question relates to objectives 1 and 2.
2. How did you feel when you were looking for a school?	To enable the parents to relate their positive and negative emotional experiences during their child's transition to special education (Gupta & Singhal, 2005; Middleton, 1995; Olsson & Hwang, 2001; Raina et al., 2004; Russel, 2003; Woolfson, 2004). Emotions of the participants are important and they have to be valued during data collection and writing up (Holloway & Biley, 2011). This question relates to objectives 3 and 4.
3. Tell us about any other experience relating to finding a school, which we have not spoken about.	To allow the parents to express their thoughts on the research topic and on other issues that may be important to them (Kvale, 1996; Polkinghorne, 2005; Yates, 2004).

The questions on the interview schedule were related to the research question as well as the information that the participants were able to provide. The interview schedule enabled the researcher to think about and clarify the research aim as well as the objectives that needed to be addressed during the interview. The guide acted as a checklist to ensure that the four objectives were addressed (Dyer, 2006). The phrasing of the questions was an important consideration during the construction of

the interview schedule. The questions were kept simple, clear and direct in order to facilitate the interview and the acquisition of credible data (King & Horrocks, 2010). Complex and multiple questions were avoided.

Three types of questions were asked, these being initiating, probing and follow-up questions (Yates, 2004). This assisted the interviewer to obtain the fullest account possible from the participants (Appendix I). The three initiating questions related to the research objectives as defined by the researcher and were used to direct the conversation and they were intended to yield spontaneous, rich, descriptions of the participants" experiences (Kvale, 1996). Probing questions were used to ask the participant for more information or to request elaboration on points already mentioned and it added depth to the interview data (Berg, 2009). Good use of probing required good listening skills by the interviewer. Reminders were written down so that they could be returned to later. Follow-up questions were used to pursue relevant responses that occurred during the course of the interview and these developed spontaneously or were used at the end. These questions allowed ideas to develop and change and made the interview process flexible and continuous. The interviewer was careful in the use of probing and follow-up questions so that the participants were not led into providing a particular answer (King & Horrocks, 2010).

3.6   Data Collection Process

The purpose of the qualitative interview was to elicit the participants" accounts of their experiences and their interpretation of meaning. Therefore, the focus group discussions and the individual interviews were semi-structured and allowed the interviewer to probe areas of interest and follow the participants" concerns. Flexibility was important in qualitative interviewing. There was openness to changes of sequence and forms of questions in order to facilitate follow-up on the answers given (King & Horrocks, 2010).

3.6.1   Focus group discussions.

Focus group research was conducted by recording the discussion of four people. The discussion was carefully planned, the purpose being to explore variables that were related to the objectives, in a permissive and non-threatening environment (Evans & Rooney, 2011). The facilitator informed the participants that

everyone may have a different response to the questions and that all these responses needed to be heard (Berg, 2009). The facilitator faded into the background and let the discourse of the group develop on its own. Furthermore, people were encouraged to talk to one another, ask questions and comment on one another"s experiences (Kitzinger, 1995). Open-ended questions in such a group discussion encouraged them to explore and clarify the issues of importance to them using their own words. It also allowed them to answer from a number of perspectives which could have taken the research into new and unexpected directions (Gavin, 2008).

The researcher was aware of factors that could have hindered open discussion during the focus group interaction (Salkind, 2006). An attempt was made to make the setting in which the focus group occurred conducive to frank and open discussion. The facilitator attempted to keep the group on task. The facilitator did not force her own opinions on the group members as it was their opinions that were important. Forceful participants were not allowed to dominate the discussion. The facilitator ensured so that all the participants were given opportunities to talk. Group norms may not have allowed a participant to express a different viewpoint. The participants were reminded that different opinions would not be judged but accepted. The presence of other participants could have compromised the confidentiality of the focus group session (Kitzinger, 1995). In this study, the participants were made aware of the nature of the focus group during the informed consent process, so that an informed decision could be made, regarding their participation and their disclosures (Berg, 2009). The participants were also asked to respect each other"s confidences and not repeat to others what was said in the group (Smithson, 2008).

The number of focus group discussions necessary for a specific study could vary depending on the purpose of the study (Greeff, 2011). Too many focus group interviews could have been a waste of time and money. It was important to consider not the amount of data but rather the richness of data and the detailed descriptions. Two focus groups discussions yielded more data as compared to one and the researcher compared themes across discussions (Kitzinger, 1995). Large focus group discussions could have become difficult to control and record (Denscombe, 2007). Focus groups discussions are usually 60 to 120 minutes in duration (Greeff,

2011). The duration of the focus group discussion in this study was approximately sixty minutes. This gave each participant sufficient time to respond to the questions (Denscombe, 2007).

3.6.2   Individual interviews.

Five parents were interviewed individually, the purpose being to find out the parents" perspectives and to gather their stories about the topic being investigated (Patton, 2002). Stories are a way of knowing and meaning is made out of this process. The researcher established rapport with the participants and gained their co-operation, thereby facilitating clear and honest communication with the participant (Leedy & Ormrod, 2010). The individual interview was approximately 30 minutes in duration.

Data triangulation was used (focus groups and individual interviews), which involved contrasting various sources of information (Denscombe, 2007). Different forms of data were compared against each other by gathering data through various methods. It also provided complimentary data that increased the completeness of the findings thereby providing a fuller picture (Greeff, 2011). The disadvantages of triangulation were that it was time consuming, costly, increased the complexity of the data analyses and could have produced contradictory results.

3.6.3   Co-ordinating and conducting the focus group discussions and individual interviews.

There were some relevant interviewer qualities that could have contributed to better discussions and interviews and produced rich information (Kvale, 1996). The researcher/interpreter became familiar with this and attempted to apply some of this information during the data collection process (Appendix H for further discussion).

All the focus group discussions and the individual interviews were conducted at the school where the participants" children were admitted. It was important that the venue was familiar and easily accessible to the participants (Perry, 2004). The interpreter and the researcher were dressed appropriately. All the focus group discussions and the individual interviews were audio recorded with a Sony ICD-PX333 recording device. The audio recordings provided a permanent recording of

the discourse and this did not pose too much of a disturbance to the interview situation (Denscombe, 2007). The disadvantage of the audio recording was that it captured only the verbal communication and missed non-verbal communication and contextual information. Therefore the audio recording was supported by field notes, with the participants being informed of the reasons for taking notes.

Field notes were the recorded account of what the researcher observed, experienced and thought during the data collection process. It was descriptive and non-evaluative. It described the people, places, activities, interactions and dialogue. This supported a full and accurate transcription and conveyed meaning during the data analyses stage of the study. The field notes filled in some of the relevant information or observations that the recording alone missed. Field notes were made promptly during or after the interviews. This ensured that important information was not forgotten and thereby excluded. Written notes were also useful if there was a technical failure with the equipment (Gorman & Clayton, 2005). As meaning is not only conveyed by words, a written record of non-verbal behaviours (gestures, facial expression or tone of voice) was also kept. The notes also included the researcher"s own ideas, reflections and observations, which allowed the participant to speak uninterrupted and enabled the facilitator to keep track of the conversation and return to certain points should this have been necessary (Yates, 2004). These notes covered the main points only and did not disturb the flow of the interview.

The researcher and the interpreter guided the focus group discussions. A comfortable, quiet and disturbance-free room which accommodated the size of the focus groups was selected. The quiet environment was not only relaxing to the participants but also improved the clarity of the recordings. All the interviews were conducted at a time which was suitable for both the facilitator and the participants, with no disruption of the academic programme at the school. The interpreter facilitated the focus groups and individual interviews in isiZulu. The researcher facilitated the focus groups and conducted the individual interviews where the medium of English was required. The researcher did have prior experience of facilitating groups and conducting individual interviews during parent meetings and other discussions.

Interviewer effects should be considered when the researcher is an overt participant in the data collection process. These effects could have been present during the focus group discussions and the individual interviews. The characteristics of the researcher, such as language, gender and dress, could have influenced the participants" willingness to participate and contribute to the discussion. Such interviewer effects could not be completely eliminated but steps were taken to control for them (Breakwell, 2000). The interviewer developed a checklist of the essential items which were needed for the interviews (water, writing materials, informed consent forms, a box of tissues, number cards, recording equipment and batteries). These were made readily available for use if they were required. The facilitator was seated in a manner that was conducive to informality. The participants were seated in a way that ensured that everyone had eye-contact with the facilitator and with all the other participants.

The facilitator/interviewer began the discussion/interview by creating a friendly, but professional atmosphere, for both the focus groups and the individual interviews. This helped to establish and maintain rapport with the participants. Rapport was seen as an important ingredient in successful qualitative interviewing (King & Horrocks, 2010). The participants were made to feel physically and psychologically comfortable and safe enough to talk freely about their experiences. If they were tense and unsettled they could have responded negatively to the questions. The interviewer/facilitator attempted to appear relaxed, used suitable non-verbal communication and appropriate vocabulary to interact with the participants. The interviewer identified herself and initially engaged in casual chat in order to make the participant feel comfortable and to open-up the channels of communication (Yates, 2004). They were welcomed and the interpreter and the researcher introduced themselves. The participants were asked to introduce themselves to each other. The participants were provided with a context for the interviews through a briefing and a debriefing session before and after the interview (Kvale, 1996).

The participants needed to know what was expected, how the session would be organized and what their roles were. The format of and reasons for the session were explained. Some of the issues mentioned in the informed consent letter were re-iterated. This was an attempt to ensure that the participants had an adequate understanding of what was going to happen and why. They were reminded that the interview would be recorded and that they could withdraw from the research at any time, both during the interview or afterwards, by informing the facilitator or the interviewer. The participants were reminded that their accounts, events and some quotations would be used to compile the final report of the study. The participants were informed that the paper based data did not reveal their identities and was stored in a locked cupboard at the research site and would be shredded after a period of five years. The Dictaphone recordings would be stored away and erased after five years.

Some ground rules were established. The participants were asked to turn-off their mobile phones as this could have disrupted the session. If they wished to keep their phones on and answer a call they were expected to leave the room quietly and return to the group as soon as they were able to. The participants were asked to respect each other"s confidences and not repeat what was said in the group (Smithson, 2008). This was important as it encouraged candid and free-flowing discussion in the group. They were informed that respectful, polite and open conversation was expected and all were encouraged to participate. The participants were requested to avoid speaking if someone else was talking as this could affect the recording. Individual members were not allowed to dominate the discussion.

The facilitator/interviewer used the interview schedule as a guide when asking the participants questions during the interviews. As the interview proceeded, the questioning process was guided by the content of the participants" responses. The facilitator/interviewer explained what the interviews aimed to achieve. The participants were requested to provide a full account of their own views and experiences and not provide answers that they thought might have been expected of them (King & Horrocks, 2010). The facilitator went around the group and gave each member a turn to participate and provide a response. Thereafter group

discussion was encouraged, with the time and progression being monitored by the facilitator.

The facilitator"s role was to guide the discussion and not to offer opinions, but to generate interest and discussion, keep the group on task and ensure that the discussion addressed the topics in the interview schedule (Smithson, 2008). The discussion was encouraged to occur among the participants rather than between them and the facilitator (Sim, 2002), with the best discussions occurring when the participants talked to each other and provided spontaneous responses. The facilitator was aware that the discussion or interview should not turn into a therapeutic situation that could not be managed (Kvale, 1996).

The role of the facilitator/interviewer also included bringing the interview to a close. The closing brought the participants back to the present environment. The participants were not left in the midst of interpretation and disclosure (Vanderstoep & Johnston, 2009). The facilitator/interviewer gradually decreased the intensity of the questions during the closing process. The use of a closing question was consistent with the values of qualitative research. An open-ended closing question gave the participant an opportunity to address or redirect the research agenda. The closing question asked if there was anything else the participant would have liked to add. This gave the participant an opportunity to express final contributions to the research topic as well as issues that were not addressed by the facilitator/interviewer. Participants could provide comments, ask questions or deal with issues that they had been thinking or worrying about during the interview. Thereafter the participants were informed that the facilitator/interviewer would not ask any more questions. The recording equipment was kept running until the very end of the interview (unless the participant requested otherwise) as it is not uncommon for interviewees to mention something relevant and significant at that stage.

The participants may have experienced some tension or anxiety because of being open about personal and emotional experiences, at the end of the interview. Debriefing occurred at this stage, during which the participants were given the opportunity to work through their experiences related to the research (Strydom, 2011). The debriefing continued after the recording was discontinued as the

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participant may have felt safer to discuss certain issues at that stage. The participants" feelings were discussed and the researcher rectified any misconceptions that may have arisen during the data collection phase. If the interview opened up personal or sensitive disclosures, the interviewer recommended appropriate referrals for counselling (Vanderstoep & Johnston, 2009). The participants were given an opportunity to request removal of comments from their recordings, with such offering being re-assuring to the participant. The interview was formally closed and the participants thanked for their participation, after which some casual chatting followed. It was deemed reasonable to compensate participants for their time spent or reimburse them for costs incurred on transport to get to the research venue. All the participants were provided with refreshments and a remuneration of R30 to cover their travel expenses, which they might have incurred by attending the interview (Smithson, 2008; Strydom, 2011).

3.6.4   Role of the interpreter.

An interpreter assisted the researcher during the data collection and the data analyses stages of the research, as there were language differences between the participants and the researcher. The first language of the participants was either isiZulu or English. The primary responsibility of the interpreter was to bridge the communication gap between the people who did not share the same language during the focus group and individual interviews. The interpreter interacted with the participants in a common language, which created a more favourable condition to gather rich information. She was proficient in both languages, had knowledge of the two cultures and the ability to convey similar meaning in the two languages (Langdon & Cheng, 2002). She facilitated the first focus group discussion as all the participants spoke in isiZulu. In the second focus group, one participant spoke in isiZulu and received assistance with interpretation from the interpreter, while the rest spoke in English.

The interpreter was provided with a written request to participate in the study and signed a declaration of confidentiality (Appendix F). A female first language isiZulu educator, who was employed at the research site, agreed to offer her services as the interpreter. She was proficient in English and was the same gender as the participants, which could have encouraged the participants to share

information more willingly (Breakwell, 2000). As an educator in the field of special education, she could have been in a favourable position to interact with the participants, given the nature of the study.

The researcher fully informed the interpreter about the study, the objectives, the methodology, interviewing strategies, research ethics and the pilot study. Special and careful training of the interpreter was essential (Patton, 2002). The interpreter was trained during mock interviews and given an opportunity to ask questions and clarify issues well before the study started. The interpreter did have prior experience of facilitating groups and conducting interviews, which occurred during parent meetings and other discussions with parents in her role as a teacher. The interpreter understood what was required, what questions needed to be asked and the need for full and complete interpretation of responses as far as was possible, and that the participants" responses should not be contaminated. The interpreter was expected to ask the central questions as well as provide cues where it was deemed necessary when isiZulu was spoken.

3.7   Data Analyses
3.7.1   Data management.
The oral data from the focus group discussions and individual interviews were transcribed from the recordings of the Dictaphone. The interpreter assisted with the interpretation of the recording of the isiZulu focus group discussion. Data reduction was conducted by eliminating data that was not relevant to the study.   The paper based data did not reveal the participants" identities and was stored in a locked cupboard at the research site and would be shredded after a period of five years. The Dictaphone recordings were stored away and would be erased after five years.

