PARENTS' EXPERIENCES OF SUPPORT IN THE PROCESS OF UNDERSTANDING LEARNERS WITH INTELLECTUAL CHALLENGES

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PARENTS' EXPERIENCES OF SUPPORT IN THE PROCESS OF UNDERSTANDING LEARNERS WITH INTELLECTUAL CHALLENGES

by

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DECLARATION OF ORIGINALITY

I, Bernard Lushozi, student number 28623003, declare that the dissertation entitled: *Parents' experiences of support in the process of understanding learners with intellectual challenges*, is my own work and that all the sources used or quoted have been indicated and acknowledged by means of complete reference.

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Mr Bernard Lushozi Date:

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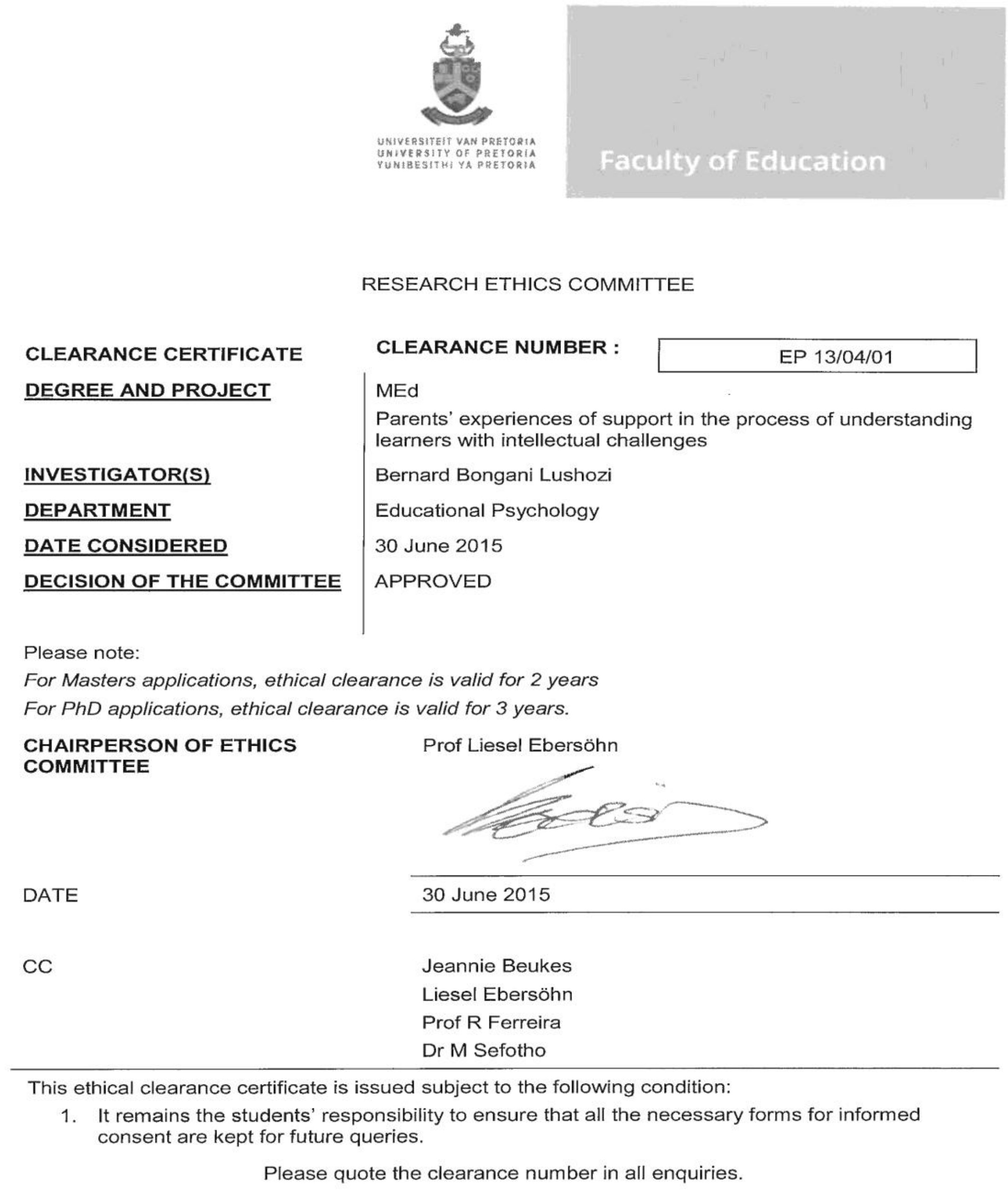

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CLEARANCE CERTIFICATE	**CLEARANCE NUMBER :** EP 13/04/01
DEGREE AND PROJECT	MEd Parents' experiences of support in the process of understanding learners with intellectual challenges
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ABSTRACT

This dissertation is about “Parents’ Experiences of Support in The Process of Understanding Learners with Intellectual Challenges”. The purpose of the study was to explore and describe the processes of support rendered to the parents of learners who are facing intellectual challenges and how these processes are experienced and understood by parents. A multi-case study design was used in this study. Data were collected via focus group discussions which took place in four schools that cater for learners with special education needs in Soweto. Thirty five (35) parents of learners who have been diagnosed with intellectual challenges participated in the study. Data were analysed using thematic data analysis method. The themes identified from focus group discussions were: 1, the process of diagnosis and referral of children who face intellectual challenges; 2, support received by parents and 3, ongoing needs for additional support. Although the views of fathers’ experiences of support were to some degree limited, the results of this study may contribute to establishing a framework for coordinated support from various agencies involved in supporting parents of learners who face intellectual challenges.

Key words*:*

- intellectual challenges
- ongoing needs for support
- initial identification
- diagnosis and referrals

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CHAPTER 1
GENERAL ORIENTATION OF THE STUDY

1.1 PRELUDE TO THE STUDY

Since time immemorial Africans had implemented helpful models of support, guidance and caring for others. The African model of support is characterised by a conscious emphasis on people, their dignity, collectiveness, solidarity, teamwork, interdependency and brotherhood of mankind called ubuntu, which embraces the spirit of hospitality, caring about others, the willingness to go an extra mile for the sake of another, believing that a person is a person through other persons, and/or that an injury to one is an injury to all (Mbigi, 2000; Letseka, 2013). At this level, being in need of experiencing support, by parents of learners who are facing intellectual challenges seem to be a logical, expected and accepted part of life. Agencies or carers of individuals facing intellectual challenges are connected around such support needs, which generally give meaning to their lives and expertise (Letseka, 2013; Ebersöhn, Sefotho, Mampane, Loots, Omidire, Sherman & Nxumalo-Tsebe, 2014).

Ever since working as a principal at a school for learners with special educational needs, I have noticed that parents often show a lack of knowledge, understanding and insight into the nature and implication of intellectual challenges in relation to the academic development of their children. This made me wonder and question why such vital knowledge and information about children who are intellectually challenged is often lacking amongst the parents. In seeking an explanation, I considered our school's admission process. I also considered how learners are referred to our school from preschools, mainstream schools, and/or hospitals. These kinds of considerations provided the foundation to my point of departure for this study (Burke and Cigno, 2000).

The above described prelude represents my pre-conceived ideas about support, typically received by parents of learners who are facing intellectual challenges, specifically in Soweto, South Africa. My focus in this regional area relates to my experiences in the school where I am currently the principal. In essence, my personal frame of reference and my cultural biases are acknowledged and declared in this preface (Artiles, 1998).

1.2 CONCEPTUAL SETTING OF THE PROBLEM

This section provides an overview of the conceptual setting of the problem underlying the research, the contextual background against which the research study was conducted and the problem statement. Research and personal experience have demonstrated that the support needs of parents of learners who are facing intellectual challenges exist within networks of interacting relationships with e.g. family members, friends, educators, caregivers, professionals and other agents that form an identifiable system around intellectual challenges (Cavkaytar, Ardic, Özbey, Sönmez, Özdemir & Akso, 2010; Hassal, Rose & McDonald, 2005).

However, the primary support system for individuals with intellectual challenges remains close family members, especially parents (McDaniel & Pisani, 2012). To this end, both the United Nations Declaration on the rights of the child (United Nations, 1959), and the United Nations Convention on the Rights of the Child (United Nations, 1989) emphasize that families are the most important setting for child rearing. This implies that family members of children who are facing intellectual challenges can provide a significant support system in meeting the needs of their children, thereby forming their children’s first and immediate support network.

This idea of parents being responsible to support their children highlights the need for a secondary support system that could in turn provide the necessary protection, to parents who are also in need of support. Parents generally need assistance in the education of their children and promoting the welfare of children at school and at home. In this regard, the importance of involving parents in the education of learners who are facing intellectual challenges is widely encouraged to ensure that families can fulfil their obligations towards their children’s growth (National Center on Secondary Education and Transition, 2007). On a broader level, governments are generally required to also do all in their power in ensuring that the economic, social and cultural rights of children are respected. For families of children who are facing intellectual challenges, the United Nations (1994) has listed a number of services that governments could provide including information, counselling and parent support groups (Beirne-Smith, Patton &Kim, 2006).

In South Africa the right to a support system is reinforced in the disability policy guideline (2009), in the sections entitled Roles and Responsibilities. According to this policy, support services provided to families of people who are facing intellectual challenges must include training on managing intellectual challenges, providing advice, and counselling services. Furthermore, Molteno (2006) states that Van Wyk’s report in 1967, was a milestone in the education of children with intellectual challenges in South Africa. This report advocated that children with an Intelligence Quotient (IQ) below 50 were entitled to state-supported training if they were able to benefit from it (Molteno, 2006). After publication of the report, the classification of children with intellectual challenges as educable, trainable and uneducable/untrainable came into common usage. In South Africa, laws and policies exist for the benefit of people with disabilities regarding their right to support systems. These policies are namely the Constitution of Republic of South Africa, Act 108 of 1996; Office of the Deputy President, White Paper on an Integrated National Disability Strategy (1997), and the Department of Education’s White Paper 6 on Special Needs Education (2001).

The Department of Education’s Gauteng Education (Act 6 of 1995) defines special education as education of a specialized nature provided to address the needs of learners who cannot benefit from the teaching provided in the course of ordinary education but who require specialized education to facilitate their adaptation in the community. This includes the provision of support, guidance, and counselling to the parents of such learners. Interpretation of this act as stipulated by Pillay and Proudlock (2000) indicate that the provision of the act requires that the parents of learners who are facing intellectual challenges must be provided with training on how to manage their children’s intellectual challenges in order to understand the needs and abilities of the children (Pillay & Proudlock, 2000). This has a bearing on South African’s government’s obligation to provide the necessary support to parents of children who are facing intellectual challenges.

However, most practitioners who have studied the phenomenon of support of the parents of learners who are facing intellectual challenges agree that the problems faced by these parents are intensive, complex and multi-dimensional in nature (Rao, 2008; Kumar, Khaique, Prakash & Sahay, 2013), thus making their parental tasks of rendering support to their children difficult. Hudson, Mathews, Gavidia-Paine, Cameron, Mildon, Radler and Nankervis (2003) reiterate that there is a clear need for families to receive support in managing any challenging behaviors their children might display. Ziolko (1991), as well as Turnbull, Turnbull, Erwin, Soodak and Shogren (2011) confirm that certain parental support needs (such as counselling and guidance on children's developmental challenges, as well as understanding and acceptance of infants' differences from other children) are often not met and addressed during the diagnosis of a disabled child. Such parental support needs have a bearing towards parents' adjustment and rehabilitation progress which in turn may affect their strength and emotional reactions. McConkey, Truesdale-Kennedy, Chang, Jarrah and Shukri (2008) and Kumar et al. (2013) also assert that parents of learners who are facing intellectual challenges need additional support to enhance their ability to support and raise their children.

Support services aimed at addressing the needs of the parents of learners who are facing intellectual challenges in South Africa, followed the same general trends as in countries such as Taiwan, Taipei, China and Jordan (Zhou, 2000; McConkey et al., 2008). They proceeded from superstitious belief, neglect and limited support, to the development of interventional support strategies which focused primarily on learners who are facing intellectual challenges while overlooking the support needs of the parents and their broader families of these learners (Loebenstein, 2005; Charema, 2004; Zhou, 2000). The focus on learners only as a locus of pathology has effectively caused what Bateson (1979) calls 'ecological hubris' which implies that the entire environment in which a problem exists is ignored. Hoffman (1981) refers to this focus as 'to chop up the ecology' meaning that one focuses on one part of the system and ignores the environment from which the behaviour takes place. Such a focus does not typically consider the importance of parental participation in supporting and raising children who are facing intellectual challenges. Against this background, this study seeks to explore the processes of support, rendered to the parents of learners who are facing intellectual challenges and how these processes are experienced by parents. More specifically, the aim is to gain insight into parents' experiences of support as these experiences may in turn determine how they support their children

1.3 CONTEXTUALISATION AND FOCUS OF THE STUDY

The contextual background against which the research study was planned and conducted relates to the practical problem experienced at the special school where I work as a principal in Soweto, Gauteng Province in South Africa. The school was founded to cater for learners with special educational needs, more specifically intellectual challenges as defined by the American Psychiatric Association APA (2000); and AAIDD (2007). Accordingly, this implies the presence of a sub-average general intellectual functioning associated with or resulting in impairments in adaptive behaviour and the onset of the disability before the age of 18. A prerequisite for admission of learners at the school is referral letters focusing on the child's cognitive functionality and potential, diagnosed by relevant professionals.

At this level the school's admission team assumes that the professionals involved in supporting parents of learners who are facing intellectual challenges must have diagnosed, identified and confirmed the existence of intellectual challenges, the educability and intellectual development of the children who are referred. Lindsay (2003) and Reschly (1996) qualify this assumption, stating that paediatricians are expected to diagnose disabilities, developmental delays and atypical language, motor and behavior growth. Practitioners are also expected to know about special educational services offered by schools and to be familiar with the rights that children with disabilities have under state law.

According to the Department of Education National Strategy on Screening, Identification, Assessment and Support (2008), all learners entering Grade 1 are supposed to undergo an assessment of hearing, vision, speech and gross motor function. When delays or difficulties are identified, a learner needs to be referred for further assessment, treatment and remediation. When learners who are facing intellectual challenges are for example admitted at the school where I am the principal, a meeting between the parents of the child, a class teacher, occupational therapist (OT) and the social worker is convened as a pre-requisite for admission in order to confirm the diagnosis and special education needs.

An individual education plan (IEP) for the learner who faces intellectual challenges is then supposed to be drawn up and agreed upon. One of the primary reasons for drawing of an IEP is to ascertain whether or not the parents are aware of the presence of intellectual challenges their child faces and understand the implications thereof. When parents understand, a foundation is provided against which an IEP for the learner can be compiled. Such a plan is supposed to indicate on which level the learner is functioning (developmentally, academically and socially) and which level s/he can potentially reach (Vaughn, Bos & Schumm, 2000).For example, when a learner presents gross motor function delays such as the inability to tie shoelaces, or button up a shirt and zip up a trouser, a plan on how to support the learner based on the specific needs is drawn up, reflecting specific timeframes and relevant professionals to involve. It is against this background that schools' admission teams often assumes that the identification of intellectual disabilities has already been determined when learners enter the school.

Teachers may observe such learners to be lagging behind developmentally, even though they may look like other children. Even though these learners may speak well like any other children, they may show limited insight, struggle to remember a series of instructions and perform poorly on an academic level (Lemay, Herbert, Dewy & Innes, 2003). Although teachers may observe these challenges, the parents of learners at the school where I am principal often show limited knowledge about the nature and implications of the intellectual challenges their children face. They may have 'unrealistic or inappropriate' expectations about the academic development of the learners.

In this regard, parents often expect learners to be competent and proficient in fulfilling societal roles and performing in some learning areas. They may even compare these learners with their peers and siblings who attend mainstream schools. For example, parents may ask when their children will get promoted to higher grades as done in mainstream schools. Rutchick, Smith, Lopoo and Dusek (2009) reiterate that more often than not, parents of children who are facing intellectual challenges are dissatisfied with the slow progress of their children in learning new things. Some parents may as a result push even harder in attempting to force their children to learn quicker and try to be on par with other children.

Rutchick et al. (2009) warns that if parents have unrealistic expectations of what their children can achieve, it may lead to disappointment not only for them but also for the child who does not understand what s/he is doing wrong. Lindsay (2003); as well as Rutchick et al. (2009) asserts that such expectations and reactions of parents are completely normal; however, that it takes time, support and accurate information to understand what the child is able to do. These expectations may therefore have implications for parents' levels of knowledge and information about the intellectual challenges their children face. In addition, limited knowledge may also have implications in terms of the processes involved in diagnosis, and counselling rendered to parents who have recently learnt that their children are experiencing intellectual challenges.

In this regard, Douma, Dekker and Koot (2006) add that the parents of children who are facing intellectual challenges often experience high levels of stress as a result of uncertainty and limited knowledge. As such, the need for guidance and support clearly exists amongst these parents. In order to support such parents, information is required regarding the type of support they need and how their needs for support and guidance can be met. This study may provide insight in terms of these needs and preferences. With regards to support, Bell and Best (1986) argue that schools form part of a welfare network. It must however be acknowledged that schools form only one piece of an extended network of agencies potentially supporting and caring for parents of children who are facing intellectual challenges. The need therefore exists to extend this network to other stakeholders. Based on the contextual background I have provided, I set out to explore parents' experiences of support in the process of understanding intellectual challenges in four special schools in Soweto.

1.4 PROBLEM STATEMENT

Both the Department of Education's Gauteng Education (Act 6 of 1995) and the National Commission on Special Needs in Education and Training (NCSNET, 1997) stipulate and commit to the provision of guidance and support to the parents of learners who face intellectual challenges. In addition, the Department of Education's White Paper 6 on Special Needs Education (2001).proposes to spread educational support services in line with what learners facing intellectual challenges require. Despite the above mentioned legislation and policies, parents at the school where I work, seem to display a limited understanding, information and knowledge on the implications of intellectual challenges for the academic performance of their children.

Parents' entitlement to know their children's progress should be guided by knowledge and understanding of the presence of intellectual challenges and how this relates to the academic development of the child. If the reason why a learner is referred to a school for special needs is given to the parent when referring the child, then legislation is addressed to some extent in terms of provision of guidance and support to the parents of learners facing intellectual challenges. However, the extent to which this happens seems less than optimal. It is against this background that I identified the problem which this study seeks to explore as focusing on: the experiences of support, received by parents of learners who are facing intellectual challenges.

1.5 RESEARCH PURPOSE

The purpose of this study was to explore and describe the processes of support, rendered to the parents of learners who are facing intellectual challenges and how these processes of support are experienced by parents (Babbie, 2004; Mouton, 2001; Cohen, Manion &Morrison, 2005; Patton, 2002). Furthermore, I attempted to gain an in-depth understanding of the identification, diagnosis and referrals of learners who are facing intellectual challenges. I also aimed to obtain insight into the interactional relationships between parents of learners who are facing intellectual challenges and professionals involved in rendering support (Babbie, 2004; Patton, 2002).

The potential contribution of this study lies in the possibility of adding new knowledge to literature on parents' needs for support from their point of view. Furthermore, the advantages and weaknesses during the processes of support may be highlighted. A framework for coordinated support could subsequently be suggested based on the various roles that agencies fulfil in the identification, diagnosis and referrals of learners with intellectual challenges, in order to support parents more sufficiently. From a policy perspective, such a framework could potentially inform the implementation of Individual Education Programs (IEP's) and provide guidelines on formalising admission policies at schools for learners with special needs, specifically in terms of learners who face intellectual challenges.

1.6 RESEARCH QUESTIONS

Against the background of the previous section, and the statement of the problem, I was guided by the following primary research question:

> *How do parents of learners who are facing intellectual challenges experience support services offered to them in schools in Soweto?*

In addressing the primary research question, the following secondary questions were explored:

- Which processes are involved in the identification, diagnosis and referral of learners with intellectual challenges?
- What are parents' levels of knowledge and understanding of intellectual challenges, including the implications in terms of academic development?
- How do support services affect parents' perceptions and expectations about the academic development of their children who face intellectual challenges?
- What is the nature of interactional relationships between parents and professionals involved in supporting parents of learners who are facing intellectual challenges in schools in Soweto?

- How are the roles of various agencies involved in the diagnosis and referral of children who face intellectual challenges synchronized to effectively support parents?

1.7 CLARIFICATION OF KEY CONCEPTS

In this section I explain the key concepts relied on in this study.

1.7.1 PARENTS OF LEARNERS WHO ARE INTELLECTUALLY CHALLENGED

A parent is a person with parental and legal responsibility to care for and raise a child (Case, 2000). According to Wadlington (1990, p. 2), “in both social and legal realms, parents are generally recognized as persons who have primary authority in all aspects of child-rearing.”Such authority is based on the belief that parents are in the position to know how and to care for their children’s needs (Harris, Waldrop & Waldrop, 1990). Throughout this study ‘parents of learners who are intellectually challenged’ refer to people who care for children facing intellectual challenges. This includes adoptive parents, foster parents and care workers in residential care settings.

1.7.2 LEARNERS WHO ARE INTELLECTUALLY CHALLENGED

The NCSNET/NCESS report (Department of Education, 1997:149) describes learners as ‘…all learners ranging from early childhood education through adult education’. Throughout this study ‘Learners who are intellectually challenged’ relate to any learner who has been identified as facing an intellectual challenge, implying the presence of a sub-average general intellectual functioning associated with or resulting in impairments in adaptive behaviour, and the onset of the disability before the age of 18 (APA, 2000).

The level of intellectual challenges can range from mild to profound. A person with an intellectual disability may:

- experience difficulty with expressive and receptive language;
- display physical disability;

- have difficulty in learning and concentrating;
- display behaviour that would appear to be inappropriate;
- be unable to read or write;
- be unable to live independently;
- experience difficulty to participate in group settings (APA, 2000).

Since the terminology used to describe the lower end of the range of intellectual and cognitive abilities has changed over time, most theorists (Lomofsky & Skuy, 2001; Stakes & Hornby, 2000; Steenkamp & Steenkamp, 2010) prefer the term intellectual disability as they believe that this term is more specific, as opposed to mental disability that could include a variety of mental states. In this study I use the term ‘intellectual challenges’ to refer to learners at the lower end of the range of intellectual and cognitive abilities (IQ scores from 20-34). I prefer the concept ‘challenges’ as opposed to ‘disability’ since I believe the latter to be disabling whereas the former represent a more positive way of stating what these learners experience. As such the use of the word ‘challenges’ implies hope as opposed to hopelessness implied by terms such as ‘disability’ (Twain, 2006).

1.7.3 SUPPORT TO PARENTS OF LEARNERS WHO ARE FACING INTELLECTUAL CHALLENGES

The open File on Inclusive Education by UNESCO (2001:71) indicates that support ‘includes everything that enables learners to learn. It particularly includes those resources which supplement what the ordinary class teacher can provide’. In support, the Department of Education Draft Guidelines on the implementation of Inclusive Education (2002, 2005) describe support as involving enhanced facilitation to learning through interaction with various support providers. This implies that support service should provide support that covers all areas of development and adaptation through various professionals and agencies involved in addressing learning barriers.

Donald, Lazarus and Lolwana (2002:19) define support as help ‘from within schools as well as to schools in areas such as school, health, social work, psychological and learning support, speech and hearing and physio/occupational therapy; and from other community resources'. In this study, support to parents of learners who are intellectually challenged includes any intervention, mechanism, or strategy that may help and empower parents to know and understand the reality of their situation, for them to be able to help themselves and their children, thereby limiting the potentially negative effects of intellectual challenges (Integrated National Disability Strategy, 1997).

1.7.4 GUIDANCE TO PARENTS OF LEARNERS WHO ARE FACING INTELLECTUAL CHALLENGES

According to the United Kingdom Department for Education and Skills (2001) DfES, guidance refers to the advice on vocational or educational problems given to children *via* their parents. It involves provision of impartial advice, information and support to all parents and/or care givers of children with intellectual challenges. The Oxford dictionary (2010) defines guidance as the process of helping, advising and giving information especially by an adult or someone with experience.

The National Committee for Education Support Services (1997) recommends that the new learning area of Life Orientation (LO), which includes life skills, should be taken as synonymous to guidance. LO provides various special services that are aimed at assisting people such as life skills, social skills, interactive skills, and educational information.

1.7.5 COUNSELLING PARENTS OF LEARNERS WITH INTELLECTUAL CHALLENGES

According to the American Counselling Association (2005) the term counselling implies a professional relationship that may empower diverse individuals, families, and groups to accomplish mental health, wellness, education, and career goals. The concepts support, guidance and counselling is used simultaneously in this study as these terms complement one another. Baker (1996) adds that guidance is only one part of the overall services provided by professional counselling. The goal in both cases is to give individuals the opportunity to see a variety of available options and then make a wise choice.