3.7.2   Data analyses process.
The researcher read through all the data several times to obtain a general sense of the information and notes were made of the main interpretations. Themes and sub-themes were identified. A coding process was used, whereby the data was coded according to the themes (Leedy & Ormrod, 2010).   Phrases, lines or paragraphs were coded.   The researcher re-read the data and looked for data that supported the themes that helped to outline the analysis (Namey, Guest, & Thairu,

2008). Different sections of the data relevant to the themes were identified and then grouped together. The researcher explored and discussed the themes in the write-up of the study. The final step in the data analysis involved interpretation of the data, where the meanings of the findings were discussed and displayed (Creswell, 2009). Contradictory information was also included. Parent quotations were used to support the themes.

3.7.3   Data representation.

Tables describing the participants in the pilot and main studies were included. The results were represented in the form of a narrative. Two metaphors were selected to introduce and unify the narrative. Direct quotes were also used to highlight the parent"s experiences and to support the themes (Miles & Huberman, 1994). The direct quotations were italicized so that they were easily identifiable in the prose. Unusual experiences were also included, and a verification of the participants" data was conducted.

3.8 Pilot Study

A pilot study was conducted two weeks prior to the main study. Six additional participants were recruited for the pilot study. One focus group of four participants and two individual interviews were conducted. The interpreter was present, during the pilot study. Recruitment, participant selection and the study procedures were similar to that of the main study. A description of the participants of the pilot study is detailed in Table 3.1. The pilot study informed the researcher of any modifications that needed to be made in the research methodology and tool (McBurney & White, 2007). The interview schedule remained unchanged after the pilot study. Changes were made to the approach to the interview and to the introductory remarks made by the facilitator and interviewer.

The suitability of the location of the dictaphone for the audio recording of the interviews was assessed. The dictaphone was placed on a table between the participant and the researcher and the researcher listened to the audio recordings for clarity. The ease of the use of the data collection instrument was assessed. The researcher and the interpreter practised and assessed their interview skills using the data collection instrument. The interview was conducted using appropriate

interviewing strategies. The purpose of the pilot study was also to determine the suitability of the data collection process and to obtain feedback regarding the type of questions asked during the interviews. A feedback interview was conducted after the pilot study, where the participants" ease in answering the questions was determined. It was also determined whether sufficient data was obtained during a focus group discussion of approximately 60 minutes and an interview of approximately 30 minutes in duration. The researcher analysed the data to determine the depth and scope of the information gathered. The process of data analysis was evaluated. The interview was transcribed verbatim and analysed according to the procedure outlined in 3.7(Langdon & Cheng, 2002) below. The researcher determined whether sufficient themes or categories could be deduced.

3.8.1   Pilot study participants.

A pilot study was conducted with six participants, four were female and two were male. The interpreter participated in the pilot study. In the focus group, two participants spoke in their first language of English and two participants who, reported a first language of isiZulu, chose to speak in English. Their decision to speak in English appeared to have not been influenced by the other two members of the group who spoke in isiZulu. The two participants who were interviewed individually spoke in their first language, which was English. The two participants who chose to speak in English, although their first language was isiZulu, were employed, one being a teacher and the other an office worker. Their professions could have determined their choice of English over their first language, during their participation in the focus group discussion. English is seen by many indigenous African language speakers as the dominant language of trade and industry (Van Louw, 1998). A description of the participants of the pilot study is provided in the table below:

Table 3.3.

Description of the participants of the pilot study

Participant number	Gender	Relationship to child	First language	Language spoken in interview	Age of child
Focus groups					
1	Female	Mother	isiZulu	isiZulu	10 years
2	Female	Mother	isiZulu	isiZulu	10 years
3	Female	Mother	isiZulu	English	11 years
4	Male	Father	isiZulu	English	7 years
Individual interviews					
1	Female	Mother	English	English	7 years
2	Male	Father	English	English	7 Years

3.9   Reliability, Validity and Trustworthiness

Six criteria to evaluate quality in qualitative research have been identified by Maxwell and Satake (2006). These criteria will be briefly outlined below.

3.9.1   Credibility.

This refers to the degree to which the researcher‟s findings represent the lived experiences of its participants. The researcher made provisions to enhance credibility. Well established research methods were carefully planned and implemented in the data collection and analyses stages (Weicke, 2007). Triangulation of the different data collection methods compensated for their individual differences and exploited their respective benefits and therefore complimented each other (Denscombe, 2007). The scope of the research was increased and this allowed for deeper understanding of ideas conveyed. Cultural and language differences were acknowledged and the services of an interpreter were sought during the data collection and the data analyses stages of the research (Langdon & Cheng, 2002). The interpreter interacted with the participants in a common language which created a more favourable condition to gather rich information and thereby enhance the credibility of the data. The researcher tried not to influence the participants‟ thoughts. They were given the opportunity to provide different meanings and a thick description to the topic of research (Tracy, 2010). The researcher ensured inclusiveness of the recordings. Field notes were taken to include a wide range of events that may have occurred during the data collection

stage. Focus group interviews were conducted to document group interaction on the research topic (Evans & Rooney, 2011). Issues of reliability were observed during interviewing, transcribing and analyzing stages of the data. Transcripts were checked for errors in transcription. In these ways credibility was enhanced. However, the findings could have been influenced by the researcher/facilitator.

The researcher was aware of reflexivity and the degree of personal influence that could have been exerted, either intentionally or unintentionally, on the research findings (Shenton, 2004). The researcher"s own pre-conceptions, previous personal and professional experiences, pre-study beliefs about how things are and motivation and perspectives related to education could have influenced the research process (Malterud, 2001). The participants were prompted, probed and encouraged to express their views of their experiences in a manner that was deemed appropriate by the researcher. Bracketing was practised where the researcher attempted to put aside personal beliefs and judgements about the situation and was open to data as they were revealed (Speziale & Carpenter, 2007). However, it must be acknowledged that as qualitative researchers we are not separate from the research but we are present in all aspects of it and essential to it (Dwyer & Buckle, 2009). The researcher could not exclude herself from data collection, analyses and reporting of the research as the self is an integral part of any study. Also as a qualitative researcher one cannot distance oneself from the people with whom one does research (Holloway & Biley, 2011). This led the researcher to think about how the origins of one"s own thinking and how one"s pre-existing understanding was constantly revised with new findings, resulting in the construction of new meaning, and how this in turn affected one"s research (Haynes, 2012). Reflection on the process of the research and understanding how one"s own values and views could have influenced all steps of the research process, added credibility to the research (Jootun, McGhee, & Marland, 2009).

3.9.2   Confirmability.

Multiple validity strategies were incorporated during the research process. This assisted the researcher to determine whether the study was comprehendible and meaningful (Tracy, 2010). A pilot study was conducted and this informed the researcher of any changes that needed to be instituted to the methodology. The researcher provided a detailed description on the context of data collection and the methods of generating data as this would have influenced the character of the data. This also allowed for scrutiny of the procedure and the results. Triangulation was used to enhance the trustworthiness of different sources of data and their accuracy for examining the same phenomenon from different points of view (Denscombe, 2007). Prior to the interviews the researcher trained an interpreter in the manner of asking questions and the use of probes to gather more information from the participants (Langdon & Cheng, 2002). Member checks were conducted during the data collection phase where the participants, at the end of the focus group discussion and the individual interview, were asked if they wanted to alter, affirm or retract any statements made by them (Gibson & Brown, 2009). This allowed them the opportunity to verify their responses. The participants" feelings were discussed and the researcher rectified any misconceptions that may have arisen during the data collection phase. The participants were given adequate time to convey their thoughts during the focus group discussions and the individual interviews. The description of the accounts were kept close to the original data, the analysis included key factors and the relationships among them and the interpretation yielded new insights. In order to ensure accuracy the researcher recorded the verbal accounts of the participants and then transcribed them with the assistance of the interpreter where necessary. Contrary or discrepant information was not excluded from the analysis. Rich and descriptive terms were used to convey the findings during the interpretation stage of the research. In this way the results could be more realistic and richer (Creswell & Miller, 2000; Gibson & Brown, 2009). The shortcomings or limitations of the study and their potential effects were outlined.

3.9.3   Meaning-in context:

Here the researcher determined the extent to which the data gathered revealed the participants" lived experiences and their understandings of life events. There were three main open-ended questions that enabled the researcher to understand and capture the points of view of the participants without predetermining their views through rigid questions (Yates, 2004). These questions in such a group discussion encouraged them to explore and clarify the issues of importance to their using their own words. It also allowed them to answer from a number of different perspectives (Gavin, 2008). The main questions had corresponding probe questions that were used to deepen, and increase the richness and depth of responses.

The interviewer attempted to respond to issues that arose during the course of the interview in an effort to understand the perspective of the participants on the topics under study. The participants expressed their meanings through their voices, however, their meanings could have been distorted while listening to them (Holloway & Biley, 2011). The participants could have also crafted their responses to appear amenable to the researcher or to protect their self-interests (Miles, Huberman, & Saldana, 2014). All participants were given an equal opportunity to respond to the questions and to express themselves. In this way, the less vocal participants were not disadvantaged from expression. The researcher does not always represent the voice of the participants. The participants" expressed their stories of their lived experiences on the topic of inquiry. Merely listening to and the researcher recording their stories was not adequate as the researcher too needed to tell her story so that the two stories merged to form new collaborative stories (Connelly & Clandinin, 1990). The researcher sometimes contributed to the participants" responses by prompting and probing where it was required. Authenticity of the data was ensured as the participants revealed their lived experiences, with the researcher being aware of differences in the voices of the different participants (Whittemore, Chase, & Mandle, 2001).

3.9.4   Recurrent patterning.

This referred to the documentation of repeated experiences, events or expressions in the participants" lives. The researcher ensured that there was enough data to support the themes that were identified. Recurring ideas from the

data were organised into themes which were later used as headings in the results section of this dissertation. The researcher re-read the data and looked for data that supported the themes that helped outline the analysis (Namey et al., 2008). The researcher discussed the themes in the write-up of the study. Data that did not support the themes was also considered for comment (Miles et al., 2014).

3.9.5   Saturation.

This phenomenon occurs when a researcher becomes intimately involved with the topic under study and uses "thick" description to extract as much meaning as possible from the data. A description of the relevant aspects of the participants in the main study was provided. This provided a deeper understanding of the participants" backgrounds. The interpreter interacted with the participants in a common language which created a more favourable condition to gather rich information. The interviews provided an enriching experience for the researcher where personal contact with the participant created opportunities to enter the participant"s lived world and to gain new insights (Kvale, 1996). The interviews yielded much useful information about the participant"s beliefs, feelings and perspectives pertaining to the research topic. The focus group discussions served to gather information on the topic under study and facilitated a lively discussion that was later analysed.

3.9.6   Transferability.

This referred to the extent to which the findings of the study could be transferred to similar situations. This research study consisted of a limited number of participants and therefore the findings of the study should be viewed with caution and not be generalised to a wider population. These findings can, however, serve to inform professionals and non-professionals about the experiences of the group of participants during their journey to access special education. Readers of the research can also achieve transferability when the story of the research overlaps with their own circumstances and creates an emotional experience. Other parents and professionals in similar situations can experience this (Tracy, 2010). The researcher attempted to achieve transferability by presenting the text in a clear and comprehendible manner. The emotions and thoughts of the participants were directly presented (in italics) in order to allow the reader to feel, think, interpret, react or

change. Two metaphors were used to highlight the richness and complexity of the parents" experiences (Miles et al., 2014).

3.10 Ethical Considerations

Researchers are usually governed by a set of ethical guidelines that assist them to make appropriate decisions and choose proper actions as data will be obtained directly from people. Research ethics refers to the responsibility of researchers to be honest and respectful to all individuals who may be affected by their research actions or their reports (Gravetter & Forzano, 2012). The respect reflects a moral concern for the autonomy and privacy rights of those to be recruited for research participation (Fisher & Anushko, 2008). The welfare of the participants was an important consideration in the production of qualitative data (Polkinghorne, 2005). This research study and methodology was planned and executed with ethical issues at the forefront of the researcher"s mind (Dyer, 2006). Procedural, relational and exiting ethics were identified (Tracy, 2010).

3.10.1 Procedural Ethics.

Ethical guidelines were applied during the research problem stage, the data collection stage and the analysis and interpretation stages of the study. The researcher obtained prior approval for the study from the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee (Reference number HSS/0988/013M). Consent was also obtained from the KwaZulu-Natal Department of Education (Appendix A), the School Management Team and the School Governing Body (Appendix B) and from the participants in the study (Appendix E). The participants were not coerced into participating in the study (Denscombe, 2007). Their participation was voluntary and they were provided with sufficient information which was expected to influence their decision to participate. They were made aware of their contributions to the study, confidentiality and security of data. The consent form contained information such as the signature of the participant (dated), the counter signature of the researcher (dated) and the signatures of other relevant individuals (Appendix E) (Fisher & Anushko, 2008). The personal identities of the participants were not disclosed in order to protect their identities. Permission to record the focus groups and the individual interviews were obtained from the participants (Appendix E). The interests of the participants were protected and the

researcher ensured that they were not physically or psychologically harmed in any way (King & Horrocks, 2010). Confidentiality of the participant information was maintained by not disclosing the data to others and by securing it in a locked cupboard at the venue of the study. The interpreter was requested to sign a declaration of confidentiality (Appendix F). In order to safeguard the participants from undue exposure, the data will be kept for a period of five years in a locked cupboard and the paper- based data will be shredded thereafter.

3.10.2 Situational ethics.

During the data collection stage, the researcher constantly reflected on the research procedures and ensured that ethical decisions were taken with the best interests of the participants in mind (Polkinghorne, 2005). The participants were provided a context for the interviews during briefing and debriefing session before and after the interviews (Kvale, 1996). Some of the issues mentioned in the informed consent letter were re-iterated at the beginning of the focus group discussions and individual interviews. This was an attempt to ensure that the participant had an adequate understanding of what was about to happen and why. The participants were informed of the reason for the discussion and the procedure that would be followed. They were reminded of the audio recording and that they could withdraw from the research at any time, either during the interview or afterwards (without penalty), by informing the interviewer. The participants were re-assured that the questions were not difficult, there could be no wrong answers and it was their perspectives which were being sought (Perry, 2004). The participants were verbally requested to keep each others" disclosures confidential.

Effective listening by the interviewer, during the interview, was an important means of support to the participant (King & Horrocks, 2010). It was possible that participants could have experienced emotional discomfort or stress during the interview (Creswell, 2009). The interviewer paused when the participant displayed signs of distress or discomfort. The participant was given time to recover and resume with the interview or was given the option of leaving the interview. If further support was required the participant would have been referred to a registered parent counsellor, within close proximity to their home. The researcher offered to cover the

initial consultation fee and the participant was expected to pay the cost of additional consultations (if required).