Guidance implies a process that is put into place at the time a choice has to be made, whereas counselling involves assistance when considering the various sides of a potential choice even before the choice is made or when the need exists to modify or reinforce such a choice. In essence, counselling is about helping, assisting, and giving direction and advice. Backenroth (2001) reiterates that guidance and counselling are of importance to parents when they lay the foundation while preparing and planning the future of a child with a disability. In this study, the concept counselling therefore implies a wide variety of approaches which share a common purpose of helping, assisting, giving direction and advice.

1.8 INTRODUCTION TO SELECTED PARADIGMS AND RESEARCH DESIGN

As a methodological paradigm, I followed a qualitative research approach, aligning with the aims of the study to discover meaning and understanding, rather than to verify truth, predict outcomes or present universal facts (Kaplan & Maxwell, 1994; Cohen, Manion & Morrison, 2005). Working from a qualitative mode of inquiry assisted me in exploring and describing the subjective experiences of the parents within a context they understand well. In addition, it provided me with the opportunity of gaining insight into multiple realities, experiences and interactions of individuals and groups (Neill, 2006; Patton, 2002).

Since the intention of this study was to explore and describe how the processes of support are experienced by parents of learners who are facing intellectual challenges, I relied on both socio-ecological and family systems theories as theoretical frameworks that guided me in undertaking the study (Bronfenbrenner, 1979, 1986; Becvar & Becvar, 2000). I found the unified model of ecological and family systems theories to be useful in identifying and allowing me to consider a wide range of relevant factors from which experiences of support take place. This collaboration has helped me to determine the roles played by the various interacting agencies involved in supporting parents of learners who are facing intellectual challenges (Bronfenbrenner, 1979, 1986; Becvar & Becvar, 2000).

As paradigm I relied on the interpretivism paradigm. This choice allowed me to interpret and understand parents' experiences of support from their perspectives

(Cohen et al., 2005). Since I entered the field with some sort of prior insight of the research context, being guided by interpretivist practice, I remained aware of my personal understanding of the phenomenon under study. Thus, I remained open to new knowledge throughout the study (Carson, Gilmore, Perry & Gronhaug, 2001; Black, 2006; Neuman, 2000).

I conducted the study by implementing a multiple case study design (Cohen et al., 2005) thus, I delved into a 'bounded system,' that is the case of parents of learners who are intellectually challenged in Soweto (Creswell, 2009) in order to produce a case description and case-based themes. I purposefully selected 35 parent participants specifically targeting a homogeneous sample of parents of learners who are intellectually challenged and attended at one of the four special schools in Soweto at the time of the study (Babbie, 2004; Maxwell 1996).

1.9 BRIEF OVERVIEW OF METHODOLOGICAL STRATEGIES

I conducted focus group interviews with parents of four schools for learners who are intellectually challenged in Soweto, one at each school (Goodson & Sikes, 2001). During focus group discussions I also observed the participants and group dynamics (Morgan, 1998).

I used field notes to record my observations and the behaviours, activities, events and other features of the participants, as well as the research settings (Burgess, 1996). Video and audio-recordings were used to supplement my field notes and prevent me from writing too much in the presence of the participants (Green, Camilli, Gregory, Elmore, Patricia, Skukauskaite, Audra, Grace & Elizabeth, 2006; Patton, 2002).

Following data collection, I conducted thematic data analysis employing Krueger's (1994) 'framework analysis' as described by Ritchie and Spencer (1994). For this purpose, I followed the following five key stages: familiarization with the data; identification of a thematic framework, indexing, charting, mapping and interpretation. I subsequently identified themes, subthemes and categories thereby clustering units of meanings together in a relevant way (Cohen et al., 2005).In chapter 3, I elaborate on the data collection, documentation, analysis and interpretation procedures I employed.

1.10 TRUSTWORTHINESS OF THE STUDY

Attempting to ensure a rigorous study and findings, I strove to achieve the criteria of credibility, dependability, transferability, confirmability and authenticity. I adopted Lincoln and Guba's (1985), as well as Streubert and Carpenter's (1999) ideas of trustworthiness. As such, I acquainted myself with the nature of the selected research paradigm and adhered to the epistemological and ontological characteristics governing qualitative research (Bryman 2001). Strategies I employed include triangulation, and member checking thereby allowing participants to validate the reported findings.

In qualitative research, *credibility* seeks to establish the level of consistency and connection between the way researchers portray the views of the participants and the way they report their views (Mertens & McLaughlin, 2004; Patton, 2002). In striving towards credibility of this study I relied on triangulation and member checking in order to enhance the possibility of the findings representing the participants' views (Holloway & Wheeler, 2002).

Transferability within qualitative research can be associated with the positivistic concept of generalization, which indicates the similarity between sending and receiving contexts (Guba & Lincoln, 1989; Smaling, 2003). The findings of this study cannot be generalized from a statistical point of view (Barbour & Kitzinger, 1999; Krueger, 1988), therefore I provide rich deep descriptions of experiences of support, received by parents of learners who are intellectually challenged (Cohen et al., 2005; Patton, 2002). In this manner, the reader can determine to what extent the results can be transferred to similar contexts.

Dependability relates to reliability within quantitative research and entails the use of an inquiry audit, where reviewers examine both the process and the product of their research for consistency (Lincoln, 1995). In this study, I include a detailed audit trail and thorough report of the processes in an attempt to obtain dependability, thereby allowing future researchers to repeat the work yet not necessarily gaining the same findings.

Confirmability within qualitative research can be associated with objectivity in quantitative data. It refers to the degree to which a researcher demonstrates the neutrality of his/her research interpretations. In this study confirmability was supported through the provision of an audit trail that consists of raw data; field notes; and analysis notes (Patton, 1990).

Finally, qualitative research is *authentic* when it accurately reflects the reality and ideas of the participants and when it delves into the participants' experiences (Streubert & Carpenter, 1999). *Authenticity* in this study is ensured by my adherence to the epistemological and ontological characteristics governing qualitative research (Bryman, 2001; Willis, 2007).

1.11 ETHICAL CONSIDERATIONS

The nature of this study implied data collection with human beings in the public domain. As such, ethical guidelines were extremely important, especially those pertaining to individual rights of participation (Durrheim & Wassenaar, 2002; Leedy & Omrod, 2005). These considerations included gaining permission to proceed with the research from the Gauteng Department of Education and the four school principals of the participating schools (annexures 1 and 2). I also obtained informed consent (annexures 3 and 5) of all participants prior to the research by providing each participant with a letter explaining the purpose of the research. Throughout, I respected the principles of confidentiality and anonymity. In addition, participants were informed that they were free to withdraw from the study, if during the process of the study; they wished to do so (Durrheim & Wassenaar, 2002; Leedy & Omrod, 2005; Vivar, McQueen, Whyte & Armayor, 2007). I discuss the way in which I was guided by ethical principles in more detail in chapter 3.

1.12 OUTLINE OF THE CHAPTERS

Chapter 1 provides an overview of the conceptual setting of the problem underlying the research, the contextual background in which the research study was done, and the problem statement. I present the purpose of the study and formulate research questions before clarifying key concepts. I provide a brief overview of the selected paradigmatic approaches and methodological strategies, and refer to the trustworthiness of the study and ethical guidelines I followed.

Chapter 2 provides an overview of the historical perspectives, milestones and existing theory in the area of support rendered to parents of learners who are facing intellectual challenges. In presenting the literature review I completed, I focus on the identification, diagnosis and referrals of learners who are intellectually challenged; and parents' knowledge and understanding of the intellectual challenges their children face. I also discuss experiences of support received by parents during their interaction with professionals who diagnose their children, and support services available. Following on my introduction of the theoretical framework of the study in chapter 1, I explain the framework in more detail.

In chapter 3 I discuss the research design and methodology. I justify and explain the research design as well as the data collection, documentation and analysis strategies I selected. My rational for selecting these methods is specifically provided in terms of the research purpose and focus. I also explain and justify the quality criteria and ethical considerations I followed.

Chapter 4 presents the results of the study, based on the data I collected during the focus group discussions, which involved parents of learners who are intellectually challenged in four schools in Soweto. I discuss the results in terms of the themes and subthemes that I identified during qualitative data analysis. I support my discussion by including direct quotations and excerpts from the raw data.

In chapter 5 I relate the results I obtained to the existing literature against the aims and objectives of the study, in order to present the findings of the study. I present the findings according to the three main themes that emerged. I highlight correlations of the findings of the study with existing literature, contradictions, silences as well as new insights that stem from the study.

Chapter 6 provides a summary of the preceding chapters of the dissertation. I reflect on the research questions that framed this enquiry and discuss the limitations of the study. I conclude with recommendations for future research, training and practice as well as recommendations to the local government.

1.13 CONCLUSION

In chapter 1 I provided a prelude to the study I undertook and completed. After explaining the conceptual setting of the problem underlying the research, I discussed the contextual background of the study and presented the problem statement. Thereafter, I formulated the research purpose, and related research questions. This was followed by my clarification of key concepts, a brief overview of the selected paradigmatic approaches I followed and an outline of the chapters.

In chapter 2, I discuss existing literature with specific reference to the identification, diagnosis and referral of learners who are facing intellectual challenges. I also explore existing evidence on parents' knowledge and understanding of the intellectual challenges that children may face; their experiences of support they may receive in interaction with professionals who diagnose their children, and the support services that are available. I conclude the chapter by explaining the theoretical framework of the study in more detail, as background to the empirical study I undertook and describe in chapter 3.

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CHAPTER 2
LITERATURE REVIEW AND THEORETICAL PERSPECTIVE

2.1 INTRODUCTION

In Chapter 1, I provided a synopsis of the conceptual setting of the problem underlying this study, followed by the contextual background in which I conducted research. I presented the purpose of the study, the problem statement and formulated research questions before clarifying key concepts. I included an overview of the selected paradigmatic approaches and methodological strategies, and outlined the chapters that follow.

This chapter provides a literature review of the historical perspectives and milestones covered in the field of support rendered to parents of learners who face intellectual challenges. I commence with an overview of learners who face intellectual challenges, with specific focus on intellectual disability, its prevalence, classification, symptoms and implication for schooling. Next, I discuss processes of identification, and diagnosis of intellectual challenges followed by referrals of children facing such challenges. I then explore parents' knowledge about intellectual challenges relating to their typical reactions to the diagnosis, referrals, and challenges of raising children who are intellectually challenged. Finally I discuss parents' ongoing need for support referring to types of support required on an advance level and potential sources of support. I conclude the chapter by discussing the theoretical framework of the study.

2.2 CHILDREN FACING INTELLECTUAL CHALLENGES

Children facing intellectual challenges do not exist in a vacuum, but, within a system, being influenced by a range of factors including legislation and policies (i.e. White Paper 6; the Individual with Disability Act [IDEA], 2004). These policies require that learners who face intellectual challenges have access to the general education curriculum in regular classrooms, to the maximum extent possible, in order to meet developmental milestones. South Africans who face intellectual challenges still confront major barriers to equality of rights. One significant barrier is the public's misunderstanding and misperception about intellectual disability (Office of the Deputy President, White Paper on an Integrated National Disability Strategy, 1997).

2.2.1 THE CONCEPT OF INTELLECTUAL CHALLENGE

Intellectual challenge is conceptualized as a developmental disorder manifested before the age of 18, and is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and adaptive behaviour (American Academy of Child and Adolescent Psychiatry (AACAP) (2007); Diagnostic and Statistical Manual (DSM-5), (2013); American Psychiatric Association (APA) (2000). To this end, the DSM-5, (2013) and APA, (2013) lists the three main criteria for intellectual disabilities as follows:

- Significant limitations in intellectual functioning (mental abilities)
- Significant limitations in adaptive behaviour (conceptual skills, social skills, and practical life skills)
- The problems begin before the age of 18.

Throughout this study and except where a direct quotation warrants otherwise the term 'intellectual disability' is replaced by 'intellectual challenges' to refer to learners at the lower end of the range of intellectual and cognitive abilities (IQ scores from 20-34). This term does not have a negative connotation, labelling and disabling effect but rather classifies disability based on the level of support required (such as intermittent, limited, extensive or pervasive), whereas traditional classification of disability is based on the level of disability a person experiences (such as mild, moderate, severe or profound (American Association of Intellectual and Development Disabilities (NAIDD) (2002).

2.2.2 PREVALENCE OF INTELLECTUAL CHALLENGES

The Mental Health New understanding New Hope Report (World Health Organization, 2001b) estimates that the prevalence of intellectual challenges is between 1.3% of the population. Similarly, Harris, Waldrop and Waldrop (1990) report the prevalence of intellectual challenges as varying between 1% and 3%

globally. Among those facing intellectual challenges, mild, moderate, severe, and profound intellectual challenges affects about 85%, 10%, 4%, and 2% of the population, respectively.

Almost all studies report that the prevalence of intellectual challenges is higher among males than females, especially among children less than 15 years of age (Leornard & Wen, 2002). Most African countries cannot yet verify the number of people who face intellectual disabilities within their borders. The absence of reliable data in both the quantity and categories of disabilities in Africa presents a problem in terms of planning for education and the general welfare of these individuals (Gaad, 2004; Abosi, 1999). However, according to Hattingh, Harvey, Saayman and Van Jaarsveldt (1987), intellectual disability features as one of the most prevalent disabilities in South Africa. In addition, Department of Social Development, Department of Women Children and People with Disabilities and UNICEF (2012) and Statistic South Africa (2005) report that the number of children who face intellectual challenges is 68 550 and the prevalence in child population is 0, 4. Currently, according to Statistic South Africa (2005) the prevalence of intellectual disability in the South African population is 12%.

2.2.3 CLASSIFICATION

A significant change in terms of issues pertaining to the classification of intellectual challenges has marked history. Traditionally, classification systems revolved primarily around the range of IQ scores achieved by people who met the criteria of an IQ score being two or more standard deviations below the mean. The classification of intellectual challenges into differentiated groups based on the level of ability, aetiology, and the degree of severity has however changed over time. The traditional classification system was thus used to classify intellectual challenges, using terms such as moron (IQ 75-50), imbecile (IQ 50-25), and idiot (IQ less than 25) (Luckasson, 2002; Barlow & Durand, 1999). However, the AMMR and the American Psychiatric Association in its DSM-IV-TR (200) changed this by classifying intellectual challenges into the following categories: mild (IQ 70-75), moderate (IQ 55-40), severe (IQ 40-25), and profound (IQ below 25) (APA, 2000).

Even though the individual classification terms have changed, the range of scores related with categories have thus remained the same.

According to APA (2000), individuals with mild intellectual challenges have an IQ of 50 to 70. Donald et al. (1997), point out that 4, 5% of South African children face mild intellectual challenges. As such, learners who are presenting with mild challenges may not be identified before the first or second grade (Sadock & Sadock, 2001). According to Donald et al. (1997) individuals with moderate intellectual challenges in South Africa constitute 0.5%. People in this range can acquire language and have adequate communication skills; however, they are often unable to achieve academically (Sadock & Sadock, 2001). Individuals with severe intellectual challenges have an IQ of 20-34 and constitute 3% to 4% of this population. Communication skills are very basic, and these people might acquire little speech or no communication during early childhood. However, during school age people in this category can be trained in elementary self-care skills. Many people in this category may require safety supervision and supportive assistance. Profound intellectual challenges constitute a very small portion of people with intellectual challenges. Only 1% to 2% falls into this category (Beirne-Smith et al., 2006; Sadock & Sadock, 2001).

2.2.4 SYMPTOMS OF INDIVIDUALS FACING INTELLECTUAL CHALLENGES

Intellectual challenges are identified in terms of two key diagnostic criteria. The first criterion relates to limited mental ability, and is measured by IQ score. Severely limited mental abilities cause many problems, such as difficulty to learn, difficulty to make wise decisions and using good judgment. It is not easy to solve such resulting in people being vulnerable to victimisation (Reynolds, Zupanick & Dombeck, 2011).

The second diagnostic criterion relates to deficient adaptive functioning. Adaptive functioning implies certain skills needed to live independently in a safe and socially responsible manner. Possible signs of intellectual challenges according to Reynolds et al. (2011) include:

- delayed development such as sitting, crawling, standing, walking and talking;

- persistence of childlike behaviour, possibly demonstrated in speaking style;
- trouble in understanding social rules such as taking turns and/or waiting in line or in a queue;
- failure to appreciate and avoid dangerous situations such as playing in the street, or touching a hot plate stove;
- difficulty in learning new information despite significant effort and repetition;
- difficulty in learning new skills despite significant practice;
- difficulty in solving ordinary, simple problems;
- trouble to remember things and meeting educational demands,
- excessive behavioural problems such as impulsivity and low frustration tolerance.

According to Hurley (2008), intellectual challenges have been associated with higher rates of conduct problems, social withdrawal, and irritable mood. The individual may engage in externalizing behaviours when distressed. People facing intellectual challenges generally possess limited range of behaviours and may therefore react to emotional issues through their only source of communication, frequently with changes in behaviour. Individuals facing mild intellectual challenges often present themselves in the same way as the general population and usually have adequate verbal skills to report symptoms for appropriate diagnostic work. However, many people facing intellectual challenges have a limited behavioural repertoire and lack communication skills, resulting in symptoms taking the form of behavioural reactions (Hurley, 2008).

2.2.5 DIAGNOSIS AND IDENTIFICATION OF INTELLECTUAL CHALLENGES

According to Donna, Daily, Holly, Ardinger, Grace and Holmes (2000) the signs and symptoms of intellectual challenges are behavioural, in nature, with many children facing this challenge not appearing to be afflicted with such behaviour. As such, mild intellectual challenges (IQ 50-69) may not be easy to observe, and may not be identified until children start formal schooling. Taub (2006) reiterates that not all children facing intellectual challenges enter the education system already identified as having intellectual disabilities. What emerges here is that some learners' support needs may not become noticeable until sometime after they have started formal schooling (Taub, 2006). If not already determined before entering school, identification of a learner facing intellectual disabilities in mainstream schools can therefore often occur late or not at all (UNCEF, 2012); However, moderate intellectual challenges (IQ 35-49) are apparent within the first years of life. Speech delays are particularly common signs. People facing severe and profound challenges need more intensive support and supervision throughout their entire lives. Luckasson (2002) adds that in terms of diagnosis, definitions of intellectual challenges maintain a developmental perspective. As such, an intellectual challenge is considered a developmental disability, because of its onset during the developmental period (before the age 18). It can only be diagnosed if the limitations in human functioning manifest during the developmental period. The diagnosis of intellectual challenges cannot be made solely based upon an IQ score. As such, during diagnosis and classification, limitations in adaptive behavior should also be considered. Adaptive behavior is defined as the collection of conceptual, social, and practical skills that have been learned by people in order to function in their everyday lives (Luckasson, 2002).

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders DSM-IV (2004), three criteria must be met for a diagnosis of intellectual challenges. These are: deficit in general mental abilities, significant limitations in one or more areas of adaptive behaviour across multiple environments (as measured by an adaptive behavior rating scale, i.e. communication, self-help skills, interpersonal skills, and more), and evidence that the limitations became apparent during childhood or adolescence. In general, people with intellectual challenges have an IQ below 70, but clinical discretion may be necessary for individuals who have a somewhat higher IQ but severe impairment in adaptive functioning. The three defining elements must be present for a diagnosis to occur.

In 2008, the Department of Education in South Africa launched the National Strategy on screening, identification, assessment and support. All learners entering Grade 1 are supposed to undergo an assessment of hearing, vision, speech and gross motor function and when delays or difficulties are identified, a learner should be referred for further assessment, treatment and remediation. However, because intellectual challenges are classified as developmental disorder and as such can only manifest behaviourally, identification of intellectual challenges are seldom determined before entering school, often occurring late or not at all (National Strategy on screening, identification, assessment and support, 2008). Furthermore, information on children in Early Child Development (ECD) does not include children with disabilities. Yet, early childhood educators are being trained on strategies for early identification and intervention (United Nation Convention on the Right of Persons with Disabilities (UNCRPD, 2012).

2.2.6 TREATMENT OF INTELLECTUAL CHALLENGES

Most scholars who have studied the phenomenon of intellectual challenges agree that there is no treatment for this developmental disorder. However, despite the lack of therapy, much can still be done to assist both the affected person and his/her family to accept and adapt to the condition, limit secondary disabilities, optimize functional abilities and family life and plan for the future (Chapman & Mitchell, 2013). Katz and Laczano (2008) reiterate that since intellectual challenges are not curable, the treatment objectives must focus on the normalization of behaviour in accordance with the norms and rules determined by society. In addition, treatment for individuals with intellectual challenges must be multi-disciplinary and include medicine (family, paediatrics, Neurology, and Psychiatry), psychology (educational and clinical), education (regular and special), rehabilitation (physical, occupational, and recreational), nursing, and social work.

According to the AACAP (1999), the treatment of youth with intellectual challenges is based on the following guiding principles: person centred planning, appropriate education, family training, community integration, and transition planning for adulthood. According to Virginia Department of Behavioural Health and Developmental Services (DBHDS) (2009), although intellectual challenges are experienced lifelong with proper services and interventions, the majority of youth facing intellectual challenges can function well in the community and can participate in employment opportunities. AACAP (1999) cites five different levels or steps as interventions for people who face intellectual challenges:

1. **Primary intervention:** To prevent any condition that might result in intellectual challenges. Primary prevention methods include, during pregnancy, using folic acid supplementation to prevent neural tube defects, and abstaining from alcohol and other substances.
2. **Secondary prevention:** The specific treatment of underlying conditions, if known to prevent or minimize brain injuries that might result in intellectual challenges.
3. **Tertiary prevention:** Provision of early intervention, education, rehabilitation and ancillary therapies (e.g., physical, occupational, language therapies).
4. **Medical care:** Treatment and prevention of general medical conditions, such as deafness or seizures in children with Down syndrome.
5. **Treatment and prevention of psychosocial dysfunction:** Prevention and reduction of maladaptive behavior, and promotion of independent functioning of an individual facing intellectual challenges.

According to the Gale Encyclopaedia (1998) an additional factor that may significantly impact on treatment efforts is the willingness of the individual and family members to participate and comply with a therapeutic plan. Education and ongoing support are essential. Detailed explanation must be given to family members in order to ensure that they understand all of the behavioral and pharmacological interventions that are being used to treat the individual who faces intellectual challenges.

2.2.7 IMPLICATIONS FOR SCHOOLING (DEVELOPMENTAL AND EDUCATIONAL SERVICES)

According to the UN Convention on the Rights of the Child UNCRC (2010) and the Convention on the Rights of Persons with Disabilities UNCRPD (2013) children with disabilities have the same right to education as all other children, and shall enjoy this right without any discrimination and on the basis of equal opportunity. With the arrival of universal education, the value of offering education to all children, including those who are facing intellectual challenges, became a universal law. As such, in Paris, Binet was given the task of developing a test (Molteno, 2006) that could identify children who would be unable to benefit from a regular curriculum.

This gave rise to one of the first intelligence tests that was developed. Intelligence tests have since become the crucial diagnostic measure of intellectual challenges (Molteno, 2006).

In South Africa the report by Van Wyk in 1967 was a milestone in the education of children facing intellectual challenges. The report advocated that children with an Intelligence Quotient (IQ) below 50 were entitled to state-supported training if they were able to benefit from it (Molteno, 2006). After publication of the report, the classification of children who are facing intellectual challenges as educable, trainable and uneducable/untrainable came into common usage. The right to a support system is reinforced in the current Office on the Status of Disabled Persons (OSDP) National Disability Policy Framework and guidelines for the implementation of the national disability framework (2008).

In South Africa, laws and policies thus exist for the benefit of people facing disabilities regarding their right to support systems. These policies include South African Constitution and Bill of Rights (May 1996), the Integrated National Disability Strategy (1997), and the White Paper on Special Needs Education (July 2001). The Gauteng Education Act of 1995 defines special education as education of a specialized nature provided to address the needs of learners who cannot benefit from the teaching provided in the course of ordinary education but who require specialized education to facilitate their adaptation in the community (Pillay & Proudlock, 2000).

However, there is little national evidence available on access to early learning for pre-school children who face intellectual challenges. Where such children do have access to early learning, it often takes place in informal community settings, with individuals (such as mothers of disabled children) running stimulation programmes (Ijsselmuiden, Nchinda, Duale, Tumwesigye & Serwadda, 2007). In spite of recommendable progress in policy and legislation development and numerous governmental and nongovernmental good practices, South Africa has yet to reverse the marked inequities in human rights and access to care and services that prevail for large numbers of disadvantaged people with intellectual challenges (Adnams, 2010).

2.3 PARENTS' KNOWLEDGE ON INTELLECTUAL CHALLENGES

Most researches that seek to investigate the support provided or received by parents of learners who are facing intellectual challenges indicate that there are certain parental support needs that may be required immediately after the diagnosis of a disabled child has been delivered. Such research findings indicate the need for guidance, knowledge and information about the nature of disability, coping with the disability, children's developmental challenges, and understanding and acceptance of the infants' differences from other children (Ziolko, 1991; Cavkaytar et al., 2010). In addition, Blacher, Neece and Packowski (2005), Keen (2007) and Tomasello, Manning and Dulmus (2010) assert that there is a need for health and social care professionals to proactively support families and listen to and value their knowledge of the child as this is essential for an effective working relationship. Douma et al. (2006) as well as Maes, Broekman, Dosen and Nauts (2003) also emphasize that the most essential basic need for support by parents and families of individuals facing intellectual challenges is knowledge and information about intellectual challenges.

According to Willingham-Storr (2014) existing studies in this area indicate that the delivery of the diagnosis as well as the information and knowledge parents receive will have a significant impact on the experiences of families (Frey et al., 1989; Hassal et al., 2005). The University of West England (2007) found that there is a significant relationship between parents' stress levels and the number of sources of information and knowledge that parents access. The more information and support parents receive the lower their stress levels will be.

Therefore, parents will be dissatisfied with lack of information related to their children's intellectual challenges. Similarly, Kenny and McGilloway (2007) found that many factors that affect the ability of parents to cope relate to the quality of information they receive during their child's diagnosis. Hudson, Mathews and Cameron (2008) after providing parents and carers with work books and DVDs that include advice, information and skills on how to manage difficult behaviour, found that such resources resulted in less anxiety, stress and depression as well as in parents being more confident in managing their children (James, 2012).

Hudson et al. (2003) reiterate that a clear need exists for families to be informed on how to manage the potential challenging behaviours of their children. Such needs for support may contribute to parents' adjustment and rehabilitation progress which in turn may affect their strength and emotional reactions when faced with challenges related to their children. Studies by Berger (2008), Centinkaya (1997) as well as Cavkaytar (2007) show that parents have a profound need for knowledge and information on how they can teach some skills at home, how they should work with their children, and special schools and special education programmes including the special school curriculum (Garan, Uysal, Adigüzel, Cavkaytar & Ceyhan, 2012; Shogren & Plotner,2012). Allied to this finding is the research by Bailey and Simeonsson (1998) indicating that parents generally require information on how to play, talk, and manage their children's development. Maes et al. (2003) add that parents typically expect to be provided with training, advice, and help in understanding the specific psychiatric and behavioural problems of their child and to be taught how to manage difficult situations (Douma et al., 2006; Maes, et al., 2003; Kenny & McGilloway, 2007).

In understanding intellectual challenges and at the level of counselling, Buscaglia (1983) adds that parents often experience a lack of knowledge in terms of the nature of a child's disability and what can reasonably be expected of him/her socially and educationally. Davis (1985) states that it is highly imperative that parents of children who are disabled, should have a clear understanding of their situation so that they can move to other progressive stages that will enable them to set explicit and realistic goals for their children. However, the author suggests that in order to achieve this, it is necessary to have a framework that may guide the counselling behaviour of all professionals so that counselling interventions may help parents understand the reality of their situations in order for them to be able to help themselves and their children effectively.

Buscaglia (1983) posits that a failure to help the disabled and their families to understand the nature and implication of a disability often causes pain and suffering for everyone concerned. In this regard, Douma et al. (2006) state that parents of children who are facing intellectual challenges often experience high levels of parenting stress as a result of a lack of knowledge about the disability. Similarly, Wolfendale and Bryans (2002) are of the view that most parents do not have experience of disabilities or special educational needs (SEN) and will thus find themselves in an 'information vacuum' at various stages of their children's lives. Rutchick et al. (2009) reiterates that many parents do not know how to get help for their children after they have been diagnosed as facing intellectual challenges. As such the parents may feel helpless. Such a sense of helplessness stem from both a lack of understanding about intellectual challenges, and a lack of information about the resources available to the intellectually challenged. It might also arise from insensitive handling of the case by health professionals who might not have enough time to talk to each family member at length about his/her experiences. Hudson et al. (2003) indicate that education programs have been developed recently in order to help parents in understanding and managing the difficult behavior of their children who face intellectual challenges. Evaluations of those programs are ongoing.

Given the above mentioned discussion and according to the United Nations (1994) the economic, social and cultural rights of children should be adhered to. For the families of children who face intellectual challenges, the UN has listed a number of services that governments should provide including information, counselling and parent support groups (Beirne-Smith et al., 2006). The right of every child to an adequate standard of living is recognized in the South African Constitution. While parents have primary responsibility for their children, the state has an obligation to support parents in the role of protecting and promoting the wellbeing of their children (DSD, DWCPD and UNCEF, 2012). In support of this augment, the South African children's Act (2005) obliges the state to provide programs which focus on developing appropriate parenting skills and the capacity of parents and care givers to safeguard the best interest of children with disabilities.

In spite of policies and legislation being in place for people facing disabilities, the Integrated National Disability Strategy (1997) has reported that people often do not have accurate information and knowledge about disabilities, its causes, its prevention and its treatment. This may be because of high illiteracy rates and poor knowledge about basic social, health and educational services. Siperstein and Volkmar. (2004) conducted a survey of South Africans' knowledge and perceptions of people facing intellectual challenges and their beliefs about inclusion. Their conclusion was that the South African public significantly underestimate what individuals who are facing intellectual challenges can do, and view them as being limited in their ability to perform self-help tasks, interact with other people and even engage in athletic activity. Literature similarly demonstrates that parents of learners who are facing intellectual challenges are usually also not familiar with the disability, and that they typically do not have accurate information and access to effective guidance. This has implications on the support needs of parents of learners who face intellectual challenges as discussed below.

2.4 PARENTS' NEED FOR SUPPORT

Literature regarding support experienced by parents of learners who are facing intellectual challenges indicates that the support needs of the parents start immediately after the diagnosis of the disability is presented to them. This normally marks the beginning of a long and often hard journey characterized by on-going needs for support, determined by the developmental stages of the child and the nature of the disability (Kumar et al., 2013; Bailey & Simeonsson, 1998; Tomasello et al., 2010). These support needs are broadly located within the following areas: knowledge about raising a child who faces Intellectual challenges, support to families living with such a child, future for older learners who leave school, and financial support.

2.4.1 KNOWLEDGE ABOUT RAISING A CHILD FACING INTELLECTUAL CHALLENGES

As literature on parents' knowledge about intellectual challenges have been discussed above, this section focuses on knowledge about raising a child who faces intellectual challenges with specific reference to support in this area and parents' interaction with professionals who diagnose their children.

2.4.1.1 Support services available

Both the United Nations (UN, 1994) and the World Health Organization (WHO, 2001) list a number of support services that governments should provide for individuals facing intellectual challenges. Amongst these services, rule number four requires of government to ensure the provision of support services including but not limited to assisting devices and technologies in order to support people who are facing intellectual challenges and increase their level of independence in their daily living while exercising their rights.

However, exploration of support services for these groups display several difficulties. Sontag and Schacht (1994) conducted a survey on the needs of parents of young children facing disabilities, finding that approximately half of all parents want to know more about the services available to their children and how existing support systems work in assisting parents to manage their children's intellectual challenges. Richardson (1996) points out that most parents of learners who are facing intellectual challenges seem unaware of how they can access counselling services that are available in the country, apart from specials schools. Similarly, findings of the study conducted in Turkey by Garan et al. (2012) revealed that most parents were not aware of the available services and existence of non-governmental agencies that provide assistance to the families of children facing intellectual challenges. Parents also indicated the need for support after learners exited the school system.

Literature, however still depicts a shortage of resources in most of the underdeveloped and some developing countries. For example, in Virginia (USA), according to the Association for retarded citizens (the Arc, 2010), a non-profit organization which supports people facing disabilities indicate that approximately 285 034 both children and adults are on waiting lists to receive support. A report by the DBHDS (2009) similarly shows that service availability for children who are facing intellectual challenges remains a serious concern in Virginia (USA).

In South Africa, the Department of Education, Gauteng Education Act 6 of 1995 commits itself to provide support and guidance to the parents of learners with special education needs. In contrast to this commitment, some inconsistencies exist even though these cannot be generalized to all areas in the country. For example, the Western Cape Court (Western Cape Forum for ID versus Government of Republic of South Africa, case no. 18678/2007) has proven that the state makes no direct provision for the education of children facing severe or profound intellectual challenges. No schools are either provided in the Western Cape for these children. Charema (2004) asserts that the present system of guidance and counselling in Zimbabwe similarly does not seem to address the problems faced by parents of children facing hearing impairments. This is evidenced by the fact that many parents of children facing hearing impairment fail to cope with the needs of their children in Zimbabwe. Many parents in South Africa and Taiwan rely on informal support received mainly from their families and community because resources for children facing intellectual challenges are not well developed (Chang & McConkey, 2008; Adnams, 2010). Russell, John and Lakshmana (1999) reiterate that resources to address the needs of parents with children facing intellectual challenges in developing countries are limited. In this regard Davis (1985) (1988) reiterates, that services for children with special needs are still limited, and that the focus of interventions typically falls on the child as opposed to the family as a whole and the relative importance of the role of the parents and, general family situation as a whole.

On the contrary, it has also been found that despite opportunities to get involved, many parents do not take advantage of opportunities which can provide a platform to create a symbiotic relationship between educators and themselves (Surujlal & Dhurup, 2009). Chiang and Hadadian (2010) assert that many parents are too ashamed to expose their children with special needs in public. Such behaviour contradicts the idea that most parents display the need for support; however, studies of this nature are limited.

2.4.1.2 Interactions with professionals who have diagnosed children

Literature on support received by parents of learners who are facing intellectual challenges indicate that parents' experiences of their interaction with professionals who have diagnosed their children are often marked by dissatisfaction from the side of the parents. For example, Morgan (1973), Mitchell (1981), Darbyshire (1982), Ziolko (1991) and recently Chang and McConkey (2008) maintain that most parents seem dissatisfied regarding the quality of the information that is conveyed to them by the professional with whom they come into contact during or after being informed of their child's conditions.

According to Davis (1985), the ways in which severe diagnoses is communicated still produce high levels of dissatisfaction, thus strengthening parents' needs for sufficient support. Findings indicate that certain terms used by professionals to describe disabilities are experienced as meaningless by most parents. Some parents feel that they are given insufficient or inadequate advice on how to best support their children's development, while others are critical about the lack of openness from professionals (Davis, 1985; Chang & McConkey, 2008).

A study conducted by Williams and Darbyshire (1982) revealed similar results. When parents of hearing disabled children were asked about their experiences with the professional who had diagnosed their children, the majority revealed a lack of understanding of what a hearing loss implies and a shyness to question the physician even though they did not understand the information given to them. In terms of communication about the diagnosis and prognosis to the parents of learners facing intellectual challenges, different and inconsistent views exist globally and locally. Lerner (1993) argues that paediatricians are expected to diagnose intellectual challenges and disclose this to the parents. Professionals are also expected to be informed about special education services offered by schools and to be familiar with the rights that children with intellectual disabilities have under state law.

In South Africa, Steenkamp and Steenkamp (2010) assert that medical practitioners have different views about when parents should be told that their children are intellectually challenged. Some feel it should be done as soon as possible, others feel that they should wait until an early diagnosis is confirmed or until the parents are better prepared. Still others prefer not to tell the parents at all, or make vague remarks such as *the child is slow but will outgrow it*. This highlights inconsistencies in the manner in which diagnoses are often communicated in the mental health system. In conclusion, this literature review has highlighted how knowledge related to my study has developed over time but, that much of it is rooted in focusing on the needs of learners who are facing intellectual challenges, thereby ignoring the needs of the parents and the broader family (McConachie, 1986).

2.4.2 SUPPORT TO FAMILIES LIVING WITH A CHILD WHO IS FACING INTELLECTUAL CHALLENGES

Families are recognized as the most important setting for child rearing. This makes the family members of children who face intellectual challenges to be a highly significant support system in meeting the needs of their children. The family is indeed the child's first and immediate support network (United Nations, 1959; UNCRC, 1989). Family, therefore, exists as the primary institution that forms the basis of all other communal institutions, where individuals are born into, raised or spend most of their lives (Cavkaytar et al., 2010; Türk Dil Kurumu; (TDK) 2010). This idea asks of the local government to provide the necessary protection and support in order to ensure that families can fulfil their obligations towards their children (United Nations, 1994).

Support services aimed at addressing the needs of the parents of learners with intellectual challenges in South Africa, followed the same general trends as in other countries. They proceeded from superstitious believe, neglect and limited support, to the development of interventional support strategies which focus primarily on children facing intellectual challenges and turn to overlook the support needs of the parents of such learners and their families as a whole (Loebenstein, 2005; Charema, 2004; Zhou, 2000). A number of studies that have examined the plight and challenges of families of people facing intellectual challenges and other developmental disorders highlight the importance of holistic family support (Douma et al., 2006; Kelly, Craig, McConkey & Mannan, 2009; Sims, 2002). Buscaglia (1983) agree that parents of children who are disabled or at-risk need additional support to enhance their interaction skills and to be most effective. Interventions should be individualised in order to address the uniqueness of each family or parent-child dyad.

However, research by McConkey, Truesdale-Kennedy, Chang, Jarrah and Shukr. (2004) reveals that support services received by parents do not always address their needs and do not offer continual support that fit with individual family. King, Kertoy and Law (2003) suggest that an ideal approach to meet the needs of people facing intellectual challenges is one that is family centred. In addition, Doody

(2012), as well as Maxwell and Barr (2003), emphasize that professionals cannot work with the individual facing intellectual challenge in isolation from his/her family, nor can parents and family members be viewed purely as a means of providing support and care, with little attention to how they feel and the fact that their lives are intimately intertwined. Failure to recognize the unique relationship in providing care and support to both the person facing intellectual challenge and the parent/family, only increases the isolation felt by the parent/family (Doody 2012).Understanding family experiences will help researchers, policy makers, non-governmental organizations, and others to identify family strengths and family support needs which can ultimately improve family quality of life and the quality of life of the members living with a disability (Doody, 2012; Maxwell & Barr, 2003).

Kelly et al. (2009) assert that children facing intellectual challenges raise various needs of parents and that these needs may vary according to the nature of challenges and parental characteristics, however that parents have to be empowered to meet such challenge. Fitzgerald and Fischer (1987) as well as Rao, (2008) state that needs expressed by families of children facing intellectual challenges vary from person to person and from family to family.

Douma et al. (2006) add that to support such parents, information is required regarding the type of support they need and whether their needs are met or not. Sims (2002) reiterates that one area where family support services have yet to effectively develop is in supporting families who have an adult member living with intellectual challenges. In this regard Turnbull and Ruef (1996) report on a qualitative study that has sought information from families about perceived needs in dealing with children facing intellectual challenges. Included in their lists were things such as: assistance with establishing structure in home routines; assisting in dealing with stress; support with provision of respite care; and assistance with engaging in advocacy.

2.4.3 PARENTS' WORRIES, ANXIETIES AND FEARS ABOUT THE FUTURE OF THEIR CHILDREN

Literature reveals that one of the main concerns of parents of learners who are facing intellectual challenges relates to their anxiousness about the future of their children and how their children will be taken care of when they die. This also include concerns about learners who exit the school system and which support they will be able to receive after school (Garan et al., 2012). Although this is a subject area that is often explored, it continues to be important and will always be relevant to families of individuals facing intellectual challenges.

In their findings, Doody (2012) and Kumar et al. (2013) indicate that parents find it hard to let go of their children, they worry about their future and support that will be available, and they worry that when their children will be older and the parents no longer around to support them. These concerns about the time are echoed by a number of researchers. For example, Todd and Jones (2005), Catherall and Iphofen (2006) and Johnson, O'Reilly and Vostanis (2006) assert that this is a recurring theme in terms of parents' hopes and fears about the prospect of death and what the future will hold for children who face intellectual challenges without their parents (Kenny & McGilloway, 2007). Similarly Willingham-Storr (2014) indicates that parents typically have a strong need for information about the future of their children who are facing intellectual challenges in terms of both a caring role and the level of support from existing services when their children reach adulthood. Chang and McConkey (2008), McConkey (2011), and James (2012) also found that most concerns relate to future service provision when these individuals reach adulthood. In addition parents are generally concerned about the children's placement when they finish school.

Closely aligned to this is an indication that support needs for parents of children facing intellectual challenges are continuous, on-going and exist throughout the life continuum (Cavkaytar, 2007).Advocates for the continuum of care argue that since intellectual challenges are considered to be a developmental disability, and can only be diagnosed once the limitations in human functioning manifest during the developmental period, the support needed by parents of children who face intellectual challenges is hierarchical, on-going and determined by the developmental stages of the child and the nature of the disability (Kumar et al., 2013; Bailey & Simeonsson, 1998; Tomasello et al., 2010; Luckasson, 2002).

Maxwell and Barr (2003), Barron, McConkey and Mulvany (2006) and Chou, Chiao and Fu (2011) maintain that for parents of children who are facing intellectual challenges, parenting can be seen as a life time commitment as the children might need special support with extra requirements existing for the child and family for the entire life of the child (Singh, India & India, 2008; Kumar et al., 2013). Given the above, it follows that these families need support throughout their lives for various reasons by counsellors, formal institutions and informal sources of support (Hassalet al., 2005). In terms of this ongoing need for support Rutchick et al. (2009) declare that such reactions in families' experiences are completely normal. It takes time, support and accurate information for parents to understand what their children's disability implies. It is very difficult to give up the hope that someday something will make the child normal. Literature therefore confirms that parents' needs for support do not end after the diagnosis, but continue throughout all developmental stages and therefore has a bearing on the financial support needs of families, which is discussed below (Celebi, 2003; Duygun, 2001; Dyson, 1997; Tamer, 2010).

2.4.4 FINANCIAL SUPPORT NEEDS

Existing studies highlight that parents and families of learners facing intellectual challenges are often disadvantaged financially, socially and in terms of employment (Beresford, 1995; Walker & Walker, 1998). Parents of children facing disabilities typically have lower status of employment and limited ways of social participation (Seltzer, Greenberg, Floyd, Pettee & Hong, 2009).According to Kumar et al. (2013) one of the needs expressed by parents of children facing intellectual challenges is the financial need, in order to be able to pay for basic expenses, special equipment, therapy, a baby sitter/day care etc. Ziolko (1991) adds that financial burden, demands and responsibilities are prevalent in the families of people who are facing intellectual challenges as a result of a continuous need for additional support in this area.

Research indicates that in most countries, financial provision is made for individuals facing intellectual challenges. However, this provision is compounded by criteria and procedures involved in determining who is eligible to access such support. For example in Taipei, according to Chang and McConkey (2008) means-tested, financial benefits are available, however only to families who pose a Disability certificate based on a medical diagnosis. Davis (1985), in his study, found that benefits of a disability grant have not objectively evaluated and that eligibility to access financial support tends to be ability oriented, to the neglect of other aspects of child’s behaviour. The psychological and social aspects of disabilities are often neglected by health services. In this regard Johnson et al. (2006) found that the process of assessment, applying for and securing funding and then finding placement and support that would meet parents’ needs, was described by such parents as ‘time wasting and fruitless.’

In South Africa, one of the core functions of the Department of Social Development is the provision of comprehensive social security, with the aim of reducing poverty among poor people. The Care Dependency Grant (CDG) is awarded in terms of the Social assistance Act and is given to poor parents or primary care givers of learners who are facing intellectual challenges and requires permanent care but are not in governmental institutions. However, parents are often concerned about access to the CDG because the South African Social Security Agency’s (SASSA) eligibility assessment tools lack consistency in terms of determining the criteria for eligibility to access this grant. This is evident in the approaches and attitudes of service providers. Concerns have thus been raised about the limitations of the CDG more specifically about the fact that the eligibility assessment tools are primarily based on the severity of the health condition or impairment, without consistent and in depth assessment of activity limitation and/or participation restrictions or environmental factors that may result in a high level of disability for the child.

2.5 THEORETICAL FRAMEWORK UNDERLYING THE STUDY

According to Guba (1990), paradigms are characterized by their ontology (What is reality?), epistemology (How do you know something?) and methodology (How to go about finding out?). These characteristics create a holistic view of how researchers view knowledge: how they see themselves in relation to this knowledge and of the methodological strategies they choose. In this study I adopted Bronfenbrenner's Socio-Ecological Systems theory and family systems theory as theoretical framework (1979).

Since the intention of this study was to explore and describe the existence of processes of support experienced by parents of learners who face intellectual challenges, I relied on both socio-ecological and family systems theories in undertaking this study (Bronfenbrenner 1979, 1986; Becvar & Becvar, 2000). Socio-ecological theory provided me with a framework to link the different levels in which the experiences of support can potentially take place. In addition, according to family systems theory I viewed the phenomenon of support in the context of mutual interaction and influence within relationships where each part influences every other part (Donald et al., 2010; Becvar & Becvar, 2000). In this study, these two theories thus assisted in directing attention away from an individual problem of person to a context of interrelationships where parents experience support (Luk-Fong, 2005; Becvar & Becvar, 2000).

2.5.1 BRONFENBRENNER'S SOCIO-ECOLOGICAL SYSTEMS THEORY

Bronfenbrenner's (1979) socio-ecological theory posits that human development is shaped through the interaction between individuals and their environments. At the level of ecological theory, an individual is regarded as a system that interacts with other systems such as the community, friends, and family. Bronfenbrenner's ecological systems theory explains how a child grows and develops. The author stipulates different levels of the environment that will influence children's development, including the microsystem, meso-system, exo-system, and macro-system. As such, since the definitions of intellectual challenges contain a developmental perspective and due to intellectual challenges being considered as a developmental disability (Luckasson, 2002), human functioning will be influenced by the various systems during the entire developmental period (Kumar et al., 2013; Bailey & Simeonsson 1998; Tomasello et al., 2010). As such, intellectual challenges experienced by a child will also have an effect on the various systems, requiring support throughout the other systems involved.

Bronfenbrenner's (1979) socio-ecological theory of the developmental stages of the child, indicate how people encounter different environments throughout their lives, and that all components of a system are interrelated. Changing one variable might impact many others. Due to its holistic approach to reality, this theory seems applicable to my study (Bateson, 1972; Keeney, 1979).

In this study, the socio-ecological theory thus provides a framework that assisted me in linking different levels where support may take place. The socio-ecological nature of family support does not require any programme to operate on all types of services needed by children and their families (Amatea & Brown, 2000; Lee, 2005). The theoretical framework for experiences of support thus reflects an ecological and contextual approach where parents and family of learners facing intellectual challenges are recognized as part of a broader community network with the potential to interact with and be supported by local friends, family, community networks and special services by the local government (Bronfenbrenner, 1979, 1986; Becvar & Becvar, 2000).

According to Bronfenbrenner's socio-ecological theory (1979), the various roles of stakeholders and agencies involved in supporting people who are facing intellectual challenges complement each other through various layers of support. In the micro-system, support can be offered by the family in the immediate environment where the child lives including any immediate relationships or organizations s/he interacts with, for example, family, caregivers, schools and day-care. The second layer of support is the experiences in the meso-system, in terms of the support by school and family partnerships. For example, if a child's caregiver attends school meetings for the sake of the child. The third layer of support is the exo-system where support is offered by community services such as health care centres and politics. This includes people and places that a child may not interact with regularly but that will have an influence on his/her development such as policy makers and local government. The fourth layer of support is provided by the macro-system, where support is influenced by very remote people and things such as national government, economy, cultural values and ideologies (Ungar, 2004; Luk-Fong, 2005).

2.5.2 FAMILY SYSTEMS THEORY

The family systems theory holds that individuals are best understood within the context of relationships and through assessing interaction within an entire family (Becvar & Becvar, 2000). This theory directs the attention away from the individual and individual problems (as locus of pathology) viewed in isolation towards a relationship and relationship issues between individuals (Becvar & Becvar, 2000). Family systems theory therefore provides a broad and comprehensive mechanism for understanding the core aspects of performance competence, by focusing on the most important components of environmental influences which is home, family and community. Since both the children and parents must be supported as a system when a child faces intellectual challenges family system theory is applied in the current study (Dowling & Barnes, 2000; Becvar & Becvar, 2000). In this study, family systems theory assisted me when asking *what* is occurring in the whole system in which the parents of learners facing intellectual challenges experience support. This theory assisted me in describing the context as well as the processes that give meaning to parents' experiences within a circuit or ecology of interdependent parts (Bateson, 1972; Keeney, 1991).

Luk-Fong (2005) adds that in order to provide comprehensive support services, the researcher needs to understand the family system as children's problems are embedded in the family. Families are fundamental to the health and strength of society, thus in this study, family systems theory implied the possibility of providing families and parents an opportunity to communicate their meanings and experiences of support processes within the context of mutual interaction. Furthermore I could understand the influences with other stakeholders and relationships, where each part influences every other part, rather than functioning as individual or isolated units (Donald et al., 2010; Becvar & Becvar, 2000).