During the data analyses stage the oral data provided by the participants was transcribed verbatim. Accounts, events and quotations provided by the participants were used in the final report, thereby validating the data. The researcher"s findings were not falsified or manipulated in the direction of a favoured outcome. Neuman (2000) stated that this could have constituted scientific misconduct. The researcher considered honesty and transparency as important attributes of the research process (Tracy, 2010).

3.10.3   Exiting ethics.

Ethical considerations continued beyond the data collection stage to include the manner in which the researcher shared the results with others. This was an important consideration in order to prevent unintended consequences. The researcher attempted to present the results in a thesis format, in a neutral manner that would be of benefit to the relevant stakeholders. The researcher provided feedback to the participants.

3.11   Research Procedure

The procedure for this research is outlined below with some of this information having been mentioned under other headings. Ethical clearance was obtained from the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee. Consent to undertake the research study was requested from the KwaZulu-Natal Department of Education (Appendix A), the School Management Team and the School Governing Body (Appendix B) at the research site. Participants were selected for the main study. The names of all the children who were admitted to the school in the years 2012, 2013 and 2014 were requested from the school management team at the research site. Data stored in the learners" personal files served to confirm the diagnoses of ID and the presence of a communication disorder. A psychologist"s report or a referral letter from the Education Service Delivery Support Services (Department of Education) confirmed the presence of ID. A report from the speech therapist confirmed the presence of a communication disorder. Letters were sent to their parents providing a brief summary of the study as well asking them if they would like to participate in it

(Appendix C). Willing participants were thereafter contacted telephonically (number provided by them) to confirm their agreement to participate in the study. They were given the letter of information (Appendix D) and the informed consent letter (Appendix E) to read and sign two weeks prior to the interviews. Illiterate participants were given an oral explanation of the consent form (by the interpreter if required) and a thumbprint instead of a signature was accepted. Eight participants were randomly assigned to the two focus groups. The remaining five participants were interviewed individually.

A pilot study was conducted two weeks before the main study, with six willing participants. One focus group discussion and two individual interviews were conducted at the research site. The results of the pilot study were not used for analyses. The outcome of the pilot study informed the researcher of any modifications that needed to be instituted during the procedure of the main study. Two focus groups discussions consisting of four participants each and five individual interviews were conducted to gather data for this study. The services of an interpreter were engaged during the data collection process. The data was analysed qualitatively (Creswell, 2009). Thereafter the research report was compiled. The research results will be disseminated to the participants in a follow-up feedback session at the research site.

Chapter 4: Results and Discussion

4.1 Introduction

This chapter will outline the results of the research study that was undertaken with respect to the parent experiences during their children"s transition to special education. This will be presented according to the four objectives of the study. Two metaphors serve to introduce and unify the discussion on parental experiences. These were chosen to assist and enhance our understanding of the parents" experiences. Metaphors are said to structure our most basic understanding of our experiences and can propel the behaviour of the readers and usher them towards action (Lakoff & Johnson, 2003). The richness and complexity of metaphors are useful to enable us to see new theoretical possibilities (Miles et al., 2014). Experiences must allow the reader to feel, think, interpret, react or change (Richardson, 2000). This led the researcher to think about how the origins of one"s own thinking and how one"s pre-existing understanding was constantly revised with new findings, resulting in the construction of new meaning, and how this in turn affected the research (Haynes, 2012). The parents" experiences will be narrated and discussed simultaneously while the results will be discussed according to four themes: formal support, informal support, negative emotions and positive emotions. At times an integrated discussion of the different themes was undertaken, these themes being linked to the study objectives.

Mosaics are a way of viewing the world, especially in the domain of disability-wholeness in brokenness and brokenness in wholeness. A parent"s life (wholeness) is shattered (brokenness) with that first diagnoses or piece of information about their child"s disability. Thereafter it"s all about putting the pieces together to form the whole again (mosaics), attempting to re-arrange them into the pattern they were familiar with prior to the diagnoses. How did they go about this? The parent can be likened to a traveller. Like the traveller who sets out on his journey in pursuit of unexplored territory, so too does the parent in search of an often unknown school that will meet the child"s special needs. The terrain ahead could be rocky with

obstacles, with dead ends or simply uncrossable, and both have to sometimes return without having achieved their desired goals or reached their destinations. The journey could also be a rollercoaster ride with highs and lows and positive and negative experiences. Emotion is at the heart of any human experience and cannot be ignored (Forlizzi & Battarbee, 2004). Their journey into the unknown can be accompanied by many fears, frustration, loneliness and sometimes confusion. However, this journey could be made more bearable and pleasant if the traveller was armed with a road map and guided by signs along the way. Even more helpful would be the availability of a base camp which would allow the traveller to communicate with others (strength through connection) or return to for guidance should he stray off track or get stuck. The parents have alluded to their journeys during this study. They related stories about how they navigated this winding and sometimes bumpy path to achieve wholeness again in brokenness. Were they armed with road maps or guided by signs along the way? Was there a base camp that could have offered them guidance, support or just reassurance when the goings got tough? The parents" actual words have been italicized and some of their expressions paraphrased to provide a coherent account of their experiences. Let us listen to their stories.

The journey begins…

4.2   Objective 1: To Explore the Parents' Experiences of Formal Support Received during their Children's Transition to Special Education.

Here the parents talked about their experiences of seeking assistance for their children, and of the formal support they received from the schools that their children attended, the District Education Office, the state health facilities such as hospitals and clinics, and from private psychologists.

4.2.1   Institutional level support (mainstream school).

The journey began when the parents were requested to meet with the teachers of the mainstream school, as their children were experiencing academic difficulties. Thus the mainstream educator is usually the person who initiates the process of transition. These teacher-parent meetings could be seen as the first opportunity for the parents to receive support from a formal system. The parents" responses

indicated their concern for their children"s education. They too could see that their children were not coping academically and they were willing to co-operate with the teacher: *"I didn't have a problem because I saw her work, she was not coping. When I was helping her with the homework she was failing. I understood and was willing to help to help her."*   The parent acknowledged the child"s academic difficulties and was willing to take action. The teacher-parent meetings also served as the initial source of stress for the parents as the teachers related their children"s responses to teaching and learning in the classroom: *"The teacher said my child my child is not learning like the other children and she will have to repeat the grade."* The parents felt anger, sorrow, frustration, guilt and pain especially when comparing their child with others (Heiman, 2002).

Parents also initiated the process of transition when they suspected that their children were not developing as they should: *"I said my child can't be this age and can't write. I went to school and found out how he's progressing."* Parent concerns, observations and insights into their children can offer professionals valuable information on the early identification of children with developmental and behavioural problems (Glascoe & Dworkin, 1995). In this way, intervention can begin earlier, which can lead to better outcomes for the child and the family (Bayhan & Firat Sipal, 2011). The process of transition starts when parents begin to think about and make decisions related to school (Docket & Perry, 2007).

The children"s difficulties included those of reading, writing, speaking, numeracy and concentration. These difficulties usually served as a catalyst for transition: *"His results were terrible. Even to write his name it was like trying to pull out a tooth without an anaesthetic. His concentration ability and his speech weren't good."* These scholastic difficulties were consistent with research findings which reported that children with ID usually demonstrate global developmental delay and have difficulties with all aspects of communication (Bacon & Wilcox, 2011). These communication difficulties translated into academic difficulties referred to by the teacher. The development of good oral language is a prerequisite for the development of reading and writing skills (Justice, Meier, & Walpole, 2005). The teachers also highlighted the children"s behavioural and social difficulties: *"He was sleeping in the class. He never used to respond to teachers in grade R, he kept to*

himself and cried every single day." Research suggests that there is a high prevalence of emotional and behavioural difficulties amongst children with ID (Cormack, Brown, & Hastings, 2000).

Some of the parents received appropriate support at the level of the institution: "*So the school phoned the department. The Head of Department helped me. The psychologists came to school and assessed them.*" The children were referred to the District Education Office when their children"s difficulties were identified. According to the National Education Policy Act 27 of 1996, the rights and wishes of learners with special educational needs, must be considered upon their admission to an ordinary public school (Department of Education, 2003). If the learner cannot be accommodated in a particular educational setting, the principal of the school must refer the learner to the head of department who will facilitate admission to a suitable public school. In this instance the relevant education policy was implemented. The level of success during transition between schools can be a significant factor in determining the child"s future progress and development (Docket & Perry, 2007). An enabling factor that assisted in the child"s transition was an appropriate referral process that was followed by the school (Fabian & Dunlop, 2002).

Parents were not always acknowledged as equal partners in the process of transition. Parents sometimes suggested solutions which they thought could help their children. They wanted to be recognised as the "expert" of their child, valued and respected by service providers and involved in the decision making: "*I told them to let him repeat grade R. They said no. They told me I cannot tell them of the child's problem, only the teachers can. They believe the teachers more than the parents.*" Parent participation is considered to be an important component in the education of children with disabilities (Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007). Teachers as well as professionals have traditionally relied on their training, knowledge and authority to make all the decisions regarding the children. Parents should be acknowledged as partners and experts and be involved in the decisions taken regarding the future of their children"s education (Englebrecht, Oswaldt, Swart, Kitching, & Eloff, 2005). This practice is consistent with the family systems theory of

service delivery which proposes that the family is in the best position to determine the needs and wellbeing of the child (Murray, 2000).

Some parents encountered problems during the process of transition and they were dissatisfied with the level of support provided by the mainstream school (Janus, 2004a).   The following four factors contributed to parental dissatisfaction with the level of support received: Children were not referred to the District Education Office; children‟s names were removed from school registers; children were placed on waiting lists at special schools indefinitely and institutions expressed their inability to cope with children with special educational needs.   This child was not referred to the education district office for further assistance in this extract: "*The principal could have given his name to the psychologist but he didn't. The biggest stress at that time was getting him into a special school.*" The parent initiated her own course of action in an effort to help her child gain access to special education: "*I took action. I made personal arrangement for her to assess my child.*" In this instance the child was not referred to the District Education Office. Lack of smooth transition between schools due to non-enabling factors, such as inadequate school structures, can result in high drop-out and repetition rates (United Nations Educational Scientific and Cultural Organization, 2012).

The children‟s names were sometimes placed on waiting lists at special schools indefinitely.   These children were refused admission and the parents should have been informed in writing of the reasons for non-admission. "*I went to two other special schools. They said they will put her on the waiting list.*" In terms of Section 5(9) of the South African School‟s Act, if admission to a public school is refused by the principal, the parent can consult the District Education Office for assistance prior to lodging an appeal with the Member of the Executive Committee. However, many parents did not know about this recourse. "*Nobody told me about the District Education Office.*" Long periods, or years passed by, where their children remained in the mainstream class. Transition to special education was delayed and the parents reported that their children did not benefit significantly from being in the mainstream class. There is a high level of unmet needs in parents of disabled children, in this case being information and advice about services (Sloper, 1999).

Many parents reported that their children were removed from the school register because the teachers could not cope with them. Some were told that the school does not have the staff to manage their children. The parents were told to find another school: *"After two weeks the teacher phoned us because they can't keep him in that school. You have to get another school. From March to end of the year she was at home."* Many teachers may not be prepared for the challenges they face with children with disabilities and they may be of the opinion that they should be placed in special schools (Arbeiter & Hartley, 2002). According to the South African School"s Act, the name of a learner can only be removed from a school"s admission register when: the learner leaves the school after grade 12, or applies for a transfer to another school and the transfer is effected, the learner is expelled from school or dies. The South African Schools Act 84 of 1996 also provides that education is compulsory for learners from 7 until 15 years of age. It also makes provision for due process before a learner may be removed from a school. Where removal of a learner is being considered, alternate placement must be provided by the Head of Department. It therefore appears that some of their children were unlawfully removed from their schools and alternate placement was not provided for them. The learners" rights to education were violated and the appropriate referral procedure was not followed as stipulated by the National Education Policy Act 27 of 1996 (Department of Education, 2003). Large class numbers, lack of staff support structures, teachers" experiences of stressful situations and lack of competency to teach children with disabilities appeared to have contributed to the manner in which the teachers responded to the children with special needs as well as their parents (Moletsane, 2004).

Some teachers complained about the large number of learners in their classes and their inability to focus on one child who had a difficulty: *"She tells me she has about 35 children in her class and she cannot neglect 35 children for one child. For me, that was like throwing my child at the wolves."* A large class number was cited as an inhibiting factor, in a study carried out on teachers" beliefs and attitudes about mainstreaming (Fuschs, 2010). It was also reported that the school did not have the necessary teachers to manage the children: *"Next year we can't cope with your child because we don't have teachers to try and manage this situation."* The success of transition to school for a child with disabilities is largely dependent on the availability

of support structures at school, to facilitate the learning process. Parents often complain of the lack of specialised teaching staff such as special teachers and support staff or programmes (Valeo, 2003).

Research has indicated that teachers can be exposed to highly stressful situations that can compromise healthy relationships with the students, their ability to effectively manage their classes and to support learning (Jennings & Greenberg, 2009). It has been found that children with disabilities are at risk for receiving inappropriate educational interactions (Cook et al., 2007). This results in stress for both the children and their parents. The classroom climate can deteriorate; teachers can become emotionally exhausted, reject the children and resort to reactive and punitive responses towards them. Teachers are at risk of becoming cynical and callous in their interaction with the children when their situation becomes stressful (Osher et al., 2007). This situation can be exacerbated where resources are difficult to access. It is advised that recommendations be instituted to improve teachers" attitudes towards disabled children (Cook, 2001). There is a need for increased knowledge, sensitivity and empathic understanding within the realm of childhood disability. Supportive professionals and educational settings contribute to child development and family well-being (Ballard, Bray, Shelton, & Clarkson, 1997).

Many teachers did not feel confident or competent to teach students with disabilities in inclusive classrooms and therefore could not cope with learners with special needs. Teachers said they felt a lack of expertise in accommodating individual learning differences when they designed and implemented their lesson plans (Prinsloo, 2001). Common challenges within their classroom contexts prevented their success in teaching children with disabilities. The teachers felt that the responsibilities and expectations of them were unreasonable. They also feel that they have not been adequately trained for teaching in inclusive environments in their pre-service programs (Hardin & Hardin, 2002). They also cited lack of daily support from special educators and support staff (Fuschs, 2010). A large number of teachers in South Africa are confused and not confident due to the many curriculum changes that have occurred over the years. Teachers need to be trained to understand the diverse needs of the learners in their classrooms, to identify their

problems, to support them in their learning and to refer them when necessary (Prinsloo, 2001). It is the task of the Education District Officials to assist educational institutions to identify and address barriers to learning, and to evaluate programmes and promote effective teaching and learning (Department of Education, 2008b).

4.2.2   District education level support.

The results indicated that some parents received appropriate assistance from the District Education Office, some did not, and some parents had to wait for a long period of time for assistance. Some children were placed within a short period of time whilst others waited for a longer period. The parents expressed joy and relief when their children were finally placed: *"I went to the Department of Education. A lady helped me to come to this school. When we got that call that the assessor was at his school, we were overjoyed. It was a long wait."* The parent was pleased with the outcome. Successful transition is associated with positive educational outcomes (Fabian & Dunlop, 2002).