In understanding this study and interpreting the results obtained important contributing factors taken from family systems theory is its perspective in working from a multi-cultural framework (Donald et al., 2010). As such this theory assisted me in exploring both the individual culture of the families who participated and the larger culture to which the families belong. For example, I could explore and interpret cultural orientation towards intellectual challenges.

2.5.3 INTEGRATING SOCIO-ECOLOGICAL THEORY AND FAMILY SYSTEMS THEORY

The theoretical framework from which I viewed this study resonates with both socio-ecological and family systems theories, as both theories attune to interrelation, complexity, and context. In this study I investigated complex multiple cases of parents' experiences of support. As such, I could describe what parents say about their experiences of communication in an interactional network of human relationships with e.g. professionals, carers, doctors etc. What seemed critical in this study is understanding how this interaction of networks (between parents, professionals and other agencies involved in supporting parents of intellectually challenged learners) is interlinked or structured. This idea follows the basic principles of systems theory described by Bateson (1972) that, if one wants to understand a phenomenon, you must consider that phenomenon within the context of all network of human relationships from which the problem exists.

Within the paradigm represented by the views of socio-ecological and family systems theories, parents' experiences of support are thus viewed as a relationship metaphor. This implies that the communicative functions of parents' experiences are seen as indicators or a sign for the ecology of relationships between all agencies involved in support rendered to parents of learners who are facing intellectual challenges (Corey, 2001; Barlow, Coren & Stewart-Brown, 2002; Becvar & Becvar, 2000). From these perspectives, schools for learners with special needs, parents of learners who are facing intellectual challenges, their families, and health agencies form part of or are subunits of support agencies. Health professionals exist yet can only define themselves in relationship with their clients (i.e. parents and learners). They therefore do not exist independently. This therefore depicts a context from which I interpreted the participants' experiences of support that take place (Bronfenbrenner & Morris, 2006).

Both socio-ecological and family systems theories direct the attention away from the individual and individual problems (as 'locus' of problems) towards individuals' affiliations, interactions, functional unity and relationship issues in the context of the whole system (Luk-Fong, 2005; Becvar & Becvar, 2000). These theories attempt to explain behavior of complex, organised systems of all sorts. I found a unified model of the ecological and family systems theories to be useful in identifying consistencies, strengths, complementarities, in-consistencies, discrepancies and conflicts in regard to experiences of support by parents of learners who face intellectual challenges and in their relationships with relevant service providers. Systems' thinking as a way of looking at the world in which objects are interrelated with one another, assisted me in identifying the strengths and weaknesses involved in the internal structures and operating processes of all agencies involved in supporting the individuals facing intellectual challenges and their parents. I could potentially also clarify how well a system is structurally adequate and operating efficiently. These keys levels of interaction are summarised in figure 2.1.

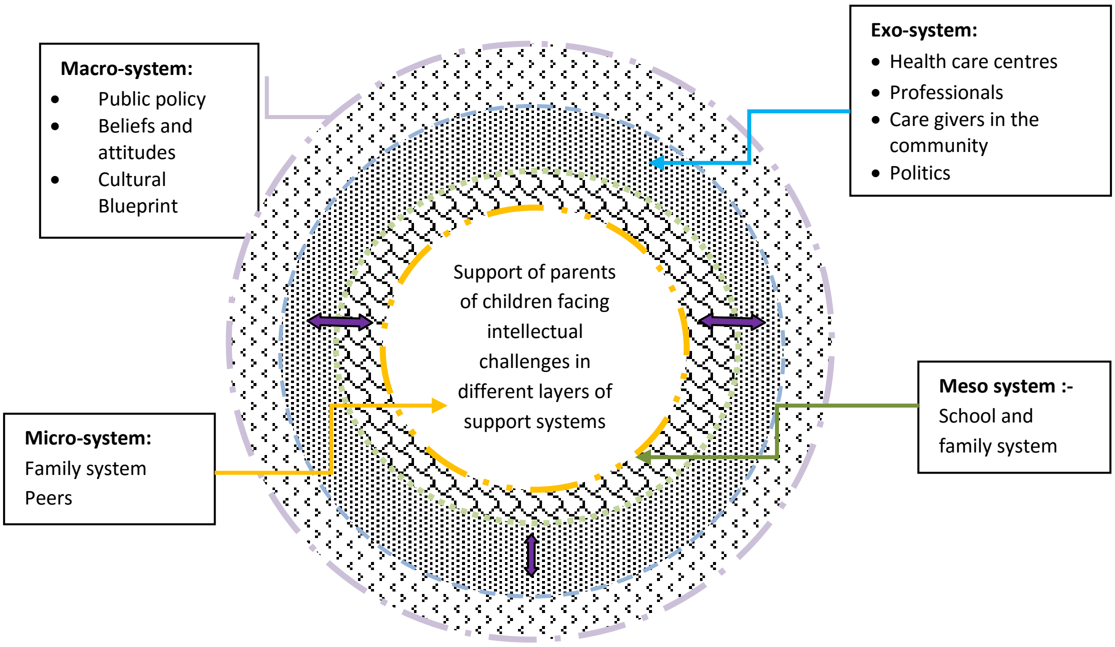

Figure2.1: Key layers of support for families of learners who face intellectual challenges

Figure 2.1 depicts how the key areas, settings and agencies involved in rendering support to parents of learners who face intellectual challenges can be linked. The two theories call for examination of multiperson systems not limited to a single system and aspects of the environment beyond the immediate setting (Bronfenbrenner, 1979). In figure 2.1 the parent, peer and family system are placed in the first circle and depicts the primary setting influencing support around family unit and is called microsystem. Emphasis falls on the importance of the family’s actions, reactions and interactions as determined by members’ beliefs and practices. Such knowledge is useful in understanding a family’s experience of support (Bronfenbrenner, 1993; Luk-Fong, 2005; Becvar & Becvar, 2000).

The second circle depicts the linkage between two microsystems working together i.e. school and family working together to support parents, through the meso-system. A third circle illustrates a setting not containing the family, but which nevertheless exerts an influence on the families’ experiences of support. This system is characterised by settings such as access to certain types of services within the community e.g. health centres, guidance professionals and education departments and it is called exo-systems. Finally the outermost circle or system depicts the larger cultural context in which families of learners facing intellectual challenges function. This cultural context includes developing and industrialised countries, socioeconomic status, policies and poverty (Bronfenbrenner, 1993). This context also influences the functionality of the other support layers and is called the macro-system.

In studying the experiences of support rendered to parents of learners who face intellectual challenges, in an environment created for able normal and cognitively functional individuals forms the backdrop system in the study. It was thus imperative to employ a framework that considers that the findings and outcomes can only be meaningful if viewed against the context of the environment within which the phenomenon exist (Devine & McGovern, 2001).

Both the ecological and family systems theories have allowed me to consider a wide range of relevant factors from which a lack of knowledge about the nature and implications of intellectual challenges and ‘unrealistic or inappropriate’ expectations about the academic development of the learners may stem. Furthermore, this framework has assisted me in determining the roles fulfilled by the various stakeholders involved in the process (Bronfenbrenner, 1979, 1986; Becvar & Becvar, 2000).

2.6 CONCLUSION

In this chapter I discussed literature in the field of support rendered to parents of learners who face intellectual challenges. I presented my review with specific reference to the concept of intellectual disability, its prevalence and classification. Next, I discussed the processes of identification and diagnoses of intellectual challenges referring to people making diagnoses and referrals. Then I explored the support received by parents, also focusing on parents' knowledge of intellectual challenges, raising a child who faces intellectual challenges and being aware of support services available.

In the next chapter I explain the empirical study I conducted. Throughout I justify the methodological choices I made in terms of the research questions that guided my investigation.

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CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

In chapter 2, I presented a literature review with specific reference to the initial identification, diagnosis and referral of learners who face intellectual challenges. I also explored literature on parents' knowledge and understanding of intellectual challenges, parents' experiences of the support received by them and their general interaction with professionals who diagnose their children, including the available support services both locally and internationally.

In this chapter, I describe the paradigmatic approaches I selected for this study. I explain my research design, selection of participants, methods of data collection and documentation, data analysis and interpretation, quality criteria strategies and ethical considerations. Throughout this section I situate the methods and choices I made within the purpose and focus of the study.

3.2 PARADIGM

I utilized the interpretivist epistemological paradigm and meta-theoretical assumptions in undertaking this study (Nieuwenhuis, 2007:59-60; Merriam, 1998). Interpretivism aims to understand and interpret the world in terms of its actors (Cohen et al., 2005). Meta-theoretical assumptions assert that the social world does not exist independently of human knowledge but within the interaction of social life, mind and behaviour. This implies that what really exist in the social context are multiple realities that originate from the human mind as source of origin or meaning (Nieuwenhuis, 2007).

Since the unit of analysis in this study was individuals' (parents') experiences of support, rendered to them, I interpreted meanings, views and perspectives constructed from parents' multiple lived realities (Cohen et al., 2005). As such, meta-theoretical assumptions allowed me to access reality *via* the spoken word and voices of the research participants. It also allowed me to gain insight into the participants' perceptions (Nieuwenhuis, 2007). To this end, being guided by the interpretivist tradition, I remained aware of my preconceived ideas and personal understanding and knowledge of the phenomenon under study.

Relying on the interpretivist paradigm has assisted me to interpret and understand parents' experiences of support from their perspectives (Cohen et al., 2005). Since I entered the field with some sort of prior insight of the research context, interpretivist practice allowed me to remain aware of my personal understanding of the phenomenon under study. As a result, throughout this study I remained open to new knowledge stemming from participants' unique views of their reality (Carson et al., 2001; Black, 2006; Neuman, 2000).

3.3 METHODOLOGICAL PARADIGM

As stated I adopted an ideographic qualitative approach since the purpose of the study was to explore and describe the processes of support rendered to the parents of learners who face intellectual challenges and how these processes were experienced by the parents. I wanted to gain an in-depth understanding of the personal subjective accounts of parents' unique experiences of support (Burrel & Morgan, 1979; Cohen et al., 2005, Patton, 2000).

According to McLeod, (2007) the term "Idiographic," comes from the Greek word "idios" meaning "own" or "private". While an idiographic approach has been defined as relating to unique facts, its connotation can be more accurately characterized as the richly detailed and uniquely holistic representation of words and actions that attempts to describe a situation as experienced by participants (Miles & Huberman, 1994). To this extent, an idiographic approach appears to align with qualitative methods. Nieuwenhuis (2007) states that qualitative research approaches attempt to gather rich descriptive data in order to understand a particular phenomenon or context within the social environment, in terms of the question under study. In this study the phenomenon of interest occurred in a natural setting, where parents experience support rendered to them (Leedy & Omrod, 2005).

The exploratory and open-ended nature of the research questions supported my decision to follow a qualitative approach (Elliott, 2000; Barker et al., 2002). Barker et al. (2002) suggest that exploratory questions, suitable as the basis for qualitative inquiry, are typically used when: there is little known in the particular research area; existing research is confusing, contradictory or not moving forward; or the topic is highly complex. In terms of the aim of exploratory questions Elliott (2000) identifies the following types of questions:

- **Definitional**: examples include: What is the nature of this phenomenon? What are its defining features? What are the parents' levels of knowledge and understanding of intellectual challenges including its implications in terms of academic development?
- **Descriptive**: include questions such as: What kinds or varieties does the phenomenon appear in? What aspects does it have? How does support services affects the parents' perceptions and expectations about the academic development of their children who face intellectual challenges?
- **Interpretive**: examples of question include: Why does the phenomenon come about? How does it unfold over time? How are the roles of various agencies involved in the diagnosis and prognosis of intellectual challenges synchronized to effect support to the parents?
- **Critical/action**: include questions such as: What is wrong or right about the phenomenon? How could it be made better? What is your view of support services for parents of learners who are facing intellectual challenges? Is there anything you would like to say about the support you have received in general? What suggestions do you have to improve the support rendered?

A qualitative approach attempts to obtain details of the experiences related to a particular phenomenon, reflecting a comprehensive and holistic understanding of individual participants' unique perspectives and experiences (Patton, 2002). In this study, the use of the qualitative mode of inquiry afforded me as a researcher with opportunities to explore and describe the subjective experiences of the participants within a context they know well (Burrel & Morgan, 1979; and Cohen et al., 2005). Elliott (2000) asserts that one advantages of this approach lie in the prolonged engagement of the researcher in the research field. I conducted my study over a four month period. In addition, my experience in the school for special needs for several years resulted in me having some insight in terms of the phenomenon even before entering the research field even though this experience was not based on structured research.

However, by being close to the specific context or situation, I faced the potential challenge of experiencing difficulty in investigating the phenomenon with sufficient detachment. In attempting to curb this, I strived to maintain a balance between knowing when to remain distant and when to engage (Cohen et al., 2011; Creswell, 1998; Yin, 2003; Durrheim & Wassenaar, 2002; Fouché & Delport, 2011). To this end, I regularly reflected on my role as researcher, and also discussed this with my supervisors.

The qualitative mode of inquiry furthermore allowed me to understand this real life phenomenon in depth, yet against specific contextual conditions (in this study, an environment created for able-minded individuals) that are highly pertinent to the study (Yin & Davis, 2007). This study sought to provide and reflect a holistic understanding of the processes involved in supporting parents of learners who are intellectually challenged. The experiences of such processes, typically varies for different people in differing contexts, necessitating a portrayal of their experiences in their own words. In this regard, qualitative research provided me with an opportunity to sensitively gain insight into the multiple realities, experiences and interactions of individuals and groups of parents (Neill, 2006; Patton, 2002).

Despite the possibilities of qualitative research, studies of this nature are often criticised for their lack of objectivity and generalisability. The word 'generalisability' is defined as the degree to which the findings of a study can be generalised from the study sample to the entire population and across settings (Polit & Hungler, 2001). However, with qualitative research the aim is to discover meaning and understanding, rather than to verify truth, predict outcomes or present universal facts (Kaplan & Maxwell, 1994; Cohen et al., 2011). I therefore did not strive to obtain generalisability.

In support of my decision to follow a qualitative approach I adopted Kaplan and Maxwell’s (1994) view that qualitative methods can encompass the whole of an event and inform a researcher about the meaning brought forward by the people involved. Therefore, in this study I was concerned with holistically understanding how parents experience learning support rendered to them, after their children have been identified as facing intellectual challenges.

3.4 RESEARCH DESIGN

According to Burns and Grove (2003) the research design refers to a blueprint or framework for conducting a study, with maximum control over factors that may interfere with the validity of the findings. Mouton (1997) emphasizes that the research design involves the planning of a study, and determining how, where and when data are to be collected and analyzed.

In this study, I selected a multi-case study design because of the complex and multiple interactions involved being beyond the extent of a single case. Explaining multiple case studies offered me with the opportunity to acquire a modest amount of comparative data from the four focus groups discussions (Yin, 2003). According to Stake (2000), a multiple case study design implies the study of more than one case in order to explore a phenomenon, population, or general condition.

In selecting a multiple case study design, I was able to gain an understanding of certain circumstances within a specific context (Henning, Gravett & Van Rensburg, 2002). Parents' experiences of support were namely considered within a natural context, allowing me to gain a close, in-depth, and first-hand understanding of their perceptions by collecting data in natural settings and considering the "real-life context" of the case (Yin, 2003). To this end, I explored the experiences of parents of learners who face intellectually challenges, from the perspective of their context of the interactional relationships between the various stakeholders involved in rendering support to the parents (Mertens & McLaughlin, 2004; Babbie, 2004). Throughout, I considered the case of parents of learners who face intellectual challenges by doing a holistic multi-perspective analysis of their experiences. I thus considered the voices of the participants as well as their interactions (Tellis, 1997).
My decision to employ a case study design is supported by Yin (2003) who states that a case study design should be considered when the purpose of a study is to answer "how" and "why" questions?, when one cannot manipulate the behaviour of

those involved in a study, or when one wants to cover contextual conditions that are relevant to the study as indicated in the purpose of the study (Yin, 2003; Baxter & Jack, 2008). In this study, I investigated a contemporary phenomenon within a real life context using multiple data collection strategies (Cohen et al., 2005). Creswell (2007) asserts that for a case study design, a researcher will delve into a 'bounded system' (the case of parents of learners with intellectual challenges in Soweto) through comprehensive data collection, involving several resources in order to produce a case description and case-based themes. Baxter and Jack (2008), Yin (2003) and Patton (1990) add that a hallmark of case study research is the use of multiple data sources, as this strategy can enhance credibility and promote a greater understanding of the case.

However, a case study design, like any other design implies some limitations. Case studies are criticized for a lack of generalization and for the fact that it may take long, and result in a large amount of data. Another objection to a case study design is that causal relationships may be difficult to establish (Yin, 2003).

In terms of these potential limitations of a case study design, I concur with Flyvbjerg (2006), Platt (1992) as well as Ragin and Becker (1992) that the purpose of a case study is not to represent the world, but to represent the case. Kuhn (1987) reiterates that in Germanic language the term *science* (*wissenschaft*) means 'to gain knowledge.' Formal generalization is only one of many ways by which people can gain and accumulate knowledge. If knowledge cannot be formally generalized it does not mean that it cannot enter into the collective process of knowledge accumulation in a given field or in society. As such I did not aim to prove something (e.g., cause effect relationship) but rather to learn something. This design was useful in gaining an understanding of parents' experiences within their specific contexts (Henning, Gravett & Van Rensburg, 2002). I also applied Yin's (1993) and Stakes' (1995) protocols for conducting the case study, which enhanced the credibility of the study.

3.5 SELECTION OF PARTICIPANTS

Thirty five parents of learners who have been diagnosed with intellectual challenges participated in the study. Parents were selected from four schools in Soweto, within three kilometres radius from each other. All four schools cater for learners with special education needs. Table 3.1 provides an overview of the participants and some background on their children.

Table 3.1: Overview of the participants

Schools	Number of Participants		Child's Age	Child's disability	Parents level of education
	Male	Female			
A	1	6	3 x 20 years 1x 18 years 1x8 years 1 x 10 years 1x15 years	2 x Cerebral Palsy (CP) 2 x Attention Deficit Hyperactive Disorder (ADHD) 3x Learning Disability (LD)	2 x junior primary 1x senior primary 1 x secondary school 3 x high school
B	1	9	4 x 12 years 2 x 14 years 1 x15 years 1 x 17years 1 x 21 years	2 x Cerebral Palsy (CP) 2 x Down Syndrome 2 x Hydrocephalus 1 x Moderate Intellectual Disability 2 x Attention Deficit Hyperactive Disorder (ADHD)	8 x high School 1 x post high school
C	0	9	1x 22 years 1 x19 years 2x18 years 3x12 years 2x11years	1x Foetus Alcoholic Syndrome (FAS) 3x Learning Disability (LD) 2 x Attention Deficit Hyperactive Disorder (ADHD) 1 x Cerebral Palsy (CP) 2x Epilepsy	6 x high school 2 x senior primary 1 x post high school
D	1	6	4 x 18 years 5x19 years	7 x Learning Disability (LD) 1x Cerebral Palsy (CP) 1X Brain Injuries	1 x junior primary 1x senior primary 4 x secondary school 2 x high school 1 x post high school

My decision on the sample size was influenced by McMillan and Schumacher's (1997) contention that sample size should correlate with the nature and purpose of the research problem, the data collection strategies and access to information (Yin, 2003). According to Holloway and Wheeler (2002) sample size does not influence the quality of a study. Streubert and Carpenter (1999) as well as Burns and Grove

(2003) add that a qualitative study requires a small/purposive sample and that the sample size is not predetermined in qualitative studies. Sample size thus depends on saturation of the data, a stage when no new data emerge, but where previously collected data are repeatedly reintroduced.

Since the participants in this study are a homogeneous sample (parents of learners who are facing intellectual challenges) with experiences of support being a common thread for discussions (Vaughn et al, 1996), I employed purposive or judgmental sampling (Babbie, 2004). Brink (2006) explains that purposive sampling is based on the judgment of the researcher regarding subjects that are knowledgeable about the question at hand and who may potentially provide rich information and comprehensive data. Miles and Huberman (1984) reiterate that focus group research often rely on purposive sampling, with researchers selecting participants based on the project and due to the potential contributions they may offer. Thus, in this instance I asked the school principals of the four targeted schools to provide the names of parents who might be willing to participate. Parents, who were interested, could in turn be able to provide names of other potential participants that I could contact. This type of recruiting is known as snowball sampling (Lindlof, 1995). As such, I subsequently employed a combination of purposive and snowball sampling.

In purposefully selecting the initial group of participants, I applied the following selection criteria:

- A participant had to be a parent at one of the four special schools selected as research sites.
- A participant had to be available after school hours.
- A participant had to be willing to participate and provided informed consent.

Purposive sampling also implies some limitations e.g. that the selection criteria can be arbitrary and subjective. Furthermore, the sample population may not necessarily be the population that the researcher is trying to reach. In supporting my choice of sampling I relied on McMillan and Schumacher's (1997) guidelines that sample size should correlate with the nature and purpose of the research problem and the data collection strategies (Yin, 2003).

3.6 DATA COLLECTION AND DOCUMENTATION

After I purposefully identified and selected the relevant sites and participants, I collected data in order to explore and describe how the process of support was experienced by parents of learners who are facing intellectual challenges. I used multiple data collection and documentation strategies, namely focus group interviews, observation and field notes (Cohen et al., 2005).

3.6.1 FOCUS GROUP DISCUSSIONS

According to Cohen et al. (2005) as well as Barbour and Kitzinger (1999), focus group discussions allow for interaction amongst participants in a group situation. Focus groups are viewed as valuable tool for exploring how points of view are constructed and expressed. In this regard Lederman (1990) view focus group discussions as a data collection technique involving the use of in-depth group interviews where participants are selected purposefully from a specific population to contribute to a discussion, focused on a particular topic.

In this study I facilitated one focus group discussion at each of the four schools for learners who are facing intellectual challenges in Soweto. Each session lasted between one and a half hour and two hours. I alerted participants in advance about their time commitment when agreeing on a date (Krueger & Casey, 2000). I view focus group interviews as suitable for this study as I was able to generate large amounts of data in a relatively short time span based on the synergy of the group interactions (Green et al., 2006). Other advantages include that the technique is flexible and adaptable, that literacy is not essential, that it provides an opportunity for explanation and that it may result in a high response rate. Furthermore, I could note physical appearance and non-verbal as well as verbal behaviour during focus group discussions (Merriam & Associates, 2002; Wolcot, 1994). Krueger and Casey (2000) summarise that focus group discussion are economical, fast, and an efficient method of collecting data from multiple participants in an environment which is socially oriented.

In line with the view of Lincoln and Guba (1985) and Strauss and Corbin (1990), multiple focus group discussions allowed me as a researcher to assess the extent to which saturation was reached as the study progressed (Sandelowski and Barroso, 2003). In addition, in line with Onwuegbuzie and Leech (2007) and Morgan's (1997) suggestion that three to six different focus groups are adequate to reach data saturation and theoretical saturation, four focus groups proved to be sufficient in this study. I audio-taped and transcribed verbatim the four focus group discussions for data analysis purposes. Participants were informed that audio-tapes will be transcribed without using their names, thus, seeking their permission for this (Green et al., 2003). The audio-taped and videotaped data have assisted me in verifying quotations of interest.

Throughout, I remained aware of the challenges that emanated from the fact that the participants were not only speaking to me as a researcher, but were also interacting with one another (Morgan, 1997; Kitzinger, 1994; Powell & Single, 1996; Gibbs, 1997). As such, I actively attempted to manage group dynamics, interactions, and dominant participants that could have influenced the facts or hindered others from participating freely (Maree, 2007). Closely related, I was challenged in attempting to identify individuals' views from the group's view (Gibbs, 1997). Furthermore, I faced the challenge of entering into discussions with parents of the school where I am a principal, and hold a certain status. I addressed this challenge by relying on Morgan (1988), supported by Maree (2007), in terms of careful planning, moderating and specifying ground rules and 'boundaries' of behaviour as desired for the research process. I tried to create a non-threatening environment which would promote self-disclosure and encourage comments and interaction amongst participants. I ensured participants that there was no wrong answer and that they could not fail during this session.

This strategy seemingly encouraged participants to openly vocalize their views without fear of being judged while knowing that their views are important (Polit et al., 2001; Gibbs, 1997; Maxwell, 2006). As a researcher I also followed the guidelines of unconditional positive regard, enabling me to interact with the participants regardless of my interpretation of their speech, attitudes or level of participation (Henderson, 1990).

3.6.2 OBSERVATION

Many scholars that have studied the phenomenon of focus group observations agree that as much as the group and individuals are the focus of analysis in focus group studies, documentation of members who do not contribute to the discussion or are too shy to speak, uses non-verbal cues, are less-articulate, or have a tendency to agree/ comply to the majority must not be left un-observed (Morgan, 1997; Kidd & Parshall, 2000). Information from such observation might increase the descriptive and interpretive value of a study (Maxwell and Barr, 2005; Kitzinger, 1994; Sim, 1998).

According to Kidd and Parshall (2000) observation entails the systematic noting and recording of events, behaviours and artefacts in the social setting chosen for a study. Dewalt and Dewalt (2002) add that observations involve more than just “hanging out”. Self-aware observers use observation systematically. As such, I used observation as an auxiliary means and source of data collection tool that could assist me in understanding and capturing the contribution of the participants.

As participant observer, I borrowed on Henderson (1990) to observe non-verbal behaviours, to look for congruence between what is said and how the participants said it and to identify actions and emotions that may have been hard to uncover in conventional interviews (e.g., some participants being angry about the way some doctors dealt with their diagnosis). However, in my role as participant observer, I did not ‘label’ non-verbal behaviours or attach external meaning to it, because of the wide range of possible explanations that might exist. I simply noted the behaviour and checked whether any verbal comments were made that could provide insight into the ‘stance’ being taken (Henderson, 1990).

Social interaction between the participants was important, as data were primarily drawn through interaction of groups (mainly verbal behaviour). This necessitated that I as the researcher observed all circumstances during focus group discussions for the purpose of qualitative analysis of the setting and interactions that took place

(Gibbs, 1997; Morgan, 1997). As such, I used video-recordings to capture behavioural patterns that could assist me in analysing the data (Henderson, 1990).

Observing focus group discussions also implies some challenges especially with regard to the in-ability to collect data in a real life setting and situation, allowing for natural behaviour. As focus groups take place in fairly controlled settings, it can never be certain how natural the interactions are. Another potential limitation is that focus groups largely rely on verbal behaviour and self-reported data. If the interaction of interest does not include a "discussion" very little can be observed.

In addressing these limitations, I relied on Agar and MacDonald (1995) as well as Morgan and Krueger (1993), Morgan (1997) and Morgan and Spanish (1984), who emphasize reliance on the researcher's focus and the group's interaction. I also drew on Carey and Smith (1994), Kidd and Parshall (2000) and Kitzinger (1999, 2004) who confirm that it is important during focus group observation to take into account the group phenomenon. In addressing the issue of multiplicity of explanation of observation, I borrowed from Lincoln and Guba’s (1985) suggestion that when carrying out observation research, the four issues of credibility, transferability, dependability, and confirmability need to be addressed (Lincoln & Guba, 1985).

3.6.3 FIELD NOTES

I used field notes for data documentation purposes, allowing me to capture in-depth background information. This helped me to remember and record the behaviours, activities, events and other features of the settings I observed (Burgess, 1996). Having adopted a qualitative mode of inquiry and following a case study design, I adhered to Patton’s (2002) definition of field notes, also supported by Lofland and Lofland (1996). These authors value field notes as the fundamental database for constructing case studies and carrying out thematic cross-case analysis in qualitative research.

According to Krueger and Casey (2000), data generated during focus groups are typically recorded for two purposes: by means of a tape recorder with written notes as a backup, or if there is a need for clarifying data collections sessions. I took notes during focus group interviews without disturbing the spontaneous nature of group discussions. I drew on Emerson, Fretz and Shaw's (1995) recommendation to note initial impressions, sensory details, key events, important incidents, facial expressions, gestures, strong personal reactions to events, strong reactions of others, and meanings attributed to reactions and events. As patterns emerged, I refined the focus without narrowing it too strictly.

As I was openly writing notes and recording observations, I remained aware of the possibility that this could be intrusive to the group of participants and could potentially influence their behaviour and responses, thereby disrupting research observations (Krueger & Casey, 2000). To address this challenge, I drew on Ball and Smith (1992) who suggest the use of visual technology in the form of video and audio-recordings to supplement field notes and avoid extensive writing in front of the participants. Green et al. (2003) add that brief note-taking during observation, and writing up more detailed notes after leaving the research site, is the most effective method to curb potential challenges that may occur as a result of note taking during group discussions. To this end, participants were informed that a recorder will be used (Green et al., 2003; Patton, 2002).

Since recordings could not stand alone as data collection method, I transcribed all discussions verbatim and added information on non-verbal details after watching the video-recordings. Participants were informed that audio-tapes will be transcribed without using their names, and that the tapes will be destroyed according to ethical guidelines' stipulations (Green et al., 2003).

3.6.4 DATA ANALYSIS AND INTERPRETATION

The analysis of qualitative data involves the aim of uncovering and identifying concepts that can assist a researcher in understanding a phenomenon. This process implies breaking up data in order to identify important statements, and code these into manageable themes, categories, relationships and patterns (Maxwell, 1996; Creswell, 2009; Mouton, 2001). In essence, qualitative data analysis is the process whereby the researcher moves from the qualitative data that have been collected into some form of explanation, understanding and interpretation of the phenomenon (Gibbs, 1997).

In this study I employed inductive thematic data analysis, being conducted simultaneously with data collection (Cohen et al., 2011; Holloway & Wheeler, 2002; Polit et al., 2002). Krueger (1994) reiterates that qualitative analysis, particularly focus group analysis, occurs concurrently with data collection. Thematic analysis implies a method of identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes a data set in (rich) detail. However, it goes further by interpreting various aspects of the research topic (Boyatzis, 1998). In implementing Krueger's (1994) 'framework analysis' as described by Ritchie and Spencer (1994) I completed five key stages of data analysis which I discuss next.

3.6.4.1 Familiarization with the data

Recording and transcribing the focus group discussions allowed me to familiarise myself with the data collected by listening to the audio tapes and reading the transcripts several times to immerse myself in the data to the extent that I was familiar with the depth and breadth of the content. I also read my observational notes and field notes compiled during the focus group discussions (Ritchie & Spencer, 1994).

3.6.4.2 Identifying a thematic framework

After familiarising myself with the raw data and transcriptions I read and re-read all data. I identified a thematic framework of ideas that appeared suitable to my analysis (Tuckett, 2005; Bryman, 2001; Boyatzis, 1998). I identified a thematic framework by writing memos in the margin of the text in the form of short phrases, ideas, and concepts arising from the text allowing me to start developing categories (see annexure 9). At this stage I was coding for as many potential themes/patterns as possible (Bryman, 2001; Ritchie & Spencer, 1994). I discussed my initial analysis with my supervisors, and then refined the themes and subthemes based on the feedback I received.

3.6.4.3 Indexing and charting

During the third stage of thematic data analysis, I began to sift the data, highlight and sort out quotations. I made comparisons within and between cases, followed by an inductive comparative analysis of all cases using categorical coding. I subsequently identified related categories and patterns (Tailor & Bogdan, 1998).

3.6.4.4 Mapping and member checking

The fourth stage of the analysis process involved lifting the quotations from their original context and re-arranging them in the developed thematic framework. The final stage of analysis thus started when I had a satisfactory thematic map of the data. At that point, I defined and further refined the themes and subthemes that I presented for my analysis, and analysed the data within them (Tailor & Bogdan, 1998).

As such, the ‘essence’ of what each theme was about (as well as the themes overall) were identified, and the aspect of the data captured by each theme was determined. I re-read the transcripts in order to ensure that all relevant data are categorised in not more than 30 codes (eg. parents’ attitude, knowledge about disability, interaction with professionals, sources of support). After identifying themes and subthemes, I reviewed these with the participants (member checking) to confirm that my analysis was consistent with the experiences of the participants (Krueger, 1994; Ritchie & Spencer, 1994).

3.6.4.5 Interpretation

I anticipated that as I progressed, findings would emerge from the various categories and themes I identified. I therefore identified clustered units of relevant meanings; determining themes from these clusters of meaning and writing a summary of each focus group interview (Cohen et al., 2011).I conducted an additional analysis in order to confirm or modify themes, identify general and unique themes, and confirm the credibility of the descriptions in all discussions.

In this study, because of the multiple case study design, one focus group was analyzed at a time. Following individual analysis of the four focus groups, I compared my analysis in order to identify themes that emerged from all discussions. A strong convergence/similarity appeared amongst the focus groups and similar clusters of opinions could be identified. As such, I was able to identify themes consisting of relevant subthemes during data analysis.

3.7 RIGOUR OF THE STUDY

The aim of this study was to gain an in-depth understanding of the experiences of support processes of parents of learners who face intellectual challenges. To ensure rigour of qualitative methodology, I adopted Lincoln and Guba's (1989); as well as Streubert and Carpenter's (1999) ideas of trustworthiness and strived to maintain quality standards in my research. According to Guba and Lincoln (1994), it is important for researchers to understand the nature of each research paradigm and accompanying quality standards. As such, I attempted to meet the criteria of credibility, dependability, transferability, confirmability and authenticity by adhering to the epistemological and ontological principles governing qualitative research (Bryman 2001; Willis 2007).

3.7.1 CREDIBILITY

Credibility in qualitative research is defined as the extent to which the data and data analysis are believable and trustworthy. Credibility within qualitative research can be equated with validity (in quantitative research) relating to how research findings match reality (Mertens, 1998; Smith & Ragan, 2005). According to the philosophy underlying qualitative research, multiple realities are possible. As a result qualitative research may be valid to the researcher and not necessary to others. It therefore rests upon the reader to judge the extent of credibility based on an understanding of the study (Smith & Ragan, 2005). In this study, I attempted to enhance credibility by conducting member checking and allowing participants to validate the reported findings as representative of their experiences. I thus revisited the participants with the summary of the preliminary findings and requested them to concur with the reported findings or indicate any changes that need to be made. Participants were thus requested to comment on the accuracy of the themes and subthemes I identified and gave me their approval to use these in reporting on the study (Lincoln & Guba, 1985).

Furthermore, I adhered to the philosophical perspectives and accompanying quality standards governing the usage of a qualitative approach. This includes rich descriptions and continually implementing reflexivity in this dissertation (Holloway & Wheeler, 2002). I relied on comprehensive data collection involving several resources of data by means of observations, taking field notes while conducting focus group interviews and personally transcribing the interviews verbatimly instead of merely summarizing what I had obtained in order to produce a comprehensive case description and identify case-based themes (Baxter & Jack, 2008; Yin, 2003; Patton, 1990). I used multiple data sources, thereby enhancing credibility and promoting greater understanding of the case (Goodson & Sikes, 2001; Press & Cole, 1999).

3.7.2 DEPENDABILITY

Dependability in qualitative research is analogous to reliability in quantitative research. According to Merriam (1998), as well as Guba and Lincoln (1989)in Mertens and McLaughlin (2004), dependability refers to the extent to which research findings can be replicated with similar participants in similar contexts. This implies that the findings of the study could be similar if a study were to be repeated in the same context. However, reliability in its traditional sense is not viable in qualitative research. Merriam (1998) recommends that reliability in this type of research should rather be determined by the question whether or not the results are consistent with the data collected.

It is against this background that I include a detailed audit trail of how data were collected and analysed in this dissertation, including a stipulation of the multiple methods I used in an attempt to make sure that anyone wanting to re-do the study could access the information I used. Hence I report the processes of the study in detail so that future researchers who may want to repeat the work may do so. Seale (1999) reiterates that dependability can be achieved through auditing which consists of the researcher's documentation of data, methods and decisions made during a study as well as through its end product.

3.7.3 TRANSFERABILITY

Transferability in qualitative research aligns with external validity in quantitative research. According to Merriam (1998) as well as Guba and Lincoln (1989) in Mertens and McLaughlin (2004), transferability refers to the possibility of generalising findings, in other words extending the account of a particular situation or population to other persons, times or settings other than those directly studied (Maxwell, 2003).Since generalizability in its traditional meaning is not viable in qualitative research due to the subjectivity of the researcher as key instrument, a qualitative researcher can merely strive for transferability. To this end, it was important for me to detail the research methods, contexts and assumptions underlying the study (Seale, 1999), for the reader to be able to determine the transferability of the findings. Since this study adopted a multiple case study design with the purpose of case study research not being to generalize I focussed on representing the case. Kuhn (1984) regards generalization as merely one of many ways by which people can gain and accumulate knowledge. Throughout, my intention was not to prove something but rather to learn something.

For this reason, I provide a thick and rich description of the study in this dissertation, in order to enable readers to appraise the significance of the meanings attached to the findings and make their own judgement regarding the transferability of findings. In chapter 1 of the dissertation, I provided a detailed overview of the conceptual setting of the problem underlying the research, the contextual background in which I selected the study, the problem statement and purpose of the study. In the following chapters I have documented and justified the selected theoretical and methodological approaches, and described in details the critical processes and procedures I relied on to construct, shape and connect the meanings associated with the phenomenon I set out to explore.

3.7.4 CONFIRMABILITY

Confirmability refers to the degree to which the research findings can be confirmed or agreed with by others. It is related to objectivity in quantitative studies and entails the extent to which a researcher is aware of and can account for individual subjectivity or bias. I provide a detailed audit trail of how data were collected and include stipulations of the multiple methods of data collection I used in an attempt to ensure that whoever wants to use the information provided can easily access it. Hence I have reported the processes of my study in detail. In support, Seale (1999) reiterates that confirmability can be achieved through auditing which consist of the researcher's documentation of data, methods and decisions made during a study as well as its end products. This required of me to provide data and descriptions of the research that are rich and comprehensive.

3.7.5 AUTHENTICITY

Authenticity implies the acquisition of a balanced view of the various perspectives, values, and believes of the participants, answering the question: 'has the researcher been fair in presenting participants' views?' Qualitative research is therefore authentic when it accurately reflects the reality and ideas of the participants, and when it delves into the participants' experiences (Streubert & Carpenter, 1999). In this study I used methodology that could empower the participants to understand their social milieu (ontological authenticity), help them to appreciate others' perspectives (educative authenticity), provoke them to engage in action for circumstantial change (catalytic authenticity) and empower them to take the necessary steps for engaging in action (tactical authenticity) (Mertens, 2005; Bryman, 2008).

3.8 ETHICAL CONSIDERATIONS

Conducting a qualitative study implied that I as the researcher interacted with the participants and entered their personal domain of values, and the challenges they experienced in raising a child who is intellectually challenges. Silverman (2000), Blodgett, Boyer & Turk (2005); and Guba and Lincoln (1989) remind researchers that while they are conducting research they enter the private space of participants.

Regardless of the nature or extent of qualitative, research goals, and the knowledge creation that subsequently take place.

Research should be conducted in an ethical way. Miles and Huberman (1994) as well as Creswell (2003) remind researchers of their obligation to respect the rights, needs, values and desires of the participants. Since the nature of this study included data collection from human beings in the public domain I had to remain cautious and aware of relevant ethical considerations, namely informed consent, the freedom to withdraw, privacy, confidentiality, dignity, and the rights of the participants and anonymity (Durrheim & Wassenaar, 2002; Leedy & Omrod, 2001).

3.8.1 INFORMED CONSENT

In this study I informed participants (the parents and school principals) of the purpose, nature, data collection methods and the amount of time they could spend during the data collection process before commencing with the study. I explained their typical role during the focus group discussions to the parents. I obtained all participants' informed consent in writing as indicated in Annexure 5. Furthermore, permission was obtained from the Department of Basic Education and the principals from the four schools where research was conducted (Annexure1 and 3). Participants were informed that, if they choose to withdraw from participating in this study they were free to do so (Leedy & Omrod, 2001). It was made clear to the participants that the research was purely for academic purposes and that their participation in it was absolutely voluntary.

3.8.2 RISK AND PROTECTION FROM HARM

Even though the study did not imply any identifiable risks for parents, I aimed to minimise risks and protect participants from any physical or psychological harm or discomfort that could be incurred during the study. I anticipated the possibility that this topic, being sensitive, could trigger emotional reactions amongst parents. I relied on Loff and Black. (2000) suggestions for assessing and minimising emotional reactions using extended listening, ventilating discussions, and referral to counselling services if required. To this end, I sought the cooperation of counselling services before the research process resumed. However, none of the participants needed the intervention of counselling services.

3.8.3 HONESTY AND TRUST

In an attempt to ensure trust between myself as a researcher and the research participants, I adopted Lee Treweek's (2002) typology of trust, which stipulates that trust is built upon the credible accounts of others who have an experience of those to be trusted. In addition, I strived to obtain the trust of the participants by building rapport, by being there and being seen, by enhancing personal attributes such as being conscientious, by displaying professional integrity and by paying meticulous attention to detail. I also focused on practicing good interpersonal skills, being respectful, showing tolerance and tact, being approachable and displaying a caring and compassionate attitude (Lee Treweek, 2002).

3.8.4 PRIVACY, CONFIDENTIALITY AND ANONYMITY

As this study included taking field notes for verbatim transcriptions, and audio and video tape recordings, I ensured that the confidentiality and anonymity of the participants was maintained. To ensure the removal of all identifying characteristics, I ensured that the participants' names are not used for any purposes or that information be shared that may reveal their identities. In this regard, participants were given pseudonyms. Field notes were treated as confidential documents, and I took care that they are not read by others (Durrheim & Wassenaar, 2002).

3.9 CONCLUSION

In chapter 3, I offered a detailed description of the paradigmatic approaches I followed in this study. I also discussed the research design, selection of participants, methods of data collection, data analysis and interpretation.

In chapter 4, I present the results of the study in terms of the themes and subthemes I identified. This is followed by chapter 5 where I situate these results in existing literature as included in chapter 2. In this manner, I discuss the findings I obtained concerning the shared experiences of support services as perceived by parents of learners who are facing intellectual challenges in chapter 5.

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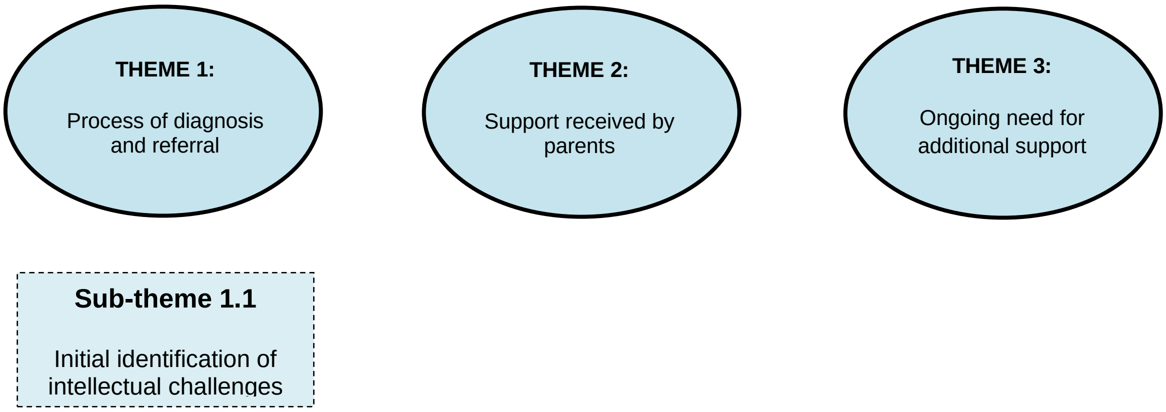
CHAPTER 4
RESULTS OF THE STUDY

4.1 INTRODUCTION

In chapter 3, I described the paradigmatic approaches that I followed, discussed the research design, selection of participants, methods of data collection and data analysis and interpretation. I also explained quality criteria strategies, ethical considerations and justified the methods I selected.

In this chapter I present the results of the study, based on the data I gathered during four focus group discussions, involving parents of learners who face intellectual challenges. I discuss the results in terms of the themes and subthemes identified. Throughout I include examples and excerpts from the raw data, to elaborate the discussion I provide.

After having familiarised myself with the raw data, reading and re-reading the transcriptions and field notes, I identified three themes and related subthemes, supported by relevant categories (Bryman, 2001; Boyatzis, 1998). Theme one relates to the process of diagnosis and referral of children with intellectual challenges. This theme entails the initial identification of intellectual challenges (subtheme 1.1), confirmation of the initial identification/diagnosis (subtheme 1.2) and referrals to special schools/institutions (subtheme 1.3). Theme two involves two sub-themes, namely sources of support (subtheme 2.1) and types of support received (subtheme 2.2). Theme three relates to types of support required on a deeper level (subtheme 3.1) and potential sources of support (subtheme 3.2).Figure 4.1 provides an overview of the main themes, subthemes and related categories.



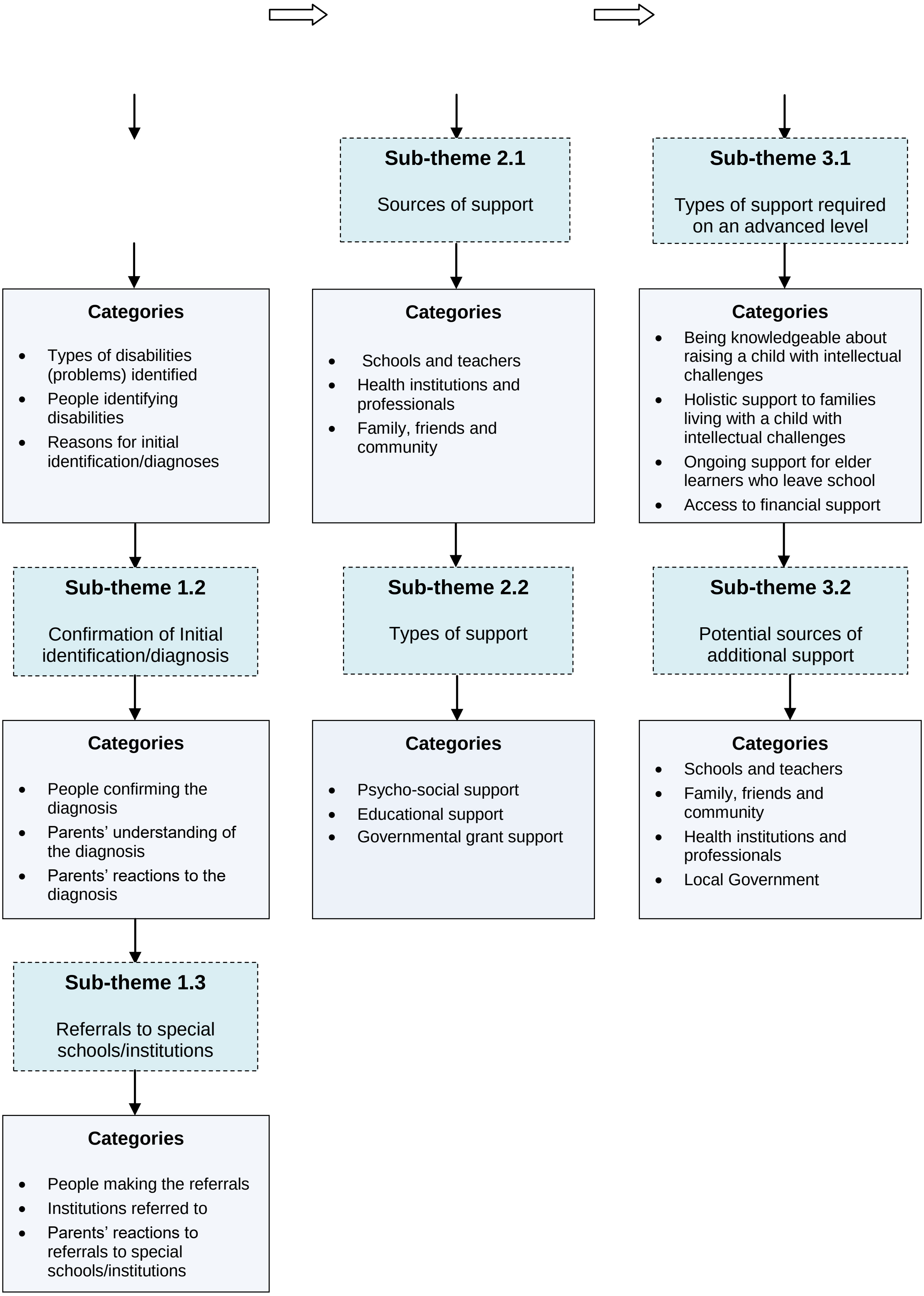


Figure 4.1: Themes, subthemes and categories

4.2 THEME 1: THE PROCESS OF DIAGNOSIS AND REFERRAL OF CHILDREN WHO FACE INTELLECTUAL CHALLENGES

Theme 1 reflects how parents experienced the process of diagnosis and referral of their children facing intellectual challenges. I identified three subthemes each consisting of related categories. Table 4.1 captures the inclusion and exclusion criteria I used in identifying the subthemes and categories for Theme 1.