Not all parents, however, were satisfied with the manner in which the Education District Office managed their concerns. A parent was disappointed that she was not given an opportunity to discuss her child"s difficulties with them, as she was given a form and told to find a school by herself: *"So someone told me about D.o.E. I thought they will do a conversation like we doing now. Only they just gave me a form and said find a school for yourself."* The South African Schools Act 84 of 1996 and the Constitution of South Africa enshrines the right of every child to education, which the State must make progressively available and accessible. This implies that it was not the parent"s responsibility to go in search of a school but the responsibility of the Department of Education to provide appropriate school placement for the child. Many of them went from school to school, with their children being rejected for a variety of reasons: *"So I started looking for a school. I went to all the schools. Nobody said yes. I had to wait for the following year. I cannot let her stay at home."* This child was denied education. The South African Schools Act 84 of 1996 states that if a principal refuses to admit a child, written reasons must be provided for such a refusal. This was not done for these parents. According to the National Education Policy Act 27 of 1996, the admission policy of a public school and the administration of admissions by an education department must not unfairly discriminate in any way

against an applicant for admission (Department of Education, 2003). The District Education Office sometimes took a long period of time to offer their services to parents and their children. It appeared as if education policies that were developed to provide support were poorly implemented by stakeholders in education (Janus et al., 2007).

There appeared to be the perception of school personnel and other professionals that the District Education Office took a very long period to reach mainstream schools to assess children who were experiencing barriers to learning: *"I spoke to the principal about the department. He said it takes years for them to finally come and assess your child. The H.o.D sent the forms to the D.o.E. But it was not processed."* Some parents were dissuaded from going to the Department of Education for the above reason. Another parent had this to say: *"I didn't go to the DoE. Because they said it will delay. A teacher said I must go to the private psychologist."* The availability of appropriate services is an important source of support for families with disabled children (Wehmeyer et al., 2008). The Department of Education officials acknowledged their staff shortage, their work backlog and delays in conducting further assessments of children: *"At the education office they said it would be a while before they assess my child because there is only two assessors in the KwaZulu-Natal region, and they were fully booked from the last years assessments."* The long waiting periods for their children went against the National Education Policy Act 27 of 1996, which states that the process of transfer to another school should be regarded as a matter of urgency, and should occur as soon as possible to ensure that the learner is not prejudiced in receiving appropriate education. Parents were advised to approach public health and other institutions in order to obtain assistance for their children sooner.

4.2.3 State health and other institutions of support.

Parents sought assistance from state institutions such as clinics, hospitals, and universities. They were assisted by a variety of professionals, some of whom even helped with school placement: *"From the clinic they sent us to the hospital and then to psychology, speech therapist and three doctors, occupational therapy and the social worker. They gave me a list of special schools."* It was reported that this process took a long period of time, as the children were referred to the various

departments for a variety of assessments and given appointments that were months apart. Disabled children and their families have needs that must be accessed from a variety of different service providers, such as health, education, social services housing and benefit agencies (Gordon et al., 1996). Beresford (1995) reported that many parents have great difficulties in finding out about available services, to know who to approach for help and to obtain services relevant to their needs and situation. Many of them go to the nearest government hospital in the hope of obtaining assistance for their children. The role of these hospitals in providing appropriate services should be viewed seriously. If this is where people most in need of assistance go to and expect to get help from, it should be adequately resourced to provide the necessary assistance. The advantages of well-run government hospitals are significant, as they are able to employ a core community of skilled healthcare workers from which primary healthcare services can be supported and organized and serve as a vital link in the referral chain (le Roux & Couper, 2015). Some parents sought assistance from private psychologists.

4.2.4   Private psychologists support.

Parents were advised to seek assistance from private psychologists as this could speed up the process of referral to a special school as well as obtain more information on the academic difficulties experienced by the child. Some parents could not afford private psychologists" fees whilst others borrowed money to meet the payments, and one parent said: "*I found out from the teacher where can I take him to be assessed. They told me about the private place. I couldn't take him there because of the cost."* Another parent was urged by the teachers to seek the services of a private psychologist twice and she stated: "*I am a single parent and did not have any finance. I borrowed a large amount of money for the psychologist twice."* This contributed to much financial stress for her and her single parent status aggravated the situation. Children with special health care needs are significantly more likely to live with poor families than children in general (United Nations, 2015). Their financial constraints were an additional source of stress for them.

In summary of the results of objective one, the parents sought formal support for their children, from their respective institutions, from the District Education Office, from the state health sector and/or from private psychologists. Their primary

motivation for seeking such support was to access appropriate education for their children. The parents did not receive consistent support from the education structures. The Bill of Rights, as contained in the South African Constitution, states that every child has the right to a basic education including those with disabilities (Republic of South Africa, 1996a). The Department of Education compiled the White Paper Six which outlined the government"s intention to include special needs education as an integrated component of the general education system, where education districts and educators would provide appropriate support to children (Department of Education, 2001). Although this policy and education districts are in place, parents did not receive appropriate assistance for their children and they were denied access to basic education. The reasons for this situation warrant closer examination.

The state health sector provided much support to them, however, the process extended over a long period of time, thereby delaying access to appropriate education. The health-care system is the only medium that has the potential to reach all young children and therefore should be sufficiently resourced to meet the needs of children with disabilities, including mechanisms to access special education (Velez et al., 2014). Private psychologists have provided much timeous support to the parents, however, this imposed much financial stress on the parents as psychological evaluations were not affordable to many parents.

4.3 Objective 2: To Explore the Parents' Experiences of Informal Support Received during their Children's Transition to Special Education

The parents related their experiences of varying levels of support which they received from their spouses/partners and their extended family during their children"s transition to special education. Parents appeared to have responded differently to their children"s difficulties.

4.3.1 Spouse/ partner.

Some spouses were supportive of their disabled children, as indicated by a parent: *"My husband was okay. He said if God gave us these children, what we gonna do. He accept and love them."* Other parents did not enjoy the support of a spouse, with another parent saying: *"I was angry because my husband had just left*

us. Now, I'm all alone sorting these things out with him. I wasn't getting help from anybody, my family nobody." In a study examining the difficulties experienced by families with disabled children, it was found that family relationships were affected after having an affected child and this sometimes resulted in separation or divorce of parents (Sen & Yurtsever, 2007). Divorce is significantly more common among the parents of disabled or sickly children than among those of healthy children (Mauldon, 1992). Some disabled children were raised by their mothers only. They had to manage both the care of the child and the financial implications of raising a child with a disability (Sen & Yurtsever, 2007). The mothers as compared to the fathers responded differently to their children"s disabilities.

The mothers appeared to have accepted and understood their children"s disabilities more easily than the fathers: *"When the teacher called me in it was easy to accept, but for her dad it was too difficult."* According to a parent only mothers are able to take care of their disabled children: *"Only the mothers are strong to take care of their disabled children."* It was suggested that the possible reason for this is that the mothers take on a larger part of the extra care and practical day-to-day work that a child with a disability requires (Marcenko & Meyers, 1991). Mothers have traditionally been seen to be the main source of information about their child"s development and the ones to actively seek out assistance for their children. Fathers often have few direct responsibilities towards their children with disabilities. As a result they may not have the opportunity to work through their mixed feelings about parenting a child with a disability (Hadadian & Merbler, 1995).

Some fathers were reported to have been in denial of their children"s disabilities. A parent said: *"I try to phone the father to tell him I need help. In his mind there is nothing wrong with the child. He didn't want to accept that there is something wrong with him."* This resulted in much friction between both parents: *"Academically we were at loggerheads with each other on a permanent basis."* One of the fathers asked the child to conceal the name of the special school that he would be attending, possibly in an effort to avoid embarrassment to him: *"His father was very stressed and took it badly. In the beginning he told us not to tell everybody that the child is going to that school. My child was surprised."* The child questioned the father"s suggestion to conceal the name of the school which he in fact was proud

of: *"My child did not want to lie and he asked his father why he should lie. My child said it was a special school, and a nice school."* Research on fathers of children with disabilities is scarce. Research to date has indicated that there is both much variability and similarity in father and mother experience in families of children with ID (Crnic, Pedersen, Arbona, Baker, & Blacher, 2009). However, research does indicate that fathers experience stress differently as compared to mothers (Krishnakumar & Buehler, 2000). A study of mothers and fathers of young children with cognitive delays in Vietnam revealed that the fathers" stress was related to the experienced social acceptance of the child. This suggested that when the child and family could not be connected to the external world, it affected the stress they were experiencing (Shin et al., 2006). The cultural context of the parents could have influenced their thoughts on disability.

A parent talked about the cultural aspect of having a child with a disability and the response of some Zulu men: *"I think the Zulu mens is frightened of disabled people. Their husbands run away and say the child is not theirs. They frightened of what the people would say about their child."* Research has shown that cultural context can influence interpretations of intellectual delays, values, the reactions of others and the experience of stress (Ferguson, 2002). Parents in developed countries tend to believe in scientific explanations of disability. In contrast, people in developing countries such as South Africa tend to have a higher belief in meta-physical-spiritual explanations of disability. Intellectual disability can be attributed to bad deeds or sins committed by the ancestors, in Chinese culture (Hunt, 2005). It can also be viewed as a punishment for the disabled person"s sins in a past life or for the sins of the parents. (Liu, 2005). Disabilities are also said to be of spiritual origin in Zimbabwe, in Africa. It is believed that people with mental illness are possessed by an evil spirit. (Mpofu & Harley, 2002). This could account for the reports that fathers sometimes ran away from their disabled children and claimed that they were not the fathers of their children. Family members also provided support to the parents of the children.

4.3.2   Extended family.

Family relationship, functioning and support play an important role in helping the family to cope with a disabled child (Stoneman, 2005). Family also assisted in

finding a school for the child. Some primary caregivers reported positive responses from their families to their children‟s disabilities, with families understanding and accepting their disability: "I*'m so happy because I've got my family, sisters, brothers to support me. They have accepted him. I showed them the psychiatrist report and they understood his condition."* Some acknowledged their strong family support systems: *"My auntie told me about this school. They got me the number and I gave it to the psychologist in the school."* Some families, however, were not always supportive, calling their children names and not associating with them: "I *say to my nephew not to call him stupid or call him names because he's the same like them. Now they know. They accepted him."* Parents reported insults and name calling from family members (Pivik et al., 2002). Parents reported feelings of pain, sadness, stress and disappointment. *"When he was growing up, the families used to tell me things and insult me. They said that he had a psychological problem and if I don't have his head checked he will be worse and get insane."* Family exert pressure on parents to act in ways that they deemed correct for the child. It appeared as if the child‟s difficulties were equated to a psychiatric condition.   A study of mothers of children with disabilities and the emotional impact of perceived stigma on them revealed that the children were stigmatized and labelled (Green, 2003).   The community also contributed to the parents‟ experiences.

4.3.3   Community.

Some parents were assisted informally by neighbours, people in the community, friends and family of children already attending the special school. Many of them relied on these informal sources of support as they did not know where to go for help or formal assistance: *"My neighbour told me about this school. My friend told me that my child might need a special school. A mother at the clinic gave me this address of the school."* The availability of social resources and the sharing of common experiences is reported to be a source of resilience, support and hope for the parents (Kausar et al., 2003). This is an important source of support for the parents. Responses from the community however were not always favourable towards them. Some parents reported negative responses to their children‟s disabilities. Neighbours complained about their children‟s behaviour and mocked them for attending a special school: "*Ja, it's sore. The other children they say they are mad. The mad children are there at that school."* Negative peer attitudes are

commonplace in inclusive schools (Vignes, Coley, Grandjean, Godeau, & Arnaud, 2008). The parents were saddened by the response of their community. "*I was sad. Even to the neighbours the child was like a joke. People say funny words to a child going to a special school. They did not understand his problem.*" The parents experienced pain and sorrow at the negativity towards their children (Heiman, 2002).

A study of the everyday lives of mothers of children with disabilities, indicated that the mothers were faced with similar reactions from others towards their children (Ryan, 2005). Some parents tried to make sense of their experiences with their children. Some tried to find reasons for having children with disabilities, thereby possibly aiding in acceptance of the disability and achieving the support that they needed. "*God wanted to see how strong I am.*" Their belief systems and their faith led them to believe that they had been purposefully selected to provide care and comfort to the child. The child was given to them in order to test their faith (Kausar et al., 2003). Parents spoke about using prayer to communicate with God and to access their faith. They turned to their spirituality and faith to find meaning and purpose in life, which could have helped them to make sense of having a child with a disability and view it in a positive light. A parent prayed in the hope that her child would become better: "*But I did everything for my children, prayers. But it's still the same. No more now, I accept it now. But it was a big thing. I believe in Zulu culture.*" The concern for the child and the efforts to help him were followed by acceptance.

The strength gained from faith provided a resource that enabled the parents to meet the challenges they faced in everyday life with their disabled children (Poston & Turnbull, 2004).   Parents with more than one affected child faced additional difficulties. Some parents had more than one child affected by disability. They questioned this and tried to find reasons for this occurrence: "*My daughter too had problems from primary school days. It was very, very hard for me because I had two children who had problems. I said to myself, why God?*" Intellectual Disability can be caused by genetic factors in approximately 25-50% of the cases, which could account for some families having more than one affected child (Kaufman, Ayub, & Vincent, 2010). Here again the parents turned to spirituality for support and answers to their questions.

In summary of the results of objective two, the parents received informal support from their spouses/partners, extended family and community. Although informal support was important to them, the nature of the support was not always favourable. It was found that family relationships were affected after having a disabled child and this sometimes resulted in separation or divorce of parents. Some disabled children were raised by their mothers only. They had to manage both the care of the child, the financial implications of raising a child with a disability and seek out relevant services (Sen & Yurtsever, 2007). Policy makers and professionals must acknowledge the parents" financial stress and create structures to relieve them of this. The mothers appeared to have accepted and understood their children"s disabilities differently than the fathers (Krishnakumar & Buehler, 2000). These differences in parent responses must be acknowledged by professionals during their interaction with them. Some parents may need to be referred for professional support or counselling. Some primary caregivers reported favourable responses from their families to their children"s disabilities. Extended family and the community were not always supportive in their responses to the parents.

Education and empowerment of the community could assist children in accessing appropriate education. Community health workers can be effectively used in outreach and delivery programs if they are provided with adequate education, support, monitoring and links to health professionals (Velez et al., 2014). Research has shown that cultural context can influence interpretations of intellectual delays, values, the reactions of others and the experience of stress (Ferguson, 2002). Delivering effective services to people from various cultures requires an understanding of the ways in which their culture influences their views of disability and how those affect their associated practices (Stone, 2005).