Table 4.1: Inclusion and exclusion criteria for Theme 1

Subtheme/Category	Inclusion Criteria	Exclusion Criteria
Subtheme 1.1:		
Initial identification of intellectual challenges	All data related to the initial identification of children experiencing intellectual challenges	Any reference to processes following initial identification by means of diagnosis
Category (a) Types of disabilities (problems) identified	All data related to types of disabilities identified as part of initial diagnoses	Data that refers to people identifying disabilities or reasons for diagnosis
Category (b) People identifying disabilities	All data related to people identifying and diagnosing intellectual challenges	Data that focuses on the types of disabilities or reasons for initial diagnosis
Category (c) Reasons for initial identification/diagnoses	All data that reflect reasons for initial diagnosis of intellectual challenges amongst learners	Data related to types of disabilities or people identifying disabilities
Subtheme 1.2:		
Confirmation of initial identification/diagnosis	All data related to confirmation of intellectual challenges experienced by children	Any reference to initial identification or referrals by means of diagnosis
Category (a) People confirming the diagnosis	All data related to people who confirmed the diagnosis	Data that reflect types of disabilities
Category (b) Parents' understanding of the diagnosis	Any data indicative of parents' understanding of the diagnosis	Data that refer to parents' reaction or initial diagnosis
Category (c) Parents' reactions to the diagnosis	Data that reflect parents' reaction after learning about the diagnosis of the child	Data that reflect initial identification or parents' understanding thereof
Subtheme 1.3:		
Referrals to special schools/institutions	Data related to referrals to special schools and other	Data that reflect referrals to doctors or other

Subtheme/Category	Inclusion Criteria	Exclusion Criteria
	related institutions	professionals
Category (a) People making the referrals	All data related to people making referrals	Data that reflect people diagnosing intellectual challenges
Category (b) Institutions referred to	All data that identifies institutions referred to	Data that reflect referrals to people or people who make referrals
Category (c) Parents' reactions to referrals to special schools and institutions	Data that indicates parents' reactions as a result of referrals	Data that reflect parents reactions to initial diagnosis

4.2.1 SUB-THEME 1.1: INITIAL IDENTIFICATION OF INTELLECTUAL CHALLENGES

Sub-theme 1.1 captures the experiences of parents during the initial phase of their children being identified as facing intellectual challenges. The experience of this process varied across families and different types of disabilities as captured in the related categories.

4.2.1.1 Category (a): Types of disabilities

The initial part of all focus group discussions focused on parents reporting on the way they discovered or learned about their children‘s intellectual challenges. In these discussions parents referred to the types of disabilities that were initially identified, illustrating some trends in the identification of different types of disabilities and the subsequent intervention and referrals thereof. The following types of disabilities were mentioned by the parents and are discussed as subcategories in this section: cerebral palsy, attention deficit hyperactivity disorder (ADHD), Down syndrome, brain defects/brain injuries (hydrocephalus), and learning disability.

- **Cerebral palsy**

Most parents who reported that their children were diagnosed with cerebral palsy indicated that they became aware of their children's intellectual disability at birth. Medical specialists such as doctors and paediatricians reportedly informed the parents about their children's condition even though some parents indicated that doctors delayed conveying the massage about their children's health condition. Few parents reported that, after giving birth to their children, they were sent home without their children. This apparently made them suspicious that something could be wrong with their children, resulting in them subsequently enquiring into this possibility and finding out about the diagnosis. Participants said:

> *"I asked the doctor as to what was the problem with my child the doctor then told me that my child is disabled and he might take time to walk, talk and any other developmental areas like brain and thinking. He also mentioned that he did not want to tell me earlier because other people run away and leaves their children behind upon discovering that their children were born with severe disabilities..."* (focus group1, P[1](i), lines 216-224*).*

> *"At birth X was not the same as other children, the doctors then referred us to the speeches and special school when he was 7 years old..."* (field notes, focus group 1, P(i), pg[2] 4).

Another participant reported:

> "... *immediately after delivery, my son was taken to the Intensive Care Unit (ICU) while I was discharged to go home and leave him behind; I was also told that when I come back I must bring an elderly person with me and they did not tell me what was happening with my child. On my return to the hospital I was told that my son was born with Cerebral Palsy..."* (focus group 2, P(d), lines 711-718).

Diagnosis of cerebral palsy was reported by parents in all focus group discussions, highlighting that this type of disability is often encountered. Examples of parents' stories include:

> *"My son was born with cerebral palsy and mental retardation, he was developing slower and it took him long to walk..."* (focus group 4, P(f), lines 2064-2066).
>
> *"She was diagnosed with cerebral palsy and they also explained many things relating to her developmental milestones...*" (focus group 3, P(g), lines 1463-1465).

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[1] P means participant

[2] Pg means page

> *"I was told that my son was born with cerebral palsy and as such he will be slower..."* (focus group 2, P(d), lines 716-718).

> *"We took her back to the hospital where she was diagnosed with cerebral palsy as a result of head injuries..."* (focus group1, P(h), lines 84-85).

❖ Attention deficit hyperactivity disorder (ADHD)

Most of the parents of learners who had been diagnosed with ADHD reported that they discovered this when their children started school or pre-school. One of the mothers said:

> *"I took him to a crèche where teachers were complaining about his inability to sit still and pay attention like other children. This pushed me to then take him to Bara for assessment where he was diagnosed with attention deficit hyperactivity disorder (ADHD)..."* (focus group 2, P(e), lines 728-734).

Another parent reported a similar experience, even though with a child who was older during the time of diagnosis. The mother said:

> *"I became worried when she was 12 and still at grade 2 and struggling at school. The district referred us for assessment where she was diagnosed with ADHD..."* (field notes, focus group 1, P(a), pg 7).

❖ Down syndrome

One parent reportedly found out that her child was born with Down syndrome at birth, while another parent indicated that she discovered this four months after birth. The first parent mentioned potential reasons for the diagnosis:

> *X was born with Down syndrome because I was already overage when he was conceived. He also had a heart problem and was attending a cardiac clinic until he was healed..."* (focus group 2, P(h), lines 771-774).

The other parent reported:

> "*After four months* my *mother told me that my son was too quiet and was not crying at night like other children of his age and this need to be*

> *investigated. As a result I took my son to hospital for check up. At the hospital they referred me to a genetic counselling ward and that is where I learned that my son was born with Down syndrome..."* (focus group 2, P(g), lines 756-763).

❖ Brain defects/brain injuries

Diagnosis of brain injuries were reported by participants in three of the focus group settings. Parents reported their cases as follows:

> *"My son was born with brain injuries, but started at kindergarten like other children and went to a normal public school..."* (focus group 4, P(g), lines 2071-2073).

> *"We took her back to the hospital where she was diagnosed with cerebral palsied as a result of head injuries..."* (focus group 1, P(h), lines 84-85).

> *"She was diagnosed with brain injury and epilepsy and I was advised to take her to a special school and that is why I am here..."* (focus group 3, P(c), lines 1405-1407).

Related reports by parents include the following examples which apply to children being identified with brain challenges as well as hyperactivity.

> *"I had to take her to Bara where an electroencephalogram (EEG) examination was conducted and she was diagnosed with moderate retardation and hyperactivity. I took her to a remedial school where she was referred to a special school as she could not cope at that school. I then took her to School B and she's been here since..."* (focus group 2, P(j), lines 807-813).

> *"At Bara the doctors confirmed that they were hyperactive in addition one of them was also diagnosed with mental retardation..."* (focus group 3, P(f), lines 1442-1444).

Two cases of children who were diagnosed with hydrocephalus were described during the second focus group discussion. Participating parents narrated their unique experiences in the following way:

> *"After giving birth to my son I was discharged without him. He was left behind at the Baragwanath hospital (Bara) for a month because he was born with hydrocephalus (water in the brain). After one month in hospital I was called by the doctors to be told formally about the health condition and its implication towards his development..."* (focus group 2, P(a), lines 659-665).

> *"After some tests were administered, a nurse came to deliver news that my daughter has hydrocephalus: a condition in which there is abnormal accumulation of fluid in the head"* (focus group 2, P(c), lines 698-701).

- **Learning disability**

Some parents reported that their children's intellectual challenges were discovered at school e.g. by the Department of Education's district officials. These parents specifically referred to children being identified as slow learners or as experiencing learning disabilities. One of the participants explained:

> *"I live with 4 children that I am taking care of; two of them had already been diagnosed with learning disability before they started attending school and were referred to a special school as a result..."* (focus group 3, P(j), lines 1484-1487).

Another parent whose child was also identified as a slow learner reported her experience:

> *"The school eventually called me and explain that she was a slow learner who needs to be taken to the special school..."* (focus group 4, P(c), lines 2041-2043).

4.2.1.2 Category (b): People identifying disabilities

The participants shared various personal experiences regarding the initial identification of their children's intellectual challenges, specifically in relation to the people being involved in the process of identification or initial diagnoses. The following people were mentioned as key figures in identifying disabilities: health professionals, schools and family members.

❖ Identification by health professionals

Many parents mentioned health professionals when asked about the initial identification/diagnosis process, primarily in hospital settings. Some example of the prominent role of health professionals are captured in the following excerpts:

> *"On my return to the hospital I was told that my son was born with cerebral palsy and as such he will be slower developmentally as this disorder affects muscle tone, movement, and motor skills the ability"* (focus group 2, P(d), lines 716-720).
>
> *"This compelled me to take him to a doctor for medical assessment. The doctor then referred us to Bara hospital where he was diagnosed with hyperactivity"* (focus group 3, P(d), lines 1421-1424).
>
> *"I took my son to hospital for check up. At the hospital they referred me to a genetic counselling ward and that is where I learned that my son was born with Down syndrome"* (focus group 2, P(g), lines 760-763).
>
> *"One day while at the crèche she had an epileptic fit attack and I was called to take her to the hospital. After some tests were administered, a nurse came to deliver news that my daughter has hydrocephalus: a condition in which there is abnormal accumulation of fluid in the head"* (focus group 2, P(c), lines 696-699).
>
> *"After giving birth to my son I was discharged without him. Then, after one month in hospital I was called by the doctors to be told formally about the health condition and its implication towards his development"* (focus group 2, P(a), lines 659-665).
>
> *"When she was about ten years old we were referred to the hospital for assessment and she was diagnosed with brain injury and epilepsy..."* (focus group 3, P(c), lines 1402-1405).

❖ Identification by schools

Several parents indicated that educators and grade-R practitioners initially identified their children as experiencing intellectual challenges. Schools were mentioned in all focus groups as being at the forefront in identifying intellectual challenges amongst children. According to the participants, most of such initial identifications were done in mainstream schools, often resulting in referrals by schools for formal assessments in order to confirm the schools' identification and initial screening process. Parents mentioned the following examples:

> *"Initially I was told by the teachers that my son is short sighted and cannot see from a distance as such he was placed in the front row of a class room. After some time, later it was discovered that my son has learning disabilities and was not coping with academic work and as such he must be taken to a special school"* (focus group 1, P(j), lines 226-230).
>
> *"My child was initially discovered by a teacher at grade 1 that she was not coping with academic work"* (focus group 2, P(f), lines 740-741).
>
> *"When she was attending a preschool educators called me to the school to tell me that my daughter was showing signs of hyperactivity and attention disorders"* (focus group 2, P(i), lines 790-792).
>
> *"In February just few weeks after his admission to the school I was called by his class teacher to tell me that my son is having learning problems as he could not write and was not coping with the school work as such they recommend that I take him to the hospital for assessment. I took my son to the clinic where a psychiatric evaluation was administered and we were referred to the special school"* (focus group 3, P(b), lines 1383-1392).
>
> *"When he was in grade one we were called to the school to be informed that our son was not making appropriate progress academically and he was showing signs that his problem were severe, but they will refer him to the district for formal assessment and screening"* (focus group 4, P(b), lines 2027-2032).

❖ Identification by parents and family members

Some parents stated that their children were initially identified by themselves and by other family members as being at risk of experiencing intellectual challenges before entering school. Often, parents themselves were not as alert as family members, as captured in the examples below:

> *"It took her long time to talk, walk and sit. People in the family have started to notice that she has a disability but I was not aware. When she was three years I had to take her to Bara where an electroencephalogram (EEG) examination was conducted and she was diagnosed with moderate retardation and hyperactivity"* (focus group 2, P(j), lines 802-810*).*
>
> *"She was discovered by my uncle that she was lacking in speech and communication as she could only articulate the word Mama (mother) and nothing beyond and she was already two and a half years old"* (focus group 2, P(i), lines 785-788; field notes, pg 45).

4.2.1.3 Category (c): Reasons for initial identification/diagnosis

From the responses provided by the parents during the focus group discussions, it became apparent that not all children experiencing intellectual challenges were diagnosed prior to entering the formal school system. Some learners who faced challenges were reportedly only noticed a while after they began formal schooling. In terms of the reasons for initial identification, three primary reasons were provided. Some parents indicated that their children were born with disabilities; others noticed that their children did not reach developmental milestones as expected, while a group of participants reported poor academic performance as the reason for diagnosis.

❖ Born with a disability

Several parents attributed the diagnosis of their children to the children being born with disabilities. The following examples demonstrate that some children born with intellectual challenges had abnormalities that were apparent at birth or shortly after:

> *"X was born short sighted but we took him to a normal public school. When he was 7 years old in grade 1, I was called to the school by the teacher to*

> *say that James was not coping well with school work, he was always lagging behind and they were suspecting that he was a learner with special educational needs (LSEN) candidate"* (field notes, focus group 1, P(j), pg4).
>
> *"X was born with birth defects or disabled as he did not look like other children, he had problems with body movement and posture as his neck was as if it was loose and could not stay upright. His body was floppy"* (focus group1, P(i), lines 122-126).
>
> *"At birth my child did not cry and even after three days. I was discharged to go home and I was told that he was going to cry maybe later and nothing was said about my child's disability..."* (field notes, focus group 3, P(g), pg 72).

❖ Not reaching developmental milestones

Various parents reported diagnoses of intellectual disabilities after the birth of a child due to concerns when the child's expected developmental milestones started lagging behind. The majority of the parents indicated that this typically occurred when their children entered school or during the pre-school phase. Parents reported on their experiences in the following way:

> *"I started to notice that X was not developing like other children of his age because when he was two years old he was not crawling like other children of his age. This worried me and tempted me to take him to the clinic to find out about this problem"* (focus group 1, P(e), lines 9-13).
>
> *"When my son was 3 years old I noticed that he was not active like any child of his age, however I told myself that perhaps this is because he is a sweet child and even in the streets people confirm this by echoing my belief that he is a sweet child. This has been happening for some time until one day my Aunt (his granny) said to me your child needs a little smacking, slapping, or spanking so that we can hear him talk, make noise and be active like other children of his age"* (focus group 1,P(c), lines 28-36).
>
> *"When my daughter was in grade R, I noticed that she was playing with children far younger than her and she was 6 years old. I thought this was*

> *just a passing phase as she was still at the preschool level"* (focus group 1, P(d), lines 46-49).
>
> *"I had a normal delivery during birth, but my daughter delayed in walking, she walked when she was two years, at that time I noticed that her head was growing bigger in an abnormal way"* (focus group 1, P(c), lines 692-695).
>
> *"I had a normal delivery at meadowlands clinic, after delivery I went home with my child. After four months my mother told me that my son was too quiet and was not crying at night like other children of his age and this needs to be investigated"*(focus group 1, P(g), lines 755-760).
>
> *"I had a normal delivery but my daughter was developing slower as compared to other children of her age. It took her a while to be able to talk, walk and sit'* (focus group 1, P(j), lines 800-803).

- **Poor academic performance**

Some parents reported that despite their children's normal outward appearance, they started experiencing intellectual challenges after the pre-school period or when expected to perform academically. Parents seemed confused and frustrated about these diagnoses. One parent expressed her disbelief and doubt about the outcome of a diagnosis by saying:

> "*Since my child was born normally and she looks normal and does not have any visible signs of disability she looks like any other child in the street I had a serious problem in accepting and understanding the outcomes of her diagnosis"* (focus group 2, P(i), lines 913-918).

Another parent recounted how her child's intellectual challenges became apparent in the early stages of schooling and what a frustrating experience this was

> "*My son X was born normal he looks normal. In February just few weeks after his admission to the school I was called by his class teacher to tell me that X is having learning problems as he could not write and was not coping with the school work .as such they recommended that I take him to*

> *the hospital for assessment"* (focus group 3, P(b), lines 1378-1389), and later:
>
> *"He is still struggling to write, though he can write his name, sometimes he refuses to write. I do not know as to what is his problem or a source of this learning disability"* (focus group 3, P(b), lines 1392-1395).

Many parents indicated that learners' challenges were often noticed only a long time after they had entered formal schooling. In all four focus groups, parents reported the fact that their children experienced a series of failures and that some even had to repeat grades before their intellectual challenges were formally diagnosed. Examples are captured in the verbatim extracts below:

> *"My child has been repeating grades and the principal was refusing to let him go to a special school until he was 12 years and still in grade 2"* (focus group1, P(a), lines 112-116).
>
> *"When she was at grade 3 because of the principle of pass one passes all, I contacted the school and demanded that they must get my child a special school"* (focus group 2, P(f), lines 749-752).
>
> *"She started to attend school in the mainstream school and has been failing and repeating grades and when she was in grade one the teachers had already started complaining that she was not coping with school work"* (focus group 3, P(c), lines 1398-1402).
>
> *"After repeating the first grade she was pushed forward to the next grade and thereafter consistently repeated other grades until the school eventually called me and explain that she was a slow learner and needs to be taken to the special school"* (focus group 4, P(c), lines 2040-2044).

4.2.2 SUBTHEME 1.2: CONFIRMATION OF INITIAL IDENTIFICATION/ DIAGNOSIS

After being alerted to the possibility of their children experiencing intellectual challenges, parents typically sought further clarity about their children's health status in the form of confirmation of the diagnosis. Three categories apply: (a) people confirming the diagnosis, (b) parents' understanding of the diagnosis; and (c) parents' reaction to the diagnosis.

4.2.2.1 Category (a): People confirming the diagnosis

Parents identified doctors, health professionals, and teachers as the people who assisted them in confirming a diagnosis of intellectual challenges with their children. One parent reported how the doctor provided confirmation:

> "*The neighbours have been saying things about his unusual behaviour and the doctors have confirmed that he is hyperactive to an extent that they prescribed medication to assist with controlling his behaviour...*" (focus group 1, P(e), lines 850-853*).*

Another parent reported on her experience:

> "*I took him to a crèche where teachers were complaining about his in ability to sit still and pay attention like other children. This pushed me to then take him to Bara for assessment where he was diagnosed with an attention deficit hyperactivity disorder (ADHD)...*" (focus group 2, P(e), lines 731-734).

Closely related, mothers explained:

> "*My child was initially discovered by a teacher at grade 1 that she was not coping with academic work. I was called to the school to discuss my daughter's academic performance and they told me that as a result she was going to repeat grade one in the following year and I agreed to that...*" (focus group 2, P (f), lines 740-745).
>
> *"When she was attending a preschool educators called me to the school to tell me that my daughter was showing signs of hyperactivity and attention disorders..."* (focus group 2, P(i), lines 789-791).
>
> *"When my daughter was about five years old and still attending a crèche the teachers made me aware that my child was at risk for learning disabilities and I must take her to the hospital for medical assessment..."* (focus group 3, P(h), lines 1470-1473).

Some parents sought further clarity about their children's health status after initial diagnosis. Confirmation was reportedly given by different agencies involved in supporting people who face intellectual challenges. A parent who consulted different professionals reported:

> "*After my son was diagnosed with Down syndrome, I did not accept this outcome, though in our family there are a number of people who have disabilities and we are an educated family. I started to seek for more information from the doctors, speech therapists and others. I then managed to accept this diagnosis and my family was behind me and supporting me..."* (focus group 2, P(h), lines 870-876).

4.2.2.2 Category (b): Parents' understanding of the diagnosis

Only a few parents seemed satisfied with the way in which diagnoses were explained to them:

> "*The diagnosis given by the professionals made sense and helped me to accept my child's predicament and look forward to support her..."* (focus group4, P(a), lines 2111-2114).

The majority of the participating parents indicated that they found it challenging to understand the professionals explaining the diagnosis to them. Participants summarised their experiences:

> *"I was sent to a psychiatric department where the doctors called me after their examination on my son and told me that my son has a mental problem. I was not sure what they meant by that. As this to me it meant that my son was crazy I sought for clarity from the doctor..."* (focus group 1, P(e), lines 16-20).

> *"Like I said earlier that when I was told by the doctors about the health condition of X and its implication towards his development, I was young and some of the things they were saying did not make sense to meet that time and I think things like schooling and education were not discussed as I was worried about my child's health..."* (focus group 2, P(b), lines 822-828).

Several parents added that their growing realisation and understanding of the implications of the intellectual challenges their children faced gradually took place in their lives and those of their children. The following serve as examples:

> *"I saw my son's neck being spongy and twisting uncontrollably and these signs made me to understand and accept the reality I was faced with and move on to support him in whatever way that I could..."* (field notes, focus group 2, P(d), pg 43).
>
> *"I did understand the diagnosis, especially after I have discovered myself when trying to help him with his school work. He was unable to repeat the tasks that he did few minutes ago..."* (focus group 4, P(d), lines 2139-2142*).*
>
> *"My son was born with cerebral palsy and I was told about the implication of this disability towards academic development and was also advised that he will have to attend at a special school. However, my son started at a normal crèche with other normal children but later went to attend at a special school when he was at the relevant school going age. I did not have a problem with that as I could see that he had obvious and visible intellectual disabilities..."* (focus group 2, P(b), lines 836-844).
>
> *"It was difficult for me to accept the diagnosis. However, I soon realised and reminded myself that in our family there is a disability. My Aunt is a disabled person. I eventually took my son to a special school and on arrival at the school, I saw worse cases than mine..."* (focus group 3, P(g), lines 1591-1595).

4.2.2.3 Category (c): Parents' reactions to the diagnosis

Parents' reactions to the diagnoses of their children as being intellectually challenged ranged from non-acceptance and denial to anger and disbelief. In all four focus groups, parents expressed their disbelief and resistance to accept the diagnosis:

> *"I did not want to accept the diagnosis but the fact that within the family there are other people with disabilities .did not matter..." (*focus group 2, P(g), lines 763-766).

> *"I was confused and angry because I made an effort by asking the doctor about the possibilities of giving birth to a normal child. I think the doctor was not honest about the report he gave me regarding my son's development..."* (focus group 1, P (a), lines 155-160).
>
> *"Initially I thought there was an error in their assessment as my child did not have any developmental deficits"* (focus group 4, P(e), lines 2149-2154*).*
>
> *"After my son was diagnosed with Down syndrome, I did not accept this outcome, though in our family there are a number of people who have disabilities..."* (focus group 2, P(g), lines 893-895).

A number of participants reported that they felt confused, based on the diagnoses that were made. They allegedly felt frustrated with the situation, as captured in the following excerpts:

> *"It was not easy to understand because my son looks normal, and as such I did not want to accept the referral. I am asking myself questions that I could not get answers..."* (field notes, focus group 3, P(b), pg 74).
>
> *"I was not sure what they meant by that, as this to me meant that my son was crazy. I then sought for clarity from the doctor ..."* (focus group 1, P(e), lines 16-20).
>
> *"This has been confusing me and I have been asking myself some questions that I could not be able to answer about the outcome of my child's psychiatric assessment. I have accepted the diagnosis without understanding..."* (focus group 3, P (b), lines 1522-1526).
>
> *"After the diagnosis we became confused and wanted to know more at the same time but we were too weak to grasp information about managing a child with intellectual disability..."* (focus group 1, P(d), lines 566-569).

Some parents managed to gradually accept their children being diagnosed as intellectual challenged as time passed, or due to the realisation that the disability is a reality that had to be managed. Examples include:

> *“Though initially I was denying the diagnosis given, as time went on I learnt to accept the health condition of my daughter”* (focus group 2, P(c), lines 851-853).
>
> *“It is painful to me as a parent but there is nothing I can do but to accept this condition...”* (focus group 4, P(h), lines 2181-2182).

> *“It was difficult for me to accept the diagnosis. However, I soon realised and reminded myself that in our family there is a disability”* (focus group 3, P(g), 1592-1595).

> *“My son was born with cerebral palsy and I was told about the implication of this disability towards academic development and was also advised that he will have to attend at a special school. I did not have a problem with that as I could see that he had obvious and visible intellectual disabilities....” (*focus group 2, P(b), lines 837-845).

4.2.3 SUBTHEME 1.3: REFERRALS TO SPECIAL SCHOOLS / INSTITUTIONS

Three categories relate to this subtheme, namely: (a) people making the referrals, (b) institutions referred to and (c) parents’ reactions to referrals to special schools and institutions.

4.2.3.1 Category (a): People making the referrals

In line with their primary role in confirming the initial identification/diagnosis, parents mentioned doctors, health professionals and the Department of Education as key figures in making referrals or advising parents to enrol their children in schools for special needs, or obtain related services. Many parents referred to doctors when discussing the referrals of their children. One of the parents explained:

> *“The doctors told us that when X reaches school going age we must take her to a special school, because all her developmental aspects will be slower than any other child and we must be patient with her...”* (focus group 1, P(h), lines 204-207).

Other parents indicated that they were referred to special schools and related services by school teachers and Department of Education district officials. One parent shared the following experiences:

> "*There was never any improvement as he started schooling at the mainstream and I was told by the teachers that he is not coping academically and I must get him a space in the nearest special school. Hence, I am here...*" (focus group 1, P(c), lines 40-44).

Another parent related a similar story:

> "*When he was 7 years and repeating grades, teachers called me to say your child need a special school; though I was not sure about what they were saying I did as I was told...*" (field notes, focus group 1, P(j), pg 10).

Participating parents, who were referred by the Department of Education, expressed their experiences as follows:

> *"I contacted the school and demanded that they must get my child a special school. The GDE district intervened and my child was sent to school B."* (focus group 2, P(f), lines 730-733).

> *"It was then that my child was referred to the department of education district office for assessment after which, we were referred to a special school as she could not cope in the mainstream school..."* (focus group1, P(a), lines 117-120).

4.2.3.2 Category (b): Institutions referred to

Although many of the contributions focused on schools for special needs, parents also described how the process of referrals led them to visit a number of professionals, clinics and other institutions, with one visit often resulting in another. Parents consulted psychologists, counsellors, speech therapists and other professionals as evident in the following examples:

> *"I consulted with the psychologist for three sessions regarding my child's learning difficulties and after the third session, I was advised to take my daughter to a special school..."* (focus group 4, P(j), lines 2184-2187*).*

> *"At the hospital they referred me to a genetic counselling ward and that is where I learned that my son was born with Down syndrome. He grew up as a sick child as I was in and out of hospitals and clinic. I even asked for his IQ to be checked and the results supported the diagnosis and that is why he was taken to a special school..."* (focus group 2, P(g), lines 740-749).
>
> *"I then consulted with a speech therapist and a psychologist as a result. Initially they advised me to take her to a school where learners are taught in their mother tongue and I did that. However, the problem was still there even in the mother tongue school and as such I was advised to take her to a special school..."* (focus group 2, P(i), lines 793-799).

Although some parents seemed satisfied with the referral of learners to schools for special needs following the identification of a learner not coping with scholastic demands, some parents complained about the lengthy process implied by referrals. Parents were of the opinion that mainstream schools often tend to keep learners in schools for too long before they would refer them. Two participants summarised this view and their associated feelings about their experiences:

> *"My child attended normal school. However, during those school years my child has been repeating grades and the principal was refusing to let him go to a special school until he was 12 years and still in grade 2..."* (focus group 1, P(a), lines 111-116).
>
> *"They told me that as a result she was going to repeat grade one in the following year and I agreed to that. As years passed by I also realised by myself that my daughter has a learning problem and I wanted her to be removed from that school as she was starting to despise school because other learners laugh at her. When she was at grade 3 because of the principle of pass one passes all, I contacted the school and demanded that they must get my child a special school..."* (focus group 2, P(f), lines 743-752).

4.2.3.3 Category (c): Parents' reactions to referrals to special schools or institutions

When discussing referrals during focus group interviews, parents indicated a range of reactions on their sides. Some reportedly merely accepted the referral, in support of their children. Others seemingly struggled to accept referrals, reacting with emotions such as anger, sadness, denial, and doubt. These subcategories are discussed below.

- **Accepting the referral**

Even though many parents seemingly reacted with initial hostility when their children were referred for professional support, a large proportion of them quickly regained their strength and accepted the reality that had unfolded. Many of the participants related their acceptance of referrals to the realisation that they were not alone and that others could support them in dealing with the challenges they faced. The following excerpts provide examples of such experiences:

> *"Though I was not sure about this I respected their advice and took my son to the recommended school. I also noticed when I tried to help him with school work that he was struggling in many areas of school work like doing simple arithmetic. In essence all these barriers were identified when he was seven years at the school. The school then advised us to seek space for my son in the special school. They assisted me to find him a space here at School..."* (focus group1, P(j), lines 232-240*).*

> *"By the time my child was sent to the special school, I had already witnessed her suffering in the mainstream school and in actual sense it was me who put pressure to her previous school to find her a special school. The school had already called me several times about her leaning problems but still kept her at the school until I stood up and pushed them to take her to the district for assessment and referral..."* (focus group 2, P(f), lines 882-889).

> *"I did not want to come to this school, until one day I decided that no; I am not going to stay with my child at home when other children are at school*

> *somewhere." Even the doctors told me that she can still learn something in the special school..."* (focus group 1, P(d), lines 184-190).

A few parents however experienced difficulty in accepting referrals to special schools, as they did not see anything wrong with their children. One parent explained:

> "*Since my child was born normally and she looks normal and does not have any visible signs of disability she looks like any other child in the street I had a serious problem in accepting and understanding the outcomes of her diagnosis..."* (focus group 2, P(j), lines 914-919).

❖ Anger, sadness, denial and doubt

Some parents experienced anger, which one parent related to her being mislead by a doctor, indicating yet another form of denial. She reported:

> *"I was referred to the Department of Education district where district official made me to fill in some forms for my child to attend at this school; she was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). I was confused and angry because I made an effort by asking the doctor about the possibilities of giving birth to a normal child. I think the doctor was not honest about the report he gave me regarding my son's development..."* (focus group1, P(a), lines 151-160).

Some parents spoke with a sense of sorrow when describing their experiences upon learning of the referrals of their children to schools for special needs. Several parents shared their experiences of disbelief and doubt, for example saying:

> *"I did not understand because my child was born normal, she looks normal, act normal. I was on denial as a result..."* (field notes, focus group 1, P(d), pg 8).

> *"It was not easy for me to understand because my son is physically and mentally healthy. I just don't get it, it hurts when I look at him and I do not see anything wrong with my son. This has been confusing me and I have asking myself some questions that I could not be able to answer about the*

> *outcome of my child's psychiatric assessment. I have accepted the diagnosis without understanding..."* (focus group 3, P(b), lines 1519-1526).

> *"I was told that I must look for a special school for her. I did not understand as to how is this diagnosis relate to her inability to learn, because except for that speech problem she is a normal child and looks like any child in the street..."* (focus group 3, P(h), lines 1606-1611).

One of the parents indicated that she was doubtful and did not trust the diagnosis or referral. She described her experiences and her need for confirmation by the school as follows:

> *"I still cannot imagine this to be true I sometimes think that I took her to the special school based on a false and shallow observation by my neighbour. Though evidence of serial failure is there, I still think the school should have informed me about this long ago..."* (focus group 3, P(e), lines 1565-1570).

Closely related, another parent referred to schools failing to identify intellectual challenges on time. As a result parents became confused and frustrated:

> "*I was confused because on the streets they said she cannot read and write but the school has been pushing her to progress from one grade to the other until they were unable and couldn't push her any further ..."* (focus group 4, P(c), lines 2128-2136).

4.3 THEME 2: SUPPORT RECEIVED BY PARENTS OF LEARNERS WHO FACE INTELLECTUAL CHALLENGES

Theme 2 relates to the support received by parents that were reported during focus group discussions. I identified two subthemes, each consisting of related categories. Table 4.2 captures the inclusion and exclusion criteria I used in identifying the subthemes and categories for Theme 2.

Table 4.2: Inclusion and exclusion criteria for Theme 2

Subtheme/Category	Inclusion Criteria	Exclusion Criteria
Subtheme 2.1:		
Sources of support	Data related to sources of support for parents of learners with intellectual challenges	Data related to any support other than support for parents of learners with intellectual challenges
Category (a) Schools and teachers	Data that referred to schools and teachers as sources of support	Data related to health institutions, professionals, family, friends and community as sources of support
Category (b) Health institutions and professionals	Data that mentioned health institutions and professionals as sources of support	Data related to any source of support other than health institutions
Category (c) Family, friends and community	Data that referred to families, friends, and community as sources of support experienced by parents of learners who face intellectual challenges	Data related to schools and teachers or health institutions and professionals as sources of support
Subtheme 2.2		
Types of support received	Data related to types of support received by parents of learners who face intellectual challenges	Data that reflect types of disabilities
Category (a) Psycho-social support	Data related to receiving psycho-social support	Data that reflect educational and financial support services by the government
Category (b) Educational support	Data related to receiving educational support	Data that reflect psycho-social or financial support
Category (c) Governmental Support	Data related to receiving governmental grants	Data that reflect educational and psycho-social support

4.3.1 SUBTHEME 2.1: SOURCES OF SUPPORT

Subtheme 2.1 captures the views of the participating parents regarding their experiences of support received from people and institutions. Three categories relate to this subtheme, namely: (a) schools and teachers, (b) health institutions, and (c) professionals, families, friends and communities.

4.3.1.1 Category (a): Schools and teachers

Parents mentioned a range of experiences of support received from schools and teachers. The majority of parents spoke with appreciation when they shared their stories of support received from schools and teachers. The contributions include:

> *"As for my child we do not attend to any clinic or hospital as she does not have any visible/ obvious intellectual deficits. However, I still utilises the available assistance that our school offers, even though it is still not sufficient to cater for all of us..."* (focus group 1, P(a), lines 250-254).
>
> *"My son and I rely on the school for any support service needed by us. My son goes to hospital or clinic if he is only sick. For anything that has to do with his behaviour and developmental needs I consult with the school..."* (focus group 1, P(c), lines 276-280).
>
> *"Schools and educators are the key people involved in supporting me and the children*..." (field notes, focus group 2, P(i), pg 92).

Even though parents indicated that they consulted schools when they were in need of guidance and support, they also raised concerns about some of the schools for special needs being under-resourced and not able to support parents or guide them in the challenges experienced. In this regard, one parent reported:

> "*I do not know anything about any other support services that the government provide for my child except the school. Even though the school is also limited and under resourced to meet the needs of all these children..."* (focus group 3, P(h), lines 1688-1692).

4.3.1.2 Category (b): Health institutions and professionals

Health institutions and other health professionals (especially doctors) were highly valued by the majority of the participating parents, as key role players offering support outside the school environment. Parents said:

> *"The doctors gave me information about my son's condition and explain to me everything including how to help my son and to take him to a special*

> *school. I have been relying on the doctors for support me medically*..." (focus group 3, P(d), lines 1767-1772).
>
> *"Because of my children's condition I interact with the doctors on a regular basis. So, doctors are the most people that are involved in supporting me...*" (focus group 3, P(f), lines 1800-1802).

Only few parents reported that they did not interact with health professionals regularly, following the diagnosis of their children as being intellectually challenged. As such a limited number of parents did not perceive health professionals and institutions as a source of support, as captured in the following extracts taken from focus group transcripts:

> *"The only support I received from the professionals who diagnosed my son was their assessment of my son and recommendation thereafter..."* (focus group 4, P(b), lines 2250-2253).
>
> *"I did not have any interaction with the professionals as my son's learning problem was identified by the children in the neighbourhood and later by the school..."* (focus group 4, P(c), lines 2278-2281).

4.3.1.3 Category (c): Family, friends and the community

The majority of parents acknowledged the support they received from their families, friends and communities. Some examples of such support include financial and moral support to deal with diagnoses and being involved in the lives of the parents and their children, as captured below:

> *"My family too also support us especially her uncles give us a financial support because as of now she must go to Bara for a check up on the 10th of October..."* (field notes, focus group1, P (h), pg84).
>
> *"I think my family and the school are the most people involved in supporting me and my son..."* (focus group 2, P(a), lines 1027-1028).
>
> *"My family was behind me and supporting me by socialising ourselves behind this disability and when it was..."* (focus group 2, P(g), lines 1158-1160).

A few participants however, were allegedly not supported by their families or community. They expressed their experiences as follows:

> *"I do have a family, but they do not give me any support, even myself I was not accepted by family as I am and I have learnt to be strong for my child..."* (focus group1, P(a), lines 354-357).
>
> *"I do not have any support from my family. My ex-husband was not supportive and other siblings do not care..."* (focus group 1, P(e), lines 422-424).
>
> *"Except for the school I do not have any other form of support coming not even from my family members. However I am still managing to give my daughter all my support..."* (focus group 2, P(i), lines 1203-1206).

Other parents reported that certain individuals within their families seemed reluctant to offer support and help. The following excerpts capture these experiences, based on family members being reluctant to provide support due to denial or apparent ignorance on how to deal with such disability:

> *"I rely on my church for spiritual support and I also pray a lot for strength, tolerance and courage. Otherwise, I get support from the school and my mother though other members of the family are still on denial regarding my daughter's condition..."* (focus group 1, P(d), lines 386-391).
>
> *"My mother is the only person that assists me with my child and as for the other family members, they get irritated by my son's behaviour and they do not want to have anything to do with him because of his abnormal behavioural patterns..."* (focus group 1, P(c), lines 365-370).

4.3.2 SUBTHEME 2.2: TYPES OF SUPPORT RECEIVED

Subtheme 2.2 relates to the types of support received as identified by the participating parents. Three categories relate to this subtheme, namely: (a) psycho-social support, (b) educational support, and (c) governmental grant support.

4.3.2.1 Category (a): Psycho-social support

As part of the focus group discussions I requested the participants to describe their interactional relationships with the professionals involved in supporting them. These discussions highlighted some interesting trends regarding the type of support parents typically received, as well as an awareness and use of various psychosocial support services and other benefits available to parents when accessing support. Amongst other things, parents seemingly valued directed advice, guidance and counselling they received from others who psycho-socially supported them. The following extracts from focus group discussions provide examples of the type of psycho-social support received by the parents:

> *"I saw a psychologist in KZN and I was advised to take my daughter to a special school...."* (field notes, focus group 3, P(c), pg 86).
>
> *"I got counselling and guidance from the doctors who diagnosed my daughter and this assisted me to accept my challenge and to move on. As such I consulted with all other relevant professionals through the referrals made and recommended by the doctors..."* (focus group 2, P(j), lines 1178-1180).
>
> *"I got the support, guidance and counselling that I needed especially from the genetic counselling department at Bara..."* (focus group, P(h), lines 1153-1156).

4.3.2.2 Category (b): Educational support

As already indicated, parents were positive about and valued the educational support they continually received from their children's schools. More specifically they seemed appreciative of the advisory role that schools fulfilled. Advice often focused on accepting the diagnosis and on ways that the school could benefit the child, as captured below:

> *"Teachers at the stimulation centre were the ones who helped to understand my child's disability. They even told me to take him to a special school as she was functioning at a higher level than that of stimulation children..."* (focus group 2, P(c), lines 1065-1070).

> *"The support and guidance I got from the educators and the principal from the previous school who advised me to take my son to a special school, plus the one he is presently receiving from this school is appreciated..."* (focus group 1, P(j), lines 636-640).
>
> *"No formal counselling was received. However the crèche helped me to accept and understand that my son will have to go to a special school..."* (field notes, focus group 2, P(a), pg 52).

4.3.2.3 Category (c): Governmental grant support

Some parents expressed their appreciation for and acknowledgement of the support they received from the South African government in the form of social and disability grants. One parent recounted:

> "*X has always been supported at Baragwanath Hospital and the school and is also receiving a disability grant from the government..."* (focus group 2, P(h), lines 985-987).

Another parent reported how a care dependency grant assisted her to foster her late sister's child:

> "*You must remember that her mother passed when she was only a year and half old. So the social development took it upon them to make sure that Fatima was in the safe hands. As such we receive a care dependency grant on behalf of X"* (focus group1, P(h), lines 303-307*).*

Similarly, another parent expressed her gratitude for the disability grant allowing her to pay her son's boarding school facility:

> "*Though my son is 19 years old now and stays here in the school, he does no longer frequent Bara hospital like before he gets all the support here. He also receives a disability grant which is used to pay for his stay here..."* (focus group 3, P(g), lines 1682-1686).

Even though most parents acknowledged and valued the support they received, especially from schools, they were also vociferous in terms of an ongoing need for additional support. This view constitutes the next theme.

4.4 THEME 3: ONGOING NEED FOR ADDITIONAL SUPPORT

The third theme I identified from the focus group data relates to the ongoing need of parents for additional support. Two subthemes apply, each consisting of related categories, namely the type of support required on an advance level, and potential sources of support. In table 4.3 I summarise the inclusion and exclusion criteria I used in identifying these subthemes and related categories.

Table 4.3: Inclusion and exclusion criteria for Theme 3

Subtheme/Category	**Inclusion Criteria**	**Exclusion Criteria**
Subtheme 3.1		
Types of support required on an advanced level	Data related to the types of support required by parents on an ongoing advanced level	Data that reflect support required by learners who are facing intellectual challenges
Category (a) Being knowledgeable about raising a child with intellectual challenges	All data that refer to the need to be knowledgeable about raising a child who face intellectual challenges	Data that reflect a need to be knowledgeable about types of disabilities
Category (b) Holistic support to families living with a child with intellectual challenges	All data that refer to the need to holistically support families living with a child who face intellectual challenges	Data that reflect a need for individual support of learners facing intellectual challenges
Category (c) Ongoing support for elder learners who leave school	All data that relate to a need for ongoing support for elder learners who leave school	Data that reflect elder learners who still attend schools
Subtheme 3.2		
Potential sources of support	Data related to potential sources of further support for the parents of learners who face intellectual challenges	Data that reflect additional sources of support for learners who are facing intellectual challenges
Category (a) Schools and teachers	Data that refer to schools and teachers as potential sources of support	Data that reflect health institutions, family and friends or government as source of support

Subtheme/Category	Inclusion Criteria	Exclusion Criteria
Category (b) Family, friends and community,	Data that relate to family, friends, and community as sources of support	Data reflecting schools and teachers, professionals or government as source of support.
Category (c) Health institutions and professionals	Data that relate to health institutions and professionals as sources of support	Data that reflect government, family or schools as sources of support
Category (d) Local government	Any data that relate to identifying governmental grant as a potential source of support	Data that reflect health and education institutions, family, friends and community as sources of support

4.4.1 SUBTHEME 3.1: TYPES OF SUPPORT REQUIRED ON AN ADVANCED LEVEL

In the previous subthemes I indicated how some parents identified various types of support they had received from different agencies. When asked about their views and suggestions to improve the support already rendered, responses indicated an ongoing need for additional support. This need was located within four main categories: (a) being knowledgeable about raising a child who faces intellectual challenges, (b) holistic support to families living with a child who faces intellectual challenges, (c) ongoing support for elder learners who leave school, and (d) access to financial support.

4.4.1.1 Category (a): Being knowledgeable about raising a child who faces intellectual challenges

Most parents expressed the need for more information on how to raise a child facing Intellectual challenges. Parents felt challenged by not having sufficient knowledge regarding their child's intellectual and related challenges, and what they could do to assist. The following quotations capture general feelings of these parents:

> *"I would really like to know more about my child's needs because sometimes I do not understand or know how to help him..."* (field notes, focus group 3, P(b), pg 95).

> *"We need to get more knowledge about these disabilities so that we can be able to help and understand our children. Sometimes these children display number antisocial behaviours and we become confused and we do not know what to do as parent..."* (focus group 1, P(c), lines 559-564).

> *"We need to get more knowledge about these disabilities so that we can be able to help and understand our children..."* (focus group 4, P(b), lines 2463-2465).

4.4.1.2 Category (b): Holistic support to families living with a child facing intellectual challenges

Many parents raised concerns about the apparent lack of holistic participation by all members of the family. They seemingly felt that other family members were not always knowledgeable about caring for the disabled child in a family situation. This raised fears among these parents, as they could not anticipate what would happen to their children should they fall away. This concern in terms of future support to children facing intellectual challenges was explained by a mother in the following manner:

> *"Families must be supported and empowered as a whole so that we can all participate as a family in helping the child. I am scared of XS' future as to what will happen to him if I die, because I am the only one who seems to know when it is time for hospital visit and other things if we can have social workers to come assist the family to be able to work as a team around this disability..."* (focus group1, P(e), lines 586-594).

Another parent whose family was reportedly not supportive and had always been ignorant of the academic development of her child voiced her frustrations in the following way:

> *"I still find it difficult to deal with questions that my family back in KZN often asks. For example they will ask me as to what is a special school, and what do they do there. In response I tell them in a special school they do a lot of things and now that my daughter is 18 years old and about to exit the school system I tell them she will be going to a university soon..."* (focus group3, P(c), lines 1539-1546).

4.4.1.3 Category (c): Ongoing support for elder learners who leave school

Related to the participants' frustration about the lack of holistic support by family members, they voiced the specific need for ongoing support for elder learners who leave school. In all four focus groups, parents highlighted their experiences that existing services lack continual support, as professionals tend to disengage as time progresses, more specifically towards the end of the school going years. As such, parents expressed anxiety and fears regarding the future of their children. The following examples typify the general concern of the parents:

> *"Some of our children will be exiting the school system and yet we do not know as to what is going to happen to them afterwards, what would be the next place?"* (focus group 3, P(b), lines 1892-1895).
>
> *"The support must not end at the school exit. Even after the age of 18 years at least tell us where to take our children to..."* (field notes, focus group 4, P(a), pg 128).
> *"Now I do not know what is going to happen to my son now that he must exit the school system because he will be turning 19 next year..."* (focus group 4, P(g), lines 2530-2533).

In an attempt to address their fears about the future of their children, some parents made suggestion of supportive action or initiatives that could potentially assist their children. They namely mentioned school leaving programmes and skills training as potential strategies, as captured below:

> *"We also need programmes for our children when they exit school, we cannot afford to see our children staying home after their school time has expired..." (*focus group 3, P(g), lines 1997-1980).
>
> *"I would be happy if our schools could empower our children with skills that they can use to get jobs when they exit their systems so that they can also be able to fend for themselves..." (*focus group 1, P(j), lines 645-648*).*

Closely aligned to anxiety and fears regarding the future careers of their children, some parents were also fearful about the future of their children if they were to fall away, saying:

> *"I am scared of X's future as to what will happen to him if I die, because I am the only one who seems to know when it is time for hospital visit and other things if..."* (focus group 1, P(e), lines 598-592).

> *"You see I am old now and I am scared as to what will happen to my daughter when I am no longer there. Who is going to take care of her? The government must provide with more sheltered workshops so that our children can go there when school time has expired"* (focus group I, P(j), lines 2505-2510*).*

In terms of medical support, parents shared the need for continual support by clinics, doctors and health services, even after learners who face intellectual challenges leave school. In terms of the quality of parent-professional relationships, some perceived interactional relationships as deficiency, saying:

> *"The support relationship between the doctors and parents of children with intellectual challenges must not just end after the diagnosis. Because we need more information and guidance afterwards*..." (focus group 1, P(d), lines 574-578).
>
> *"I think doctors abandon us too early when we need them the most since they are the ones who revealed the disability to us*" (focus group 1, P(d), lines 571-573).
>
> *"The support rendered by the entire agency involved in supporting learners with intellectual challenges must not end at the school exit, even after 18 years these people still require some assistance and guidance in terms of their placement after their school time has lapsed...*" (focus group 4, P(a), lines 2448-2453).

4.4.1.4 Category (d): Access to financial support

Even though several parents seemingly appreciated and acknowledged the help of social grants, certain problems and challenges were also raised concerning procedures related to accessing such grants. Parents complained about the South African Social Security Agent's (SASSA) eligibility measure that, according to the participants lacked consistency in terms of the application of grant criteria for eligibility. Parents expressed their views as follows:

> *"My only concern is about those Doctors who work for SASSA to assess and determine whether beneficiaries are still entitled to social grants. They would say if X has two hands and she is able to take herself to the toilet, therefore what is the reason for receiving grant? This confuses me a lot and makes the process of applying and accessing grant horrible and inhumane..."* (focus group 4, P(e), lines 2453-2462).

> *"My son is wheelchair bound and this situation makes it difficult to transport him to the grant reviewing counsel regarding showing up to prove that he is still alive and therefore can continue to access his grant it is very expensive and costly. I have to pay for a special transport to take him there..."* (focus group 2, P(d), lines1245-1251).

> *"The SASSA administrators should review their policy regarding renewal and reviewing of the beneficiaries of grant. When they want us to bring our children they must consider all the challenges involved like the long queues, the transport fares. In actual sense I would like them to go to the schools if they need to see if the beneficiary is still alive or not instead of letting us be absent from work and children from schools just to prove to SASSA people that they are still alive ..."* (focus group 2, P(a), lines1205-1215).

4.4.2 SUBTHEME 3.2: POTENTIAL SOURCES OF FURTHER SUPPORT

Subtheme 3.2 captures the potential sources of support identified by the participating parents. Four categories relate to this subtheme, namely: (a) schools and teachers; (b) family, friends and community; (c) health institutions and professionals; and (d) local government.

4.4.2.1 Category (a): Schools and teachers

During focus groups discussions, parents complimented schools and teachers as sources of support. However, several parents expressed the need for more support from these potential sources, as captured in the following contributions:

> *“I think most of the support I receive comes from the school teachers and the school’s Occupational Therapist (OT). We still lacking the services of other* specialists like a social worker, speech therapist and a physiotherapist...” (focus group 3, P(b), lines 1646-1650*).*

> *“The support we get from the school is still not good enough; we still do not have the services of a speech therapist, social workers and other relevant services for our children...*” (focus group 3, P(h), lines 1988-1991).

> *“If we can beef up our schools with other relevant professionals for learners with intellectual disabilities. Because we have very few professionals at this school, and they cannot cover all the needs required by learners and parents. I would like to see parents improving their knowledge in supporting their children...*” *(*focus group, P(f), lines 1960-1966).