4.4 Objective 3: To Explore the Negative Emotional Experiences of Parents during their Children's Transition to Special Education

When parents learnt that their children had to attend a special school, they experienced feelings of disappointment, helplessness, hurt, irritation, anger and depression: *"At that time I was quite angry, irritated, depressed and hurt that he had*

this problem. It was difficult to accept the special school. We couldn't handle it." Emotionally, parents generally experience and express feelings of disappointment, sadness, anger and guilt when they are told that their child has a disability (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). They enter a territory in which they have no experience or knowledge and there are no signposts or maps (Kearney & Griffin, 2001). There was concern over their child"s inability to communicate clearly: *"Before, at a younger age it was so difficult for her to talk. I was so worried."* Children with ID usually demonstrate global developmental delay and have difficulties with all aspects of communication (speech, language, cognition and myofunctional patterns) (Sachse & Suchodoletz, 2008). A parent talked about her child"s emotional outbursts: *"He would be kicking me, screaming, crying and complaining every day when he comes from school. He would be so frustrated."* It has been found that children with communication disorders are at higher risk for emotional and behavioural disorders as compared to the community at large (Bishop & Leonard, 2000). Parents also expressed confusion about the "diagnoses" of the child"s problem during this period.

The parents spoke of sometimes conflicting emotions, information and advice, ambiguous prognoses, of their own observations being in conflict with the information they were given by the teachers and other professionals, of not knowing what to expect and sometimes of simply not knowing what to do. A parent had to seek many professional opinions due to the contradictory findings: *"At the clinic and the hospital they said there was no problem with her. I was confused because the child was a problem at the crèche. Then I went to the specialist who said she had a big problem."* This report was consistent with findings from other studies (Jones & Passey, 2005). Some parents reported the need for perseverance and determination when acquiring supports or second opinions for their children, and others were confused about their children"s disabilities. According to the parents, their children were quite capable of performing many other tasks unaided, but yet they experienced great difficulty in their schoolwork. They could not fully understand this: *"How could he be so oblivious to education yet he can do everything else? It was very confusing for us because at the schoolwork he just couldn't."* The parent appeared to have tried to make sense of her confusion about the disability, this being a stage of acceptance where questions are asked (Barnett et al., 2003).

School refusal became a problem for parents. The morning routine caused much stress for some parents: *"He cried every morning because he didn't want to go to school. I had to drag him out of bed. He said he wanted to kill himself."* School refusal is a serious problem that is very stressful to children, families and school personnel, and is often associated with anxiety and depression. Children with ID are at risk for emotional, behavioural and mental health problems (Pfeiffer & Baker, 1994). There is often avoidance of specific fears related to the school environment and escape from threatening social situations related to classmates or teachers. A child can present with symptoms such as crying episodes, temper tantrums and threats of self-harm as reported above (Fremont, 2013). Grade repetition due to poor academic performance was commonly reported.

Some children repeated grades and their parents were concerned about this. Some were condoned into the next grade due to their age and the education policy regarding repetition of grades: *"They told me her mind is not matured for grade one. I told them to take her back to grade R, she won't cope. They refused and said that her age took her to grade one."* Some parents argued against promoting their children to the next grade. The parent wanted to have a say in determining the well-being of the child (Dunst, 2002). According to the national policy pertaining to the programme and promotion requirements of the National Curriculum Statement, a learner who does not meet the requirements for promotion can be progressed to the next grade in order to prevent the learner being retained in the foundation phase for more than four years, excluding grade R (Department of Education, 2011). *"My child repeated grade one and was condoned into grade two."* The learners who were condoned were placed in higher grades due to this policy and they continued to struggle as the academic demands increased. This policy of promotion based on age appeared to have slowed down the transition to special education and should be reviewed. Some parents were unhappy with the responses of the teachers to their children.

Some parents expressed feelings of unhappiness and disappointment with the teachers. Some teachers were reported to have been unsupportive and impatient toward their children: *"I was disappointed with the teacher and she was rude. They*

only complained about his schoolwork and the teachers started treating him like the naughty child in the corner." It was reported that their children were singled out, isolated from the rest of the class and not given adequate attention or personal assistance: *"The teacher had them kept in one side of the classroom or outside, while she taught the rest of them. She said that she did not have time for that."* The parents felt that their children were not treated in the same way as the other children were, and felt hurt and helpless in this situation: *"The teachers didn't want to help me."* A parent felt sad and angry when the teacher commented on her child"s ability, contending that her child should have been motivated rather than made to feel incapable. She was afraid to question the teacher for fear of victimisation of her child, and fear that he will not have another school to go to: *"As a teacher she told my son that he's going to a special school because he don't know nothing. I was angry and feeling sad. I said I must leave it because my child won't get a school."* The parent had to carefully consider the situation and act in the best interest of her child for fear of her child being excluded from school. Parents experience stress where schools are rejecting of children with disabilities (Cook, 2001). These children are often subjected to negative teacher reactions (Pivik et al., 2002).

The child"s disability was highlighted and he was made to feel like he did not belong in that school and he should be removed: *"The teacher said that he must stay at home and help to clean the house or he must become a garden boy."* It appeared as if teaching such a learner was not her responsibility and he should be passed on to other professionals or specialists in the field (Arbeiter & Hartley, 2002): *"They said the child has a disability. He's got a problem with his leg. They said I must just place him in the special school."* Another child"s learning difficulties were equated to a psychiatric condition. A sense of fear was created in the parent about her child"s emotional wellbeing if the child was not removed from the school. The parent felt hurt, alone and helpless. She reported an emotional breakdown thereafter: *"The teacher said to me if I leave him in this school he's going to go psycho. Then I broke down."* It has been found that children with disabilities are at risk for receiving inappropriate educational interactions. Teachers complained about the children"s behaviour. The South African Schools Act states that where a learner"s behaviour is objectionable in that it violates the rights of others, the matter must be referred to the principal. Through consultation with the educator, Institution Level Support Team

and the parent every effort should be made to assist the learner to adjust or be referred appropriately.

A summary of the results of objective three revealed the negative emotional experiences as narrated by the parents in this study. Some of these negative emotions emanated from the parents own feelings at the time of diagnoses of the child"s disability and the realization that the child had to attend a special school. Professionals including teachers must be aware that parents must experience and express feelings of disappointment, sadness, anger and guilt when they are told that their child has a disability (Barnett et al., 2003). They also experienced conflicting emotions and continually questioned their predicament. Asking questions and searching for answers is a necessary stage of acceptance of the child"s disability and it does not end (Barnett et al., 2003). Teachers and professionals must be aware of this and be able to identify this occurrence. Some parents may require professional counselling in this regard. Grade repetition and condonement was also a source of concern, which did not result in appropriate action being taken and admission to a special school being delayed, indicating the need for the relevant policy to be reviewed.

School refusal was a further source of negative emotions for them. There is often avoidance of specific fears related to the school environment and escape from threatening social situations related to classmates or teachers (Fremont, 2013). It is important for teachers to examine the possible cause of the child"s fears and provide support to the child and the parent. If the child is not coping with the curriculum, appropriate recommendations and referrals should be made timeously. The parents" negative feelings were also caused by external factors such as negative responses from the teachers towards their children and rejection of their children in the classroom. The unsupportive teacher responses indicated the need for increased knowledge, training, support structures, sensitivity and empathic understanding of childhood disability (Cook, 2001).

4.5 Objective 4: To Explore the Positive Emotional Experiences of Parents during their Children's Transition to Special Education

Some teachers were supportive towards the children who experienced scholastic difficulties. They assisted the parents in understanding their children"s difficulties. Parents felt good about this. A parent was reassured that her child was not the only one with a problem: "*The teacher said my child was not the only one with the problem. There were others too.*" The teacher expressed care and understanding of the child: "*The new class teacher was so sweet and understanding. She was the one who called me and told me that she loves my child and understands her.*" A child"s formal learning context is largely determined by the teacher (Eccles & Roeser, 1999). Socially and emotionally competent teachers foster supportive and encouraging relationships with their learners and motivate them, and are also responsive to individual differences and learner needs (La Paro & Pianta, 2003).

Some parents displayed a realistic understanding of their children"s disability and accepted the transfer to a special school: "*I was prepared for him to come to a special school. I was all for him to prosper and move on because I knew in my heart that he wasn't going to make it there.*" Emotionally parents must accept and move past negative feelings to experience the pleasures, rewards, joys and connection with their child (Barnett et al., 2003). Some parents expected the search for a special school to be a long one: "*We didn't expect him to get the school the same year because it was February.*" Some also assumed that the fees charged by special schools were very high and they could not afford them: "*We were also happy the school is not expensive. Dad is not working only our mum is. Other schools are expensive.*" Some of the parents kept their children at home assuming that they could not afford the school fees. Financial and material support is important for parents of children with disabilities (Kyzar et al., 2012). Services for such children must be free or at a low cost (Janus et al., 2007).

Some parents also acknowledged positive and good qualities about their children. Finding positive attributes in their children is a coping strategy that parents employ (Graungaard & Skov, 2006). Acknowledging their children"s abilities rather than their disabilities could be a source of hope for them which could have assisted

in their acceptance of them (Kausar et al., 2003). These reports support research findings that there are positive aspects to raising a child with disability (Hastings et al., 2005). *"She is so appreciative and friendly. She is so talkative she's challenging, she's lovable, you cannot ignore her even if you like to. She's very good in doing chores."* Benefit-finding in the midst of stressful situations assists in finding meaning in life challenges, thereby helping people to move forward in their lives (Folkman & Moskowitz, 2000).

The results of objective four alluded to the positive emotional experiences of the parents. The benefits of supportive teachers were expressed and how they contributed to the parents" and children"s positive emotional states. Parents who accepted their children"s"disabilities were happy and looked for the strengths in their children. Positive perceptions played an important role in the coping process and results in a better quality of life for the entire family and improve the child"s prognosis (Gupta & Singhal, 2005). Parents become more action orientated and this is important and useful to the parent who is raising a child with a disability as they are more motivated to seek out services to assist them and the child (Fredrickson, 2006). This could assist parents in acceptance and facilitate admission to special education. Disability service systems, including schools, should attempt to support families by helping the family system to function better and to improve various aspects of their family life which can result in happier families (Samuel et al., 2012).

4.6   From Brokenness to Wholeness... the Journey has Come to an End

The parents" destinations were finally reached, all of them were happy that their children were placed at the special school: *"I was happy when he was finally accepted into this school."* They were pleased that their children enjoyed and liked school compared to previously: *"Even now she loves the school."* They reported that their children"s happiness made them happy and they were feeling better now. External opinion did not matter to them: *"We don't care what people have to say because my child is happy. Now we are so much happier."* The transition process concludes when children and their parents feel secure and accepted within the school environment (Docket & Perry, 2007): *"But since we came here it was so nice.*

so warm. We love the school. It makes me feel good now that there is a school that is helping him." A parent reported reduced personal frustration and anger: *"Ever since he's in this school I don't get frustrated, angry or scream at him because I'm relieved. He is in a better place, where he is comfortable and happy."* When children are happy they are more likely to experience school more positively, with school experiences and happiness influencing each other (Stiglbauer, Gnambs, Gamsjäger, & Batinic, 2013).

There was a change in the child"s attitude towards his schoolwork and in his behaviour and these in turn relieved parents of their stress: *"He's enthusiastic to do his work. He's not so frustrated like before. He's much happier."* His relationships with others improved: *"The relationship that he now has with everybody is better."* A parent noted a marked difference in her child: *"You can see she's totally different but some of the things are still there, since it's natural. But she's so disciplined now. I am proud of her because I can see where she came from."* Creating positive school environments plays an essential role in children"s overall happiness throughout the academic year. Children are likely to engage in positive behaviours and therefore experience school more positively (Stiglbauer et al., 2013). A child"s happiness leads to parent happiness. Most of all, the parents were impressed with the scholastic improvements that their children had made: *"There is a 100% difference in him now compared to all the years he spent at the mainstream school. Progress is very great."* Their children were now more willing and enthusiastic to perform academic tasks, unlike before: *"He's enthusiastic to do his work I saw improvements in him in the first three weeks.* I *am happy now because I can see the difference."* A good start to school is linked to positive educational and social outcomes (Fabian & Dunlop, 2002).

The parent was pleased that others too noticed the difference in her child: *"Even at the farm people are shocked. So they didn't think the child will cope so good like this."* They indicated that their children were performing much better than they did at the mainstream schools and they had gained much: *"I'm just proud of him that he's accomplished so much in the time that he's come here. The difference in the school that he was in and the school that he is in now is that he has gained."* The child"s self-esteem had improved: *"It's built his self-esteem up with his*

schoolwork." The increase in positive school experiences and happiness seems to manifest itself within a short period of time (Stiglbauer et al., 2013).

The parents were proud that their children had learnt to speak and understand English. The majority of black parents favour English as the language of teaching and learning as it is thought to be a gateway to a better education and economic empowerment (Van Louw, 1998). They saw this as a sign of scholastic progress, as expressed by a parent: *"The English she's speaking, you cannot say it's her! He's talking English and can understand English. That shows there is progress at school."* The parent expressed much joy at this.

4.7   Reflections after the Journey

The parents reflected on their journeys of helping their children through their transition to special education. One parent was happy that her child appeared normal to most people: *"People don't see that she has a problem. She looks normal. It's only me who knows and close family members."* Identifying positive attributes in their children is a coping strategy that parents employ (Graungaard & Skov, 2006). Other parents hoped that their children will become "normal" with time and be able to return to mainstream education: *"I was thinking that when she goes to the special school, she will get better and go back to the mainstream school."* Retaining hope is an emotional coping strategy used by parents (Graungaard & Skov, 2006). Another parent, even after claiming to have accepted the child"s disability, continued to question it: *"But sometimes when I'm sitting I'm just asking myself, why God why?"* Asking questions and searching for answers is a necessary stage of acceptance of the child"s disability and it does not end (Barnett et al., 2003). For another parent, her child"s disability brought about new and greater insight into children"s differing abilities, which helped her understanding and acceptance of reality: *"I now understand that not all children are the same. As much as we all want the perfect child, I have not got the perfect child."* She learnt that learning, for a child with a disability in a mainstream class, can be a struggle and a challenge: *"For other children it is not a struggle to get an education. For him it's been a struggle so far and I've got a new respect for his disability, so to speak."* Increased tolerance and acceptance towards disability was also reported: *"I can tolerate it and cope with it*

and I'm not ashamed of the fact that my son is different." Evaluating belief systems is also another coping strategy used by parents (Graungaard & Skov, 2006).

Other parents wished that their children could have received assistance much earlier: *"If I knew my child had this problem when he was about six years old, maybe if he could get help early."* Here too the parent appeared to be searching for answers which is a stage of acceptance of the disability and it is a lifelong process (Barnett et al., 2003). They felt that their children lost out on many years of education because they did not benefit from being in a mainstream class: *"My child never benefitted from the primary school. If he was found early and helped, he shouldn't have lost out all those years. It took four years for him to be correctly placed."* Early intervention is important for children with cognitive disabilities because of its relationship to optimal cognitive development. Early intervention and support programmes can help prevent significant, negative effects of cognitive disability on the cognitive, language, self- care, social-emotional, and academic development of infants and young children (Bayhan & Firat Sipal, 2011). The long waiting periods for their children went against the National Education Policy Act 27 of 1996 which states that the process of transfer to another school should be regarded as a matter of urgency and should occur as soon as possible to ensure that the learner is not prejudiced in receiving appropriate education.

A major global initiative towards disability is "Education for all" (Robson & Evans, 2003). It was hoped that this study supported this global initiative in ensuring that all children, including those with disabilities, are educated. The first Millennium Development Goal is to eradicate extreme poverty and hunger and the second is to ensure that all children complete primary education (United Nations, 2002). In order for children with ID to attain education and for them to complete primary schooling, they must be able to access schooling as soon as is possible and in a relatively trouble-free manner. In this study, it was seen that children with ID were still experiencing difficulties in accessing education. According to the National Education Policy Act 27 of 1996, the rights and wishes of learners with special educational needs must be considered upon their admission to an ordinary public school (Department of Education, 2003). This act requires ordinary public schools to

admit learners with special educational needs, where this is reasonably practical. This however is not being practised.

Children were denied admission to special schools for various reasons, while others were placed on waiting lists indefinitely, and some were taken off the school register and asked to find another school. These factors resulted in children not being educationally appropriately placed or not being schooled at all for long periods of time. This situation did not support the global initiative of "Education for all". In South Africa, cognitive ability and achievement at the end of grade one predicted later school progress (Liddell & Rae, 2001). Interventions at this young age can have lasting cognitive and school achievement benefits (Walker, Chang, Powell, & Grantham-McGregor, 2005). Owing to the difficulties experienced by children in accessing education, children were often admitted to school later due to the difficulties experienced. This further delayed intervention for the child and this could have affected the educational outcomes.

4.8 Summary

The aim of this study was to explore the experiences of parents of children with communication disorders associated with intellectual disability, during their children"s transition to special education. The results were discussed according to four themes: formal support, informal support, negative emotions and positive emotions. These themes were linked to the primary aim of the study. The findings revealed that at a formal level, parents accessed support from the teachers, the institutions, the District Education Office, state health and from private psychologists. At this level, parents and their children were exposed to both supportive and unsupportive responses. Their journey began with meeting the teacher to discuss the child"s scholastic difficulties and they talked about the nature of the teacher-child relationship and all the factors related to it. At the level of the institution, some parents were guided on how to access special education for their children, whilst others reported that they were not.

At the District Education Office level, some parents were assisted timeously and some were not. When parents failed to receive institutional or District level assistance, they sought assistance from public health and other institutions as well as private psychologists. Parents also related their experiences of informal support systems, such as the spouse or partner, their extended family and the community. During their children"s transition to special education, the parents talked about their associated negative emotional experiences as well as their positive emotional experiences. The end of their journey culminated in satisfaction at having their children admitted to a special school. For some, reflections on the journey resulted in renewed hope, an altered view of disability, lingering questions and some regrets. It has been seen that the major global initiative towards disability of "Education for all" is still not being achieved despite policies in place to support this initiative.

Chapter 5: Conclusion

5.1 Introduction

While South Africa has a number of policies that address the needs of children who require admission to special schools, many parents are unaware of how to access them and receive little support in this regard. This study explored the experiences of parents of children with communication disorders associated with intellectual disability, during their children"s transition to special education. The formal and informal support received and the positive and negative emotional experiences during the period of transition were explored. This chapter contains the summary of the results discussion, the significance of this study and the recommendations, followed by study limitations and the conclusion. The limitations will include a critical discussion of the methodological choices and the possible external influences that could have had an effect on the outcome of the study.

5.2 Summary of the Results

The study found that parents had a range of experiences during their children"s transition to special education, which was largely influenced by a considerable lack of knowledge relating to access to schooling. This is further addressed by indicating the main findings from each of the four objectives.

Objective 1: To explore the parents' experiences of formal support received during their children's transition to special education.

The parents accessed this from schools, the District Education Offices, private psychologists and state facilities. At the school and district levels, some parents were assisted during their children"s transition, whilst others were not. Some children were removed from school registers whilst others waited for a long periods for appropriate school placement. Parents sought assistance from state health facilities in order to secure appropriate schooling for their children, and private psychologists were also approached for assistance.

Objective 2: To explore the parents' experiences of informal support received during their children's transition to special education.

The parents sought assistance from their spouses, parents of other affected children, extended family, the community and from their own cultural beliefs. Some of the responses received were supportive whilst others were not, with unsupportive responses resulting in additional stress for the parents.

Objective 3: To explore the parents' negative emotional experiences during their children's transition to special education.

The parents gave accounts of their negative emotional experiences. Initially parents experienced disappointment, helplessness, confusion, hurt, anger and depression. Children who struggled academically were forced to repeat grades or condoned into the next grade, which caused considerable stress for the parents. Some teachers were reported to have been unsupportive towards the parents and their children. Some children, who could not cope with the academic demands, were unlawfully removed from their schools with no alternate placement being provided for them. These children remained at home, and were denied basic education.

Objective 4: To explore the parents' positive emotional experiences during their children's transition to special education.

Supportive teachers contributed to the parents" positive emotional experiences. Many of the parents expressed and acknowledged positive and good qualities about their children, which supported research findings that there are positive and good aspects to raising a child with a disability (Hastings et al., 2005).

5.3 Significance of the Study

This research study has provided stakeholders involved in education insight into the experiences of parents of children with communication disorders associated with ID during their children"s transition to special education. Knowledge in this area has been lacking. We can address these gaps in our knowledge by asking questions and taking a closer look at the issues involved (Leedy & Ormrod, 2010). New knowledge can be translated into action and act as a tool for improving service delivery. This could decrease the gap between what we know and what we do

(Graham & Tefroe, 2007). Experiences must allow the reader to feel, think, interpret, react or change (Richardson, 2000). Therefore, information in this area could help the relevant stakeholders make transition to special education, quicker and more pleasant. The use of evidence to inform policy and practice is important and this can occur over three stages, namely: sourcing the evidence (parent experiences); using this evidence in policy making and implementing the evidence (Bowen & Zwi, 2005). The use of evidence is a powerful and continuous process, during which knowledge accumulates and changes thinking over time (Walt, 1994). It is hoped that more research of a similar nature could change the thinking of policymakers and relevant professionals in favour of the needs of parents of children with ID. The ability to implement policy and stated objectives is the challenging stage as its success depends on many factors (Lafond, Brown, & Macintyre, 2002).

The nature and degree of formal and informal support received could have influenced their ability to access special education for their children. The parent"s emotional experiences could have been determined by the degree and nature of support they received along their journey. Here too, all stakeholders along the parents" journey can play a role in making their emotional experiences pleasant. In order to effect changes that could result in a better outcome for parents and their children during their journey to special education, various aspects need to be examined. If there are laws governing the admission of children with special needs into special and mainstream schools, the reasons for non- admission could be investigated. Improvements to the system may be required or management issues should be examined. Monitoring and evaluation of the implementation of policies is important. As many parents access services from the Department of Health, this department can be strengthened to meet the needs of these parents. The curriculum of teacher training courses can be developed to include knowledge on special needs education. A more effective service delivery model for parents could be developed. Some of these issues will be expanded in the discussion below.

5.4 Recommendations

The results of this study highlighted many issues that warrant closer examination.

5.4.1 Parent emotions.

When parents learnt that their children had a disability and had to attend a special school, they experienced feelings of disappointment, helplessness, hurt, irritation, anger and depression. Emotionally parents must experience and express these feelings (Barnett et al., 2003). The parents spoke of sometimes confusing and conflicting emotions, information and advice, ambiguous prognoses, of their own observations being in conflict with the information they were given by the teachers and other professionals, of not knowing what to expect and sometimes of simply not knowing what to do. It is important that the professionals be sensitive to the feelings of parents and to provide accurate information to them. The parents who coped well, indicated that they had been well informed of their children"s diagnosis and treatment and they had actively sought to cope in the stressful situations (Taanila et al., 2002). Interdisciplinary collaboration could help to reduce conflicting professional information to parents which was highlighted in White Paper Six (Department of Education, 2001).

Many parents continued to ask questions about their children"s disability many years after diagnoses or being placed in special education. Asking questions and searching for answers is a necessary stage of acceptance of the child"s disability and it does not end (Barnett et al., 2003). Teachers and professionals must be aware of this and not be quick to judge parents who struggle to accept their children"s disability and the school that they have to attend. Parents should be given more time to work through their feelings and some of them may require professional assistance in this regard and they could be referred for such a service.

5.4.2   Parents and stress factors.

Parents of children with disabilities have to contend with various stress factors which professionals need to be aware of. Managing daily care and the financial implications of raising a child with a disability can become overwhelming for the parents (Sen & Yurtsever, 2007). The sources of stress for the parents must be acknowledged in order to provide appropriate services for them and better outcomes for the child. Single parenthood can aggravate the situation. The roles and responses of mothers and fathers must be acknowledged.   Research does indicate that fathers experience stress differently compared to mothers which must be considered during professional interaction with them (Krishnakumar & Buehler, 2000). Efforts must be made to encourage greater engagement of men in meeting family needs (Shonkoff et al., 2012).

5.4.3   Positive aspects of disability.

Some parents also acknowledged positive qualities about their children. This has supported research findings that there are positive aspects to raising a child with disability (Hastings et al., 2005).   Positive perceptions play an important role in the coping process and it results in a better quality of life for the entire family and improves the child‟s prognosis (Tugade, 2011). It is therefore important for professionals to elicit and highlight positive responses from parents during their interaction with them.

5.4.4   Parents as partners and initiators of change.

Most of the parents understood and accepted their children‟s academic difficulties. Teachers can use this as a starting point to develop a good working relationship with the parents, in order to assist their children. Parents should be acknowledged as partners and experts and their views must be considered during decision making, especially regarding the future of their children‟s education (Englebrecht et al., 2005). The role of parents in identifying and addressing barriers to learning was acknowledged.   It is important that professionals listen to the concerns and suggestions of parents.   Parents sometimes offered solutions that they thought would help their children. They

wanted to have their expertise on their child recognised, feel valued and respected by services and to be involved in decision making. Family choice and decision making in services must be considered by stakeholders and service providers (Dunst, 2002).

5.4.5   Poverty

Poverty and financial constraints have been found to affect access to education. In this study, some parents could not afford private services that would have enabled them to access special education sooner. Some children were not admitted to schools because they could not afford the fees, which is unlawful, and the school management should be held accountable for this. There should be laws in place to bridge the access gap for the most marginalised sectors of the population, such as the poor and those with disabilities. An equity based approach to outcome in the allocation of resources to those most in need of services could reduce the existing inequalities. There should be laws, funding, infrastructure, services and programmes to meet the needs of the most marginalised (Ricter et al., 2012). Services for these families should be free or affordable (Janus et al., 2007).

5.4.6   Role of the community.

The community played a significant role in the lives of the parents. Many of them relied on these informal sources of support as they did not know where to go for help or formal assistance. Research findings have found informal support to be a more effective stress buffer than formal support (Dyson, 1997; Raina et al., 2004). Some parents have however, reported negative responses from the community to their children‟s disabilities. Parents could receive greater informational and emotional support from their communities and disability could be viewed more positively. Early learning and support for child development should not be restricted to services provided by centres but also include home and community based programmes (Ricter et al., 2012). The White Paper Six acknowledges working in partnership with the community to building effective schools. One of the suggestions was to provide training to community members to facilitate their inclusion in the support process. At present there are community workers who are trained to direct children to Early

Childhood Centres. More of these workers may be required to meet the needs of the community.

Empowering the community with knowledge about disability and related aspects could be valuable as this helps the child too (Samuel et al., 2012). The community must also be made aware of the educational rights of their children and the policies governing this. If individuals know their rights they are empowered to claim them. Civil society plays an important role in promoting the right to education and holding the State accountable for it"s obligations. It could help if people advocate and campaign for the full implementation of the right to education, holding the state accountable. Parents should monitor the implementation of the right to education and report on deprivations and violations of the law. Solutions must be found where there are violations of the right to education.

5.4.7   The expansion of Early Childhood Development Programmes.

It was recommended that a broader definition of Early Childhood Development programmes was needed to cover all aspects of children"s development, from conception to the foundation phase of schooling. The services offered by the programme must be aimed at preventing and timeously identifying disability and subsequently referring children and their families for assistance. No screening programmes have been developed and implemented to identify disorders, from birth to three years, or management programmes once a disability has been identified, an important gap that must be closed. There should be more support for children under five years of age. Early Childhood Development services in South Africa requires strong leadership, inter-sectoral vision, commitment, action and a proper funding model to attain the desired goals. High level authorization and a well-resourced central agency or mechanism is required to successfully implement the key strategies of such programmes. A basic "package of service" must be urgently developed to reach vulnerable children. Early Childhood Development programs can facilitate a child"s transition to special education, should this need arise, with proper training being one of the dimensions of a good quality programme (Britto et al., 2011).

Health care workers therefore need to be trained to identify typical and atypical child development and to make timeous and appropriate referrals for assistance to parents and their children (Sebastian, Khan, & Roychowdhury, 2010). An early intervention programme should comprise resource and social supports as well as information and services. This study revealed that many parents and teachers did not know how and where to access special education. Improvements in access to and quality of Early Childhood Development programmes must be sought. Thorough provision must be made for children with disabilities (Ricter et al., 2012).

5.4.8   The District Based Support Team.

The role of the District Based Support Team appears to be an important source of assistance in meeting parent and child needs. Could this team be the base camp that the traveller (parent) needs to communicate with (strength through connection) or return to for guidance or just re-assurance should the path become long, rocky or full of obstacles? Parents reported many negative emotional experiences that contributed to their stress, and encountered problems with services and not being able to access education. Parents and their children endured inappropriate interaction and comments at a formal and informal level. Providing information and support to the relevant individuals could reduce the negative reactions of others to disability. The District Based Support Team could be strengthened to provide the necessary services to the parents and children. Many of the parents" unmet needs can be accessed from the DBST if it is adequately resourced. The White Paper Six states that the key purpose of this team is to support all children, educators and the system as a whole so that the full range of learning needs are met (Department of Education, 2001). It is also responsible for the early identification of barriers to learning and intervention.

At the first signs of academic difficulties it would be advisable for educators to refer these children to the District Education Office for further evaluation. The Institution Level Support Team must make the necessary

referrals to the District Based Support Team so that the parents and their children can receive the help that they need. Timeous follow up and appropriate action is vital. It needs to be determined to what extent this is being achieved. A monitoring tool would be useful to keep track of progress in this regard. In order to assist districts to fulfil their responsibilities the Department of Education has developed a policy on the Organisation, Roles and Responsibilities of education districts (Department of Education, 2008a). It is hoped that this initiative would enable children to access education quicker.

5.4.9   Teacher training.

Some teachers were reported to have been unsupportive and impatient toward their children. Research has indicated that teachers can be exposed to highly stressful situations that can compromise their relationships with the children whom they teach (Jennings & Greenberg, 2009). It is advised that recommendations be instituted to improve teachers" attitudes towards disabled children (Cook, 2001). There appears to be a need for increased teacher knowledge, sensitivity and empathic understanding within the realm of childhood disability. The training that they have received may not suit the new composition of the classroom needs, and they also feel that they have not been adequately trained for teaching in an inclusive environments (Hardin & Hardin, 2002). Insufficient teacher knowledge in the field of special needs and education can delay children"s access to special education. In an effort to address the need to include children with disabilities, the Ministry of Education compiled the White Paper Six which is a policy document that addresses special education and education of learners with disabilities (Department of Education, 2001). The role of educators in identifying and addressing barriers to learning was also highlighted. It is the responsibility of the education system to ensure that teachers in mainstream schools are trained and given the necessary resources to undertake their tasks. In the Education White Paper Six, support is described as the provision of training, mentoring, monitoring, consultation and collaboration. To what extent this is being achieved and how it can be improved should be determined periodically by the relevant stakeholders.

Teacher training must be reviewed so that teachers can be trained to determine the learning needs of individual children and adapt their learning programmes, teaching techniques and materials accordingly. Pre-service teacher-training programmes must be adapted to include special needs knowledge and the existing cadre of teachers need to be provided with the necessary skills to cope with a changing education system (McConkey & Bradley, 2010). Where an accurate assessment of a child"s learning difficulties need to be made the skills of specialists should be accessed. Teachers can benefit from the help of speech therapists and psychologists (McConkey, 2007). Therapists can assess and support children with communication disorders and collaborate with teachers in planning appropriate and meaningful learning programmes for all learners, not just in the context of special education (Kathard et al., 2011). The employment of more speech therapists in the Department of Basic Education can provide systemic support in language and literacy assessment and development in an effort to improve learning outcomes. The psychological referral service provides an essential mechanism to assist children with ID and scholastic problems and place them appropriately in special schools. These services should be made available to children as soon as the need arises so that transition to special school is made easier and quicker. Considering that these services are not adequate, development of secondary care-level community mental health services should be prioritised. Also, people responsible for service development need to be much more effective in the way they use formal and informal resources that are available in the community. Specialist staff should be used as supervisors rather than as clinicians (Saraceno et al., 2007).

5. 4. 10   Teacher-pupil ratio.

A large number of pupils was cited as an inhibiting factor in the mainstream schools. Urban schools have become oversubscribed as children have moved from the township schools to the urban schools in search of a better education. The teacher-pupil ratio of schools needs to be reviewed in an attempt to possibly reducing class sizes. In this way the needs of children with disabilities could be met.

5. 4. 11 Use of state hospitals to provide comprehensive services.

This study revealed that many parents could not afford private service providers and sought the services of the state health system. In most countries governments implement Early Childhood Development services through national health systems. Such programmes are based on the premise that, health care systems have the potential to reach all young children (Independent Evaluation Group, 2011). The South African National Department of Health has committed itself to restructuring and improving primary healthcare as a precursor to the planned implementation of National Health Insurance. There has, however, been little improvement in primary healthcare (le Roux & Couper, 2015). The reason proposed for this situation is that the role of a well-resourced and well-functioning district hospital as an essential part of the delivery of primary healthcare services has not been given much attention. Also, in most health districts the management and organization of the primary healthcare clinics has been separated from that of district hospitals. District hospitals need to be strengthened and fully resourced in order to meet the needs of parents and their children. Feedback and communication between district hospitals and clinics needs to improve and skills and resources must be shared to improve clinic and community care (le Roux & Couper, 2015).

5.4.12 Synergy among different departments to yield better outcomes

The multidimensional features of Early Childhood Development (i.e. health, protection welfare and education) have been highlighted. In South Africa the Department of Health prioritizes child survival and physical well-being, and the Department of Education focuses on schooling. Inter-sectoral collaboration is advised in an attempt to yield expanded service delivery, cost saving through shared resources and more efficient delivery of services (Ricter et al., 2012). A unifying framework by promoting greater synergy between the various departments has been suggested, in order to generate greater societal benefits, which could result in better outcomes for children accessing services and education (Shonkoff et al., 2012). Team members should be in frequent contact with one another, work co-operatively with the parents and make decisions in the best interest of the child (Bayhan & Firat Sipal, 2011).

5.4.13   Professionals must care enough

Meeting the educational needs of children require caring individuals, not just a substantial budget. It is important that all professionals who are involved in the lives of children act in their best developmental and educational interest. Some parents wished that their children could have received assistance much earlier as their children lost out on many years of education as they waited for placement in a special school. Early intervention is important for children with cognitive disabilities because of its relationship to optimal cognitive development (Bayhan & Firat Sipal, 2011). This study showed that once children with special educational needs were placed in the appropriate learning environment, they experienced school more positively, were happy and they progressed and parental stress was also markedly reduced (Stiglbauer et al., 2013) . Therefore professionals and education officials need to work together to ensure that children with special needs are placed in the appropriate learning environment in the shortest possible time.

5.4.14   Accessing education.

Despite the fact that South Africa spends 18,5% of it"s annual budget on education the education system is still in a poor state of affairs. Over the past five years the education budget has doubled (Modisaotsile, 2012). The parents of the children in this study still experienced difficulties in accessing special education for their children, although legislation has been in place since 2001. One of the extrinsic barriers contributing to this appeared to lie within the education system itself. According to the National Education Policy Act 27 of 1996, ordinary public schools should admit learners with special educational needs, where this is reasonably practical (Department of Education, 2003). Many children were still turned away from schools and principals are violating education policy.   Others were deregistered and asked to find a school themselves and this action goes against policy, which violates the right of a child to basic education, as enshrined in the constitution of South Africa. Laws and policies are being repeatedly violated and there is no accountability for this, indicating a gap between policy and practice. Rights cannot only be recognised in law, there must be a plan in place and it must be implemented by the state.

Implementation strategies should include all possible means of delivery and progress must be tracked against targets (Ricter et al., 2012). It is important to examine the difficulties being faced at all levels and the possible reasons for non-compliance to laws and regulations. Eliminating problems at the different levels can make access to education easier for children.

Parents are generally not aware of their children‟s rights and do not question authority, as indicated by their children‟s names being placed on waiting lists indefinitely. Some of the reasons for non-admission provided by principals were a lack of teachers and classrooms, and a shortage of special schools. All reasons and factors relating to non-admission of children to school should be investigated by the Department of Education in order to reverse the situation. A directive from the highest level in education would provide clear procedures or guidelines regarding the admission of children with barriers to learning. The Department of Education should take appropriate steps towards the full realisation of the right to education to the maximum of it‟s available resources. It must be demonstrated that every effort is being made to improve access to education, even when resources are limited, and schools should respond to learner admissions in a uniform manner. There should be consequences for violating policy, and individuals should be held accountable for their actions or decisions, as this can make a difference to effective or efficient service delivery. Holders of public office and those in authority are accountable for their decisions and actions to the public, and must submit themselves to scrutiny if required. Their adherence to the principles of accountability and following an ethical code of conduct can result in better outcomes for parents and their children when accessing education. Being guided by ethics is an ongoing process that officials should be aware of in their daily decision making and execution of their duties (Raga & Taylor, 2005).

5.4.15 Gap between education policy and implementation.

This study revealed that education policies were not being implemented as they should have been. Policy is mainly a political enterprise that should ensure that appropriate services are available and resources are allocated to obtain these services. Greater political will is necessary for policy makers to

take action. Policy needs to be implemented to create social action and organize service delivery. How can greater implementation of policy be achieved in education? Structures that bridge policy and implementation are required. Greater monitoring and evaluation of policy is needed, with clear outcomes and performance indicators, with centres of collaboration being initiated as a possible solution. Audits (performance and financial) can be used as an evaluation method during monitoring, as this will enable accountability to be achieved (Jansen, van Oers, Kok, & de Vries, 2010).

Collaborative governance has been recommended as a strategy to improve making and implementation of policy. State and private service providers can work collectively to make decisions and establish laws and rules to enhance service delivery (Ansell & Gash, 2007). Stakeholders" level of commitment to collaboration is important to its success (Lynn, Crowther, & O' Hara, 2003). Building trust is also important (Imperial, 2005). Strong leadership is seen as a critical ingredient during this process, this being important for embracing, empowering and involving stakeholders, and for driving collaboration forward (Vangen & Huxham, 2003). Face-to-face dialogues between stakeholders can facilitate identifying opportunities for mutual gain, with each sector having arguments that can be used to defend their actions. Collaboration should combine the best of each sector in order to achieve value and quality improvement in education. During these meetings, issues can be explained and stakeholders can develop a shared understanding of what can be achieved collectively (Lynn et al., 2003). Discipline specific knowledge and professional jargon can inhibit the successful implementation of policy.

5.4.16 Education as an investment.

The importance of investing in human capacity such as education has been recognised as one of the major drivers of better economic welfare of a country as well as of poverty reduction (Jaramillo & Mingat, 2008). The year 2015 marks the deadline for achieving the „Education for All" and the Millennium Development Goals; however, there are still 131 million children of primary and lower secondary school age across the world, out of school. Marginalised groups such as girls and those with disabilities are still left behind and there is concern worldwide over the poor quality of education. Access to and quality of

education are important and this must be measurable and proved (Tikly & Barret, 2009). At the United Nations Sustainable Development Summit in 2015, world leaders put forward the 2030 Agenda for Sustainable Development which includes seventeen Sustainable Development Goals, one of them being quality education. A set of specific education and learning targets has been proposed and indicators are to be developed to monitor the progress of these targets. Greater transparency and accountability by States has been emphasized (Programme, 2015).

African countries such as South Africa have the opportunity to use the newly launched Sustainable Development Goals to continue to work on education for all children (United Nations Development Programme, 2015). Perhaps the Department of Education could emulate this plan of action on a smaller scale in an effort to improve access to education in South Africa. It is hoped that the government"s "Operation Phakisa" aimed at fast tracking improvements would make a positive difference to access and quality of education in South Africa. The educational rights of those children with ID and other disabilities could also be included in this initiative.

5.5 Study Limitations

The study had a number of limitations

- It is possible that the use of a different data gathering approach may have yielded a larger base of information, and could even have resulted in different results.

- Although focus groups of between four and eight participants were recommended, a larger focus group of more than four participants could have resulted in a more active and lively discussion as well as a greater variety of responses.
- Although an interpreter was present during the data collection process, some of the participants chose to speak in English and not in their home language. The language spoken by the researcher (English) could have influenced the

participants" choice of language. Their expressions of their experiences could have been compromised by their not speaking in their home language, thus affecting the quality of the data. During the process of translation of the data from isiZulu to English, information could have been lost or meaning may have been distorted.

- During the individual interviews, some participants may have felt intimidated by being alone with the interviewer, which could have negatively affected their responses. During the focus group discussions and the individual interviews, interviewer bias could have occurred in the manner in which the interviewer responded to the participants. This could have been in the form of comments made by the interviewer or body language. During the focus group discussion, factors could have hindered the open discussion although an attempt was made to make the setting conducive to frank and open discussion (Salkind, 2006). Participant responses could have been have been misconstrued or untruthful (Greeff, 2011).

- During the data collection stage of the study, the interviewer/facilitator was required to remember and retain what the participant had said, recall earlier statements, ask for elaboration and create links about what was said during different parts of the interview. Interpreting, by clarifying and extending the meanings of the participant" statements, was an important role of the interviewer. Although the facilitator/interviewer was trained in this regard, the degree to which this was achieved was questionable. Much data could have been lost in this process, had it not been adequately covered by the facilitator/ interviewer.

- The data accumulated during the interviews provided evidence for the experiences being investigated. The evidence was the accounts that people gave of their experiences. Evidence related to human experience has certain limitations (Polkinghorne, 2005). Experience is not directly observable and the data thereof depends on the participant"s ability to reflect on their experiences and effectively communicate their interpretation of it through language. There

was the concern that the participants may not have been able to fully access their own thoughts or effectively communicate them. Furthermore did the question posed by the researcher actually capture the fullness of and variations within the experiences? The researcher attempted to address some of these concerns by the use of open-ended questions which could have facilitated the expression of the participant"s thoughts (Yates, 2004). The interviews were semi-structured and allowed the interviewer to probe areas of interest and follow the participant"s interests and concerns. It was important to note that self-reported evidence of the participant"s experiences may not have been mirrored reflections of their actual experiences. Inner experiences of people are not completely accessible. Their accounts of their experiences could have been influenced by factors such as language, gender, social class, race and ethnicity (Denzin & Lincoln, 1998). Their reflection on their experiences could have changed their experiences. Furthermore the research interview may not have been a clear window into the participants" experiences. It was the joint production of an account by the facilitator/interviewer and participant through the dynamic interaction between them (Alldred & Gillies, 2002). Therefore the participants" responses could have been shaped by the facilitator or interviewer depending on the information being probed.

- The translation of an experience into a „languaged" expression can further distance the two entities. Many researchers have questioned this interaction between the experience and it"s description in language (Wierzbicka, 1999). Despite the controversy surrounding the transforming of human life experiences into language, language is the primary medium used to access people"s experiences. However, the researcher was aware of certain issues related to the use of „languaged" expressions of experiences, one issue being the first language of the participant. The meaning of expressions provided by the participants whose first language differed from that of the facilitator or interviewer needed to be clarified. In this study, participants were allowed to speak in their home language which was either isiZulu or English. An interpreter was present. The translation of data from isiZulu to English could have distorted meaning, and the participants could have varied in their ability to explore experiences and to express them in language. Information and nuance

could have been lost when oral data was transcribed (Henning, van Rensburg, & Smit, 2004).

5.6 Implications for Future Research

This study provided some insight into the experiences of parents of children with communication disorders associated with ID. This information was, however, not substantial enough to act as a catalyst to effect changes that could benefit parents and their children with special educational needs. Further related research using a larger sample size could add to or support the findings of this study. It would be beneficial for all stakeholders in education to know why some schools are able to provide the necessary support to parents and their children and why some are not. Research in this area could shed light on the possible reasons for this and hopefully structures could be instituted in order to support parents and their children. More research could be conducted to determine exactly what barriers are preventing access to education. Perhaps the role of the Institution Level Support Team could be more closely examined. Since the District Based Support Team forms an important support base for schools, parents and their children, research should aim to determine how best this platform can be resourced so that it can provide the much needed service to those it should be serving. A well-resourced central agency is what is urgently needed and how this can be best achieved could be investigated.

5.7 Conclusion

This study explored the experiences of parents of children with communication disorders associated with intellectual disability, during their transition to special education. The experiences that were explored were the formal and informal support received and the positive and negative emotional experiences during the period of transition. The results indicated a variety of experiences. Parents related supportive and unsupportive experiences and negative and positive emotional experiences. Knowledge of the nature of the parents" experiences can lead to improved service delivery which could result in better outcomes for the parent, and the child with a communication disorder associated with intellectual disability. It is hoped that this information and the recommendations would serve to improve the services offered by all stakeholders to children with disabilities and their families. In

this way their experiences on their journey to access special education could be made easier and more pleasant.

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APPENDIX A

Request for consent from KwaZulu-Natal Department of Education

Discipline of Speech-Language
Pathology
University of KwaZulu-Natal
X54001
15 April 2014

The District Manager
The Superintendent Education Manager
Department of Education
KwaZulu-Natal

RE: Request for permission to conduct research with participants who are the parents of learners attending a public special school.

1. Request for names of parents from the school.

2. Use of the school premises to conduct parent interviews

I am conducting a research study for a Masters Degree in Communication Pathology (Speech-Language Pathology) through the University of KwaZulu-Natal. The aim of the study is to explore the experiences of parents of children with communication disorders associated with intellectual disability, during their transition to special education. Approximately 13 parents of children who were admitted to the school in 2012, 2013 or 2014 will be required to achieve the aims of the study. Their names are hereby requested. They would be contacted to determine whether they would like to participate in the main or pilot study. The identity of the school, the learners and their parents will remain confidential. A copy of the interview schedule will be attached.

I intend to obtain the research data by conducting two group discussions (four participants each) and the duration of this would be approximately 60 minutes each. Five individual interviews would be conducted. Each interview would be approximately 30 minutes long. These would be conducted on a Saturday morning, during the month of October. Permission has been obtained from University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee.

The data obtained from the parents will be audio recorded, transcribed, analysed, interpreted and reported on in this study. Information on the outcome of this study will be provided in the form of a feedback session at the school. It is hoped that this study would benefit the Department of Education, the children and their parents.

Yours sincerely   Research Supervisor
S. Laalje (Researcher)   Desiree John
031 207 1424   M. Speech Pathology (UP)
                                                           031 2607846

School Post Graduate Research Coordinator   Humanities and Social Sciences
Phindile Nene   Research Ethics Committee
(HSSREC)
031 2608280   Miss P. Ximba
                                                                    031 2603587

Reply:

I, the District Manager (Department of Education, KwaZulu-Natal):

 (Tick appropriate block)

Agree to ☐   Do not agree to ☐

1) The request for permission to conduct research with participants who are the parents of learners attending a public special school.
2) The release of names of parents as per request
3) The use of the school premises to conduct parent interviews

_____   _____

District Manager

Date: _____   Date: _____

APPENDIX B

Request for consent from the School Management Team and the School Governing Body

                                                    Discipline of Speech- Language
                                                    Pathology
                                                    University of KwaZulu-Natal
                                                    X54001
                                                    15 April 2014

School Management Team

School Governing Body

RE:

1. Request for permission to conduct research with participants who are the parents of learners attending a public special school.
2. Request for names of parents from the school.
3. Use of the school premises to conduct parent interviews

I am conducting a research study for a Masters Degree in Communication Pathology (Speech-Language Pathology) through the University of KwaZulu-Natal. The aim of the study is to explore the experiences of parents of children with communication disorders associated with intellectual disability. Approximately 13 parents of children who were admitted to the school in 2012, 2013 or 2014 will be required to achieve the aims of the pilot and main studies. Their names are hereby requested. They would be contacted to determine whether they would like to participate in this study. The identities of the school, learners and their parents will remain confidential. It is hoped that this study would benefit the learners and their parents and the Department of Education.

I intend to obtain the research data by conducting two group discussions (four participants each) and the duration of this would be approximately 60 minutes each. Five individual interviews would be conducted. Each interview would be approximately 30 minutes long. These would be conducted on a Saturday morning, during the month of October. Permission has been obtained from the University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee. I will ensure that the venue used for the interviews will be left neat and tidy. Should you have further queries you may contact the relevant individuals who are listed below.

The data obtained from the parents will be audio recorded, analysed, interpreted and reported on in this study. It is hoped that this study would benefit the learners and their parents. Information on the outcome of the study will be provided to all relevant individuals in the form of a feedback session at the school. Thank you for your consideration of this request.

Yours sincerely   Research Supervisor
S. Laalje (Researcher)   Desiree John
031 207 1424   M. Speech Pathology (UP)
                                                          031 2607846
School Post Graduate Research Coordinator   Humanities and Social Sciences
Phindile Nene   Research Ethics Committee
(HSSREC)
031 2608280   Miss P. Ximba
                                                          031 2603587

Reply:

The School Management Team and School Governing Body: (tick appropriate block)

Agree to [ ]   Do not agree
                                                 to [ ]

1) Request for permission to conduct research with participants who are the parents of learners attending a public special school.
2) Request for names of parents from the school.
3) Use of the school premises to conduct participant interviews.

_____

_____

SMT   SGB

Date: _____

Date:_____

SCHOOL STAMP

APPENDIX C. Request for parent participation in a research study

Discipline of Speech- Language Pathology

University of KwaZulu-Natal

X54001

2 May 2014

Dear Parent

RE: Request for participation in a research study

I am Sitha Laalje and I am conducting a research study for a Masters Degree in Communication Pathology through the University of KwaZulu-Natal. The aim of my study is to explore the experiences of parents of children with communication disorders, associated with intellectual disability, during their transition to special education. The information obtained from you will be audio recorded, analysed, interpreted and reported on in this study. It is hoped that the outcome of this study would benefit you as well as other parents, in respect of improved services.

I obtained your name from the administration officer at the school that your child attends. Permission for the study was granted by the Department of Education. Parents of children who were admitted to this school in 2012, 2013 or 2014 are required for this study. Please indicate if you would like to participate in this study. Should you agree to participate, a letter of information pertaining to the study will follow, as well as an informed consent form. Thank you for considering this request.

Reply: Please tick the appropriate box below

I would like to participate in this study and receive more information ☐

My name is _____ Contact number _____

I would not like to participate in this in this study ☐

Sign _____   Date _____

APPENDIX D. Letter of information for participant

Discipline of Speech- Language Pathology

University of KwaZulu-Natal

X54001

02 May 2014

Dear Parent

Re: Information about the study

I am Sitha Laalje, a speech therapist, and I am conducting a research study for a Masters Degree in Communication Pathology through the University of KwaZulu-Natal. The aim of my study is to explore the experiences of parents of children with communication disorders, associated with intellectual disability, during their transition to special education. The information obtained from you will be audio recorded, analysed, interpreted and reported on in this study. It is hoped that the outcome of this study would benefit you as well as other parents in respect of improved services. I obtained your name from the administration officer at the school that your child attends. Permission for the study was granted by the Department of Education. Parents of children who were admitted to this school in 2012, 2013 or 2014 are required for this study. Please read the information below.

"Letter of information" and "Informed consent form"

Should you agree to participate in this research study, you will be given a "Letter of Information" and an "Informed Consent Form" to read and sign. You may discuss the contents of this form with family and friends before you make a decision regarding participation. Please return the form within seven days or later if you require more time to make a decision. You will be requested to participate in a group discussion together with three other parents of children who attend the same school or in an individual interview. Thereafter you will be given a date on which to come to the school that your child attends. These discussions and individual interviews will be audio recorded. The duration of the group discussion would be approximately sixty minutes. The duration of the individual interview will be approximately thirty minutes.

Participation in this study is voluntary and you may withdraw from it at any stage and for any reason, without penalty. After the interview you will receive refreshments as well as R30 to assist you with the transport costs that you may have incurred to attend the interview. You will be invited to a feedback session to inform you about the outcome of the study.

The interview questions

The 3 questions during the group discussion and the interview will be:

1. *Most parents wish to find a good school for their child. Let's talk about how you found this school for your child?*
2. *How did you feel when you were looking for a school?*
3. *Tell us about any other experiences related to finding a school that we have not already spoken about.*

These questions do not have a right or wrong answer, and will be asked to seek your opinion. The researcher may ask you more questions should further information be required. You may choose not to answer any question that causes you discomfort. Should you require further support or counselling as a result of the interview, you will be referred to a registered parent counsellor within close proximity to the venue of the interview. The researcher will cover the cost of the first consultation. Should further consultations be required thereafter the participant will be expected to pay the costs thereof. You may request the help of an interpreter, should you prefer to speak in isiZulu and be asked the questions in that language. The information collected from you will be kept confidential and anonymous. Should an interpreter be present, she will be required to sign a "Declaration of Confidentiality" document before the interview. This will ensure that your information is kept confidential by the interpreter. Should you choose to participate in this study; the researcher will ensure that you will not be harmed in any way.

Recording, use and protection of information

The interviews will be audio recorded. The researcher will conduct the interview and take notes as required. The group discussion and the responses from the interview will be transcribed and analysed and used to compile a comprehensive report on the outcome of the study. The information that you provide will be combined with the

information provided by other parents. Accounts, events and quotations provided by you may be used in the final report that will be compiled, by the researcher, in the form of a Master"s Thesis. All the information that you provide will be kept in a locked cupboard for a period of five years. The written information will, thereafter, be shredded and destroyed.

Please read the above information carefully and consider the accompanying implications. If you would like more details about something mentioned here, or on any aspect not included here, please feel free to ask the researcher. Thank you for your time and interest shown in this study.

Yours sincerely   Research Supervisor

S. Laalje (Researcher)   Desiree John

031 207 1424   M. Speech Pathology (UP)

                                                              031 2607846

School Post Graduate Research Coordinator   Humanities and Social Sciences

Phindile Nene   Research Ethics Committee

031 2608280   Miss P. Ximba

                                                               031 2603587

Date: _____

APPENDIX E

Letter of informed consent for the participant

Declaration by Participant

Instruction: please tick either "Yes" or "No" to each of these statements.

Table 4. *Participant Responses to Informed Consent*

Consent statements	Yes	No
1. I hereby confirm that I understand the nature of this research study and the contents of this document.		
2. I agree to the audio recording of the group discussion or individual interview.		
3. I understand that I can withdraw from the study at any time, without penalty.		
4. I would like the assistance of an interpreter during the interview or group discussion.		
5. I would like to attend the feedback session, informing me about the outcome of the study.		
6. I agree to pay for any additional services that I may request, from a parent counsellor.		
7. I agree to take part in this study.		

Name of participant　　:

_____

Signature of participant　　:

_____

Dated　　　　　　　:

_____

Contact Information:

Telephone number　　: _____

 Address　　　　　　: _____

Home language　　　:_____

Name of researcher　　: _____

APPENDIX F
Requesting the services of an interpreter and the declaration of confidentiality

Discipline of Speech- Language Pathology

University of KwaZulu-Natal

X54001

02 May 2014

Dear Colleague

RE: Requesting your service as an interpreter

I am conducting a research study for a Masters Degree in Communication Pathology (Speech-Language Pathology) through the University of KwaZulu-Natal. The aim of the study is to explore the experiences of parents of children with communication disorders associated with intellectual disability, during their transition to special education.

I intend to obtain the research data by conducting focus group discussions and individual interviews with 13 parents and asking them a set of questions. Each focus group session would be approximately 60 minutes long and each individual interview would be approximately 30 minutes long. An interview schedule will be used. The interviews would be conducted on a Saturday morning, and I would like to commence on 02 May 2014 and end on 14 May2014. The information obtained from the parents will be audio recorded, analysed, interpreted and reported on in this study.

Some parents may prefer to speak in isiZulu. In this case, the services of an interpreter will be required. Your assistance is hereby requested. Should you agree to offer your services as an interpreter, you will be expected to sign a declaration of confidentiality. This will request that you keep the participant information confidential, in order to respect his/her privacy, consider certain ethical issues during the interview and follow certain guidelines and procedures during the focus group

discussions and the individual interviews, in order to ensure reliability and validity of the data. These will be explained to you, by the researcher. I thank you for considering this request.

Yours sincerely   Research Supervisor

S. Laalje (Researcher)   Desiree John

031 207 1424   M. Speech Pathology (UP)

                                                              031 2607846

School Post Graduate Research Coordinator   Humanities and Social Sciences

Phindile Nene   Research Ethics Committee

031 2608280   Miss P. Ximba

                                                              031 2603587

Declaration by Interpreter

I, _____ (name of interpreter) hereby

confirm that I understand the contents of this document and the nature of this study

and I agree to assist as an interpreter in this research study.

I agree to:

1) To keep all the participant information confidential.

2) Respect the ethical issues involved in the research, as will be explained to me by the researcher

3) Follow certain guidelines and procedures during the interview, as advised by the researcher.

_____

_____

Signature of interpreter   Date

Witness _____

APPENDIX G

Interview Schedule

Biographical Data

Date: _____   Participant number

Place: _____   Age of learner: _____

Diagnosis of learner: _____

Date of admission to the school:_____

Participant"s First Language: _____

Relationship of Participant to Child: _____

Facilitators: _____   _____

Below is an outline of the questions that may be covered during the focus group discussions and individual interviews with the participants. These questions are intended to promote open and active focus group conversation amongst the participants. There will be three questions, and probe questions. The probes will be used to encourage participants to provide more detail, should this be lacking.

QUESTION 1: Most parents wish to find a good school for their child. Let"s talk about how you found this school for your child?

Probe Questions

1.1.   Tell us about the places that you went to when you were looking for a school?

1.2.   Tell us about the people that you met in those places?

1.3.   Tell us about what they told you about finding a school?

QUESTION 2: How did you feel when you were looking for a school?

Probe Questions

1.   Tell us about the positive (good) feelings?

2.   Tell us about the negative (not so good) feelings?

QUESTION 3:

Tell us about any other experiences related to finding a school that we have not already spoken about?

APPENDIX H

Important Considerations for the focus group discussions and the individual interviews

There are some important interviewer qualities that could have lead to good interviews and that produce rich information (Kvale, 1996). The interviewer should have been knowledgeable about the interview theme and been able to conduct an informed conversation about the topic. Structuring of the interview was important (introduce a purpose for the interview, outlines the procedures, rounds off the interview). The interviewer could have posed clear, simple, easy and short questions and not used academic language. Double- barrelled questions should have been avoided (Berg, 2009). A gentle manner by the interviewer would have allowed participants to finish what they were saying and let them proceed at their own rate of thinking and speaking. The interviewer could have listened actively to the content of what was being said and sought to understand the many nuances of meaning in an answer. It was important to have been sensitive to the feelings of the participant. Listening to the conversation with an open mind could have allowed new aspects, which may have been important to the participant, to be introduced and followed-up. The interviewer could steer and control the course of the interview and not be afraid of interrupting digressions. It was necessary to be critical as this tested the reliability and validity of what the participant said. The interviewer could have attempted to remember and retain what the participant had said, recalled earlier statements, asked for elaboration and created links about what was said during different parts of the interview. Interpreting, by clarifying and extending the meanings of the participant" statements, was an important role of the interviewer.

APPENDIX I

Types of questions and techniques used for the focus group discussions and the individual interviews

There were three types of questions that were asked: Those were the initiating, probe and follow-up questions.

1. The initiating questions began with: "*Let's talk about...?*; *How did you feel...?* or *Tell us about...*."

2. The probes that could have been used were clarifications ("*What do you mean by that?*"), justifications ("*Why did you say that?*"), requesting examples to make things clear ("*Can you think of a specific instance when you felt like that?*"), extensions ("*Can you tell me more about that?; Can you remember anything else about that; What happened then?*"), affective probes ("*How did that make you feel?*") and a few echoes (repetition of participant"s response).

3. Follow-up questions developed spontaneously as the interview progressed. The participant"s answers could have been extended through a curious, persistent and a critical attitude of the interviewer (Kvale, 1996). This could have been done through direct questioning of what was just said. Also a nod or a *("mm")* would have indicated to the participant to go on with the description. Structuring questions could also have been used. As the interviewer was responsible for the course of the interview, she could have politely indicated when a theme was exhausted by saying, "*I would now like to introduce another question…*"

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