Closely related to schools and educators being viewed as sources of support, parents also appeal for the curriculum to be enhanced. This is in order to prepare learners who are intellectually challenged, to be able to access the work market. As such parents specifically indicated the need for professional service delivery/support e.g., by speech therapists, occupational therapists and social workers associated with the school. Two parents explained:

> *“I would be happy if our schools could empower our children with skills that they can use to get jobs when they exit their systems so that they can also be able to fend for themselves...”* (focus group 1, P(j), line 626-629*).*

> *“We need a speech therapist, an Occupational therapist and a social worker here at Takalani in order to get more support so that we can be able to help and understand our children”* (focus group 3, P(h), line 1940–1943).

4.4.2.2 Category (b): Family, friends and community

In line with the participants’ experiences that their families, friends and community supported them in the past, they voiced the need for continued support by these people/groups. They shared their views as follows:

> *"The communities must also be informed about the existence of intellectual disabilities so that they may begin to be supportive to these people and stop laughing them...”* (focus group 3, P(i), lines 2005-2008).
>
> *"We need to teach our communities about intellectual disabilities so that they can be able to accept our children as human beings...”* (focus group 4, P(h), lines 2548-2550).
>
> *"Our neighbours and child's friends were the first people to identify that there was something unusual about my son's behaviour and the doctors who have confirmed that he is hyperactive gave me courage to seek help for my son”* (focus group 2, P(e), line 1083-1088).
>
> *"I have been interacting with the school and family for support and guidance”* (focus group 4, P(h), lines 2355-2356).

The perceived general sense of responsibility was also expressed in terms of the need to extend the network of support agencies by starting to support one another and form support groups as parents of learners with intellectual challenges. Two parents explained this need:

> *"We need to support and empower each other as parents of intellectually challenged children. Form parents support groups and speak with one voice on behalf of our children*..." (focus group 3, P(b), lines 1887-1890).
>
> *"I think we need to realise as parents of intellectually disabled children that we need each other and we need to form our own support groups...”* (focus group 2, P(j), lines 1360-1362).

4.4.2.3 Category (c): Health institutions and professionals

Even though the parents highly appreciated and acknowledged the support they received from health institutions and professionals. They also emphasized the need for continued support by such professionals and institutions. Parents expressed their needs in the following manner:

> *"The support relationship between the doctors and parents of children with intellectual challenges must not just end after the diagnosis. Because we*

> *need more information and guidance afterwards..."* (focus group 1, P(d), lines 574-578).
>
> *"Like I have said the interaction with the professional ended after the presentation of the diagnosis and a referral for counselling. There is currently very little interaction between us and the hospital except when we collect medication for him on monthly basis...*" (focus group 3, P(a), lines 1730-1735).
>
> *"Doctors as the ones who have revealed the disability to us should not desert us too soon after the diagnoses is made. Sometimes the service providers we are referred to are few and only available in certain areas, and one has to wait for months before assistant is offered...*" (focus group 3, P(c), lines 1911-1916).

4.4.2.4 Category (d): Local government

Another potential source of support that was identified by the participating parents is the local government. Most comments related to such support focussed on accessing a financial grant:

> "*I think the government should set clear criteria and conditions for eligibility to access disability grant because there seems to be confusion around this process*..." (focus group 1, P(h), lines 609-612).

Allied to the apparent lack of clear criteria for grant eligibility was the process of reviewing one's eligibility to receive a financial grant. Parents generally felt that this process was costly and requires revision. A parent shared some ideas:

> "*I am not satisfied with the way SASSA administrators do when they want to see if our children are still alive or not. They must check them at their schools, instead of letting them to travel distances that makes them absent from school and are costly..."* (field notes, focus group 2, P(d), pg 64).

4.5 CONCLUSION

In this chapter I presented the results of the study in terms of the themes, subthemes and categories I identified. I relied on verbatim quotations from focus group discussions to enrich and demonstrate the themes and subthemes I discussed. I also included some excerpts from my field notes. Three themes emerged. Theme 1 relates to the process of diagnosis and referral, Theme 2 entails the support already received by parents of learners who are facing intellectual challenges, and Theme 3 relate to the ongoing need for additional support to parents of learners who face intellectual challenges.

In the next chapter I present the findings of my study, when I interpret the results I obtained in terms of existing literature. I discuss correlations and contradictions between what I found and what existing literature states. I also identify silences in the data I obtained when compared to existing studies. Finally, I highlight new insights that stem from the findings of this study.

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CHAPTER 5
DISCUSSION OF FINDINGS

5.1 INTRODUCTION

In chapter 4, I presented the results of the study in terms of the themes, subthemes and categories I identified. I included excerpts from the data to enrich my discussions.

In this chapter I discuss the main findings and offer my interpretation of the results according to the three themes that emerged. I discuss the findings with specific reference to correlations with existing literature, contradictions, silences and new insights that stem from my study. In my interpretation of the results I obtained, I rely on the literature presented in chapter 2.

5.2 FINDINGS OF THE STUDY

In this section, I discuss correlations and contradictions between the findings of this study and that captured in existing literature, with regard to the initial identification of intellectual challenges, confirmation of initial identification/diagnosis, referrals to special schools/institutions, sources of support, types of support received, types of support required on a deeper level and potential sources of support.

5.2.1 INITIAL IDENTIFICATION OF INTELLECTUAL CHALLENGES

As indicated in the literature review I provided in chapter 2 (Taub, 2006 and UNCEF, 2012), the responses of the participants in this study confirm that initial identification of intellectual challenges may be recognised at different times or levels of childhood development by parents, health professionals, doctors and nurses. However, the findings of this study also suggest that the process of identification, diagnosis and referrals of learners who face intellectual challenges may be determined by the nature of the disability, noticeable signs of disability and severity of the disability. This is in agreement with existing literature that most disabilities with a clear medical basis (like Down's syndrome and cerebral palsied) are often recognised by the child's physician soon after birth (Reschly, 1996).

In this study, I found that many children facing intellectual challenges are identified during school going ages by grade R-teachers, or educators at the junior primary level. Data indicate that only a few learners are identified during high school years. Research by Taub (2006) similarly indicates that before learners are identified, they will typically experience a series of failures at their respective mainstream schools. In essence, most learners facing intellectual challenges are admitted to schools for special needs after having started their schooling in a mainstream school. This finding of my study correlate with what Taub (2006) found indicating that some learners' support needs may not become noticeable until after they had started formal schooling and through poor academic performance. This finding is further supported by (Luckasson (2002) and Holmes et al. (2000) who stipulate that because intellectual challenges are a developmental disorder, it can only manifest through behaviour. As a result, identification of intellectual challenges is seldom determined before children enter the formal school system.

This study indicates some contradicting findings regarding the initial identification of intellectual challenges, which could be linked to inconsistencies in the manner in which diagnoses are communicated to parents by relevant professionals. For example, there were significant trends across various groups regarding the presentation of diagnoses. Some parents learned of their child's intellectual disability at birth through medical specialists, such as doctors and paediatricians while other parents claimed that doctors delayed to inform them about their children's health condition. This indicates that there is still a gap in the manner in which diagnoses are communicated to parents in the mental health system. Literature depicts that this contradiction has long been in existence; Steenkamp and Steenkamp (2010) assert that medical practitioners have different views about when parents should be told that their children may be facing intellectual challenges. Some doctors feel it should be done as soon as possible, while others feel that they should wait until an early diagnosis is confirmed or until the parents are better prepared. Others do not want to tell the parents at all, or would make vague remarks like: *the child is slow but will outgrow it*.

5.2.2 CONFIRMATION OF INITIAL IDENTIFICATION/DIAGNOSIS

Findings of this study indicate that after being alerted to the possibility of their children experiencing intellectual challenges, parents reacted to the diagnoses in various ways that ranges from acceptance, to denial, anger and disbelief. These findings are consistent with what Rörich (2008) found, namely that parents' reaction to diagnoses will be characterised by denial, anger, frustration, shock, disappointment and disbelief. As a result of these emotional reactions, parents are typically motivated to seek further clarity about their children's health status and confirmation of the diagnoses. This marks the beginning of what literature calls "shopping behaviour", where parents seek second opinions from different professionals following initial diagnosis. Anderson (1977) reiterates the "shopping around" phenomenon. According to Anderson the "shopping behaviour" of parents of learners who face intellectual challenges may result from ineffective communication between the parent and the professionals.

Findings in this study indicate that parents were dissatisfied about their experiences of interaction with professionals who had diagnosed their children. This dissatisfaction is echoed by Morgan (1973), Mitchell (1981), Ziolko (1991) and recently Chang and McConkey (2008) as well as Rörich (2008) who confirm that most parents show dissatisfaction about the quality of the information that is conveyed to them by the professionals with whom they come into contact during or after being informed of their children's conditions. In addition, Chang and McConkey (2008) as well as Davis (1985) affirm that communication of severe diagnoses still produce high levels of dissatisfaction as a result of insufficient or inadequate advice provided by professionals. This could have a bearing in strengthening parents' needs for sufficient support which may result in "shopping around" behaviour.

In this study, I also found that confirmation of the initial identification of intellectual challenges take place within a wide range of agencies. This could be attributed to symptoms manifesting during different developmental stages. Taub (2006) echoes this finding by asserting that most children facing intellectual challenges may not look afflicted in the early developmental stages and may not be identified until they start attending formal school. Luckasson (2002) adds the fact that intellectual challenge is considered a developmental disability indicating that the signs and symptoms of such challenge are all behavioural and can only be diagnosed if the limitations in human functioning manifest during the developmental period. This complexity may lead to un-acceptance, denial, anger and disbelief, which may trigger the act of “shopping around”, visiting a number of different professionals, clinics and other institutions in such a manner that one visit may lead to another while parents seek confirmation of the diagnosis.

In this study I found that there are contradicting issues regarding the confirmation of initial identification/diagnosis. Findings indicate that parents of learners who were born with visible signs of intellectual challenges were confirmed immediately after birth by doctors and health professionals. Similarly Taub (2006) found that children born with cerebral palsied, Down syndrome and other challenges with a clear medical basis are generally confirmed immediately after birth.

In contrast to the above, parents of children born without visible signs of intellectual challenges were either confirmed later or at advanced developmental stages by teachers and grade R practitioners within the schooling system or by family or neighbours within the community. This contradiction is confirmed by Reschly (1996), who states that sometime there are no clear demarcations between learners who are afflicted with intellectual challenges and those who are not.

Findings in this study illustrate another contradiction levelled at parents’ reactions to the confirmation of the diagnoses. Findings reveal that some parents were satisfied with the manners in which the diagnoses were explained and confirmed to them, whilst others experienced problems in understanding the professionals explaining and confirming the diagnosis.

However, findings also reveal that as time progressed, parents gradually understood and accepted the confirmation of diagnosis of their children facing intellectual challenges. This finding is in line with what Kübler-Ross and Kessler (2005) describe as a final stage of the phases of parents’ reactions to the diagnoses. This is where parents come to accept their child’s learning disability.

5.2.3 REFERRALS TO SPECIAL SCHOOLS/INSTITUTIONS

Findings in this study indicate that referrals of learners who face intellectual challenges take place within a wide range of agencies responsible for such referrals. My findings depict schools as being at the forefront of instituting referrals especially when the health professionals did not identify disability. Bell and Best (1986) also identified schools as immediate support system for the family. However they argue that schools are one part of an extended welfare network of agencies potentially supporting parents and as such the need exist to extend this network to other stakeholders. In contrast, Levine (in Lerner, 1993) argues that paediatricians and other relevant health professionals are expected to be informed about referring learners to special schools. This therefore confirms that some learners may be referred by schools, while others may be referred by doctors and other professionals for assessment or to schools for special needs.

What also emerged from this finding is that referrals to special schools and other related institutions depended on the types of disability and the period at which intellectual challenges were identified. This is echoed by Luckasson (2002) who asserted that, since confirmation of disabilities takes place within a wide range of agencies, some children facing intellectual challenges may be referred to schools for special needs earlier because their disabilities are apparent at birth, whilst others may be referred later as a result of their not so visible disabilities.

Findings, however also imply that in some instances parents approached the school or the district office requesting referrals of their children due to poor academic performance identified by them. As such these children were assessed and referred to relevant institutions based on the request of parents. This pattern was also found by Rörich (2008) that parents often approached the teachers first to say that they suspected that their children have problems. Findings further portray an outlier where recommendations for referrals were suggested by people in the neighbourhood, when schools and parents seemed unaware of such a need.

5.2.4 SOURCES OF SUPPORT

In this study I found that families were depicted as the primary source of support for parents living with a child who faces intellectual challenges. This is similar to the findings reported by Chang and McConkey (2008) and Adnams (2010) who revealed that, many parents in South Africa and Taiwan rely on informal support mainly from their families as their main sources of support services because community resources for children who are facing intellectual challenges are not well developed in these countries.

However, findings maintain that schools are still regarded by parents as their most important source of formal support system. This finding is in agreement with what Levine et al. (2004) have found namely that schools overwhelmingly function as the primary source of information about related support services for families. They indicated that parents of 81% of youth facing intellectual challenges reported that they have learnt about support services from their children’s schools.

Findings in this study indicate that parents also regard professionals and health institutions as important source of support. This may be attributed to children being born with signs of disabilities, as this condition may become a catalyst for a series of close interactions between parents and doctors and health professionals. This finding correlates with what Reschly (1996) found, confirming that most disabilities with a clear medical basis (like Down’s syndrome and cerebral palsy) are recognised by the children’s physicians soon after birth and that this may lead to immediate intervention by relevant professionals. What is also depicted from the participants’ accounts as a source of support is the local government in the form of financial assistance. Literature by Chang and McConkey (2008) reiterate that in most countries, financial provision is made for individuals facing intellectual challenges.

5.2.5 TYPES OF SUPPORT RECEIVED

Findings of this study indicate that the types of support received by parents of learners with intellectual challenges include psycho-social support; educational support and governmental grant support. With regard to receiving psycho social support, data suggest that most parents of learners who were born with disabilities that have obvious signs of intellectual challenges like cerebral palsy and Down syndrome received counselling, guidance and other relevant support services shortly after birth. This finding correlates with what literature says in chapter 2 that "the more severe disability, and most disabilities with a clear medical basis (like Down's syndrome and cerebral palsied) are often recognised by the child's physician soon after birth" (Reschly, 1996).

Data indicate that most support services parents claim to have received are from schools (see section 5.2.4). Since schools are institutions where intellectual functionality of the child is the core business, their main task is to enhance cognitive functionality of the child. As such, schools remain at the forefront in supporting learners who are facing intellectual disabilities. This trend is depicted in many studies about support services rendered to parents of learners who are facing intellectual challenges. Levine et al. (2004) found that schools overwhelmingly function as the primary source of information about related support services for families and parents of children who face intellectual challenges.

Findings indicate that parents also received financial support from the government in the form of social and disability grants, even though this is not accessible to all parents of learners who face intellectual challenges. This pattern is consistent with what McConkey and Chang (2008) as well as Davis (1985) have confirmed that in most countries financial provision is made for individuals with intellectual challenges. However, this provision is compounded by the criteria and procedure involved in determining how, and who is eligible to access such support.

Findings in this study indicate that most parents acknowledged receiving support from different agencies. However, the support received especially from professionals and schools lacked continuity because doctors seemed to abandon them after confirmation of diagnoses and the schools lack programmes for elder learners who exit the school system. McConkey et al. (2004) revealed similar results that support services received by parents do not always address their needs and do not offer continual support that fit with individual family.

Though there is evidence indicating that some parents do receive financial assistance from the government, data however, also indicate the contradictory. For example, in South Africa, one of the core functions of the Department of Social Development is the provision of social security, with the aim of reducing income poverty among poor people. The Care Dependency Grant (CDG) is awarded in terms of the Social assistance Act and is given to poor parents or primary care givers of learners who are faced with intellectual challenges and require permanent care but are not in state run institutions.

However, data suggest that parents have concerns about access to the Care Dependency Grant (CDG), because the South African Social Security Agency's (SASSA) eligibility assessment tools lack consistency in terms of determining the criteria for eligibility to access grants. This is always evident in the approaches and attitudes of service providers. The tool lacks reflecting the complex and dynamic nature of intellectual challenges, as well as the contextual factors that shape it (A Situation Analysis, 2001-2011). Concerns have been raised about the limitations of the Care Dependency Grant (CDG) including the use of the eligibility assessment tools that are primarily based on determination of the severity of the health condition or impairment, without consistent and in depth assessment of activity limitations and/ or participation restrictions or environmental factors that may result in high levels of disability for the child (A Situation Analysis, 2001-2011).

5.2.6 TYPES OF SUPPORT REQUIRED ON A DEEPER LEVEL

Research findings indicate that there are a number of needs for ongoing support. Amongst these needs is being knowledgeable about raising a child with intellectual challenges. This finding is similar to other studies as indicated in Chapter 2. Garan et al. (2012); Cavkaytar and Pollard (2009); Ozcan and Cavkaytar (2009) and Bailey and Simeonsson (1988) confirmed that parents need information about the nature of disability, how to help their children, and need to know the problems that a child will go through. Data also suggest that holistic support to families living with a child with intellectual challenges is eminent since most support received was focused on the child alone and ignored the entire family system, and this resulted in lack of support from other family members. Chang and McConkey (2008) and Zhou

(2000) echoed this finding that the greatest need is for professionals with training and experience in "family- based services" that will benefit family as a whole and not just target the child with the disability.

Consistent with some reports from other studies is the need for ongoing support for elder learners who leave school. Parents' responses suggest a dire need for information about the future of their children when they leave school. Chang and McConkey (2008) and Garan et al. (2012) also found that, the most sought after support need was placement of the child when the child finishes school and information about support after school. The parents' responses also indicated an ongoing need for access to financial support from the government. This is echoed by Kumar et al. (2013) who assert that one of the needs expressed by parents of learners with intellectual challenges will be a financial need which is about paying for basic expenses, paying for special equipment, paying for therapy, paying for a baby sitter/ day care etc. Ziolko (1991) adds that financial burden, demands and responsibilities are prevalent in the families of persons with intellectual challenges as a result of a continuous need for extra support.

At the level of the need for financial support, data suggest that parents of learners who are facing intellectual challenges in Soweto significantly need clear criteria for grant eligibility and to have the process of assessment for eligibility to receive a grant reviewed. This is because the South African Social Security Agency's (SASSA) eligibility assessment tools seemingly lack consistency in terms of determining the criteria for eligibility to access grants (A Situation Analysis, 2001-2011). This is similar to the findings by other researchers who said that in most countries financial provision is made for individuals with intellectual challenges. However, this provision is compounded by the criteria and procedures involved in determining how, and who is eligible to access such support. For example in Taipei, according to Chang and McConkey (2008) means-tested, financial benefits are available, however, to families who have a Disability certificate based on medical diagnosis. Davis (1985), in his study found that the benefits for disability grants were not objectively evaluated; one of the four conclusions from his work was that eligibility to access financial support tends to be ability oriented, to the neglect of other aspects of child behaviour. The psychological and social aspects of disabilities are neglected by health services. Johnson et al. (2006) found that the process of assessment, applying for and securing funding and then finding placement and support that meet parents' needs, was described by such parents as 'time wasting and fruitless.'

Literature on the types of support needed by parents of learners with intellectual challenges states that the right of every child with disability to an adequate standard of living is recognized in the South African Constitution. While parents have primary responsibility for their children, the state has an obligation to support them in the role of protecting and promoting the wellbeing of children (DSD, DWCPD and UNCEF, 2012 p. 43). The South African children's Act (2005) obliges the state to provide programs which focus on "developing appropriate parenting skills and the capacity of parents and care givers to safeguard the best interest of children with disabilities." However, findings in this study indicate the existence of contradictions because even though there are policies and legislation available to support parents of learners with intellectual challenges, data indicate that such support does not exist as some of the parents do not have accurate information and knowledge to manage disabilities.

5.2.7 POTENTIAL SOURCES OF SUPPORT

Findings in this study indicate that the potential sources of support relate to schools and teachers; family, friends and community; health institutions and professionals; and local government. Literature on sources of support confirms that health institution; families; educational institutions; and states remain at the forefront as sources of support for the parents of learners with intellectual challenges. Regarding health institutions as sources of support, literature in chapter 2 (Lerner, 1993) correlate with the findings of this study. According to Lerner (1993) globally, paediatricians, medical practitioners and other related professionals are expected to diagnose intellectual challenges, disclose them to the parents, and are also expected to know about special education services offered by schools and to be familiar with the rights that children with intellectual disabilities have under state law.

With regard to families, as the first and immediate source of support, literature echoes the findings in this study that family members are a highly significant support system in meeting the needs of children with intellectual challenges (United Nations, 1959; UNCRC, 1989). It is against this background that a number of studies that had examined the challenges of families of people with intellectual challenges emphasize the importance of family support as a whole (Douma et al., 2006; Cavkaytar et al., 2010; Türk Dil Kurumu [TDK], 2010). This idea requires the state to provide the necessary support services to families of learners who are facing intellectually challenges. The support services include training on managing intellectual challenges, providing advice and counselling services; to ensure that such families are able to fulfil their obligations towards their children (United Nations 1994; Molteno, 2006). At this level, family therefore exists as the primary support institution that forms the basis of all other collective support networks.

In relation to the educational institutions as sources of support, data in this study validates what literature says regarding the important role of schools in providing the necessary support services to the parents of learners with intellectual challenges. According to Levine et al. (2004), schools overwhelmingly function as the primary source of information about related support services for parents of learners with intellectual challenges. They emphasize that parents depend on their children’s schools to provide information about specific services and ultimately to arrange for the services and support that include their children’s Individual Educational Programme (IEP). At the level of legislation, the United Nations Convention on the Rights of the Child (UNCRC) and the Convention on the Rights of Persons with Disabilities (UNCRPD) provide that children with disabilities have the same right to education as all other children, and shall enjoy this right without any discrimination and on the basis of equal opportunity. In South Africa, the Integrated National Disability Strategy (1997), and the White Paper 6 on Special Needs Education (July 2001) emphasize the need for including persons with disabilities within educational systems by providing relevant support, assistive devices and promotion of collaboration with parents of learners with intellectual disabilities.

Even though data have revealed health institutions; family; educational institutions; and local government as sources of support, there is contradiction in this study because data indicate that most parents are not aware of the available sources of support services and other existing non-governmental agencies that provide assistance to the families of children with intellectual challenges. This condition could suggest that families of learners with intellectual challenges in Soweto are not sufficiently aware of other available alternative support services, (like non-governmental organisations) or that such services do not exist at all. Furthermore, literature still depicts a shortage of resources (sources of support services) in most of the underdeveloped and some developing countries. For example, in Virginia (USA) according to the Association for retarded citizens (The Arc, 2010), a non-profit organization which supports persons with disabilities, approximately 285 034 children and adults are on waiting lists. A report by the DBHDS (2009) shows that service availability for children with intellectual challenges is a serious concern in Virginia, as 1 564 children and adolescents are still on the waiting list for intellectual disability service.

5.3 SILENCES AND NEW INSIGHTS THAT STEM FROM THE STUDY

Data indicates that there seem to be noticeable new insights and silences emanating from this study regarding the process of identification, diagnoses and referrals of learners who are facing intellectual challenges. With regard to the process of identification, findings of this study depict that late identification, the nature of birth and types of disabilities may have influence on the process of referrals. These factors may also influence the parents' level of interaction with professionals (limited or no interaction), lack of access and support including social grants. In this study data suggest that there are certain instances where the parents are the ones who have approached the school concerning their child's academic progress and the schools as a result will confirm the existence of the intellectual disability. This indicates a gap in early identification by teachers and this could be attributed to a number of factors in schools, such as lack training by teachers in identifying intellectual challenges and the absence of relevant professionals in schools.

In this study, I have found that there are participants who have received certain types of support and those who have not. This could be related to a number of factors indicated by participants. A number of participants attributed this to the lack of visible signs of disabilities. Regarding the nature of birth and types of disabilities, data seems to suggest the tendency by parents to associate the absence of visible/obvious signs of intellectual disability with the absence of such developmental disorders. As a result, it may be difficult for parents to understand how intellectual challenges affect the academic development of their normal looking children. Such parents do not have sound interactional relationships with the professionals involved in supporting children with intellectual challenges.

At the level of diagnoses, data regarding the different agencies involved in confirmation of intellectual disability suggest that there are discrepancies in the manner in which confirmation of diagnoses are communicated. Data suggest that medical practitioners' confirmation of diagnosis differed from parent to parent, even though their children were diagnosed with the same disability. Literature is silent regarding the rationale behind inconsistencies in informing and confirming the diagnoses. This indicates that there is still a gap in the manner in which diagnosis are often confirmed in the health system.

With regard to the process in deciding when is the right time to refer learners to special schools and other institutions, data indicate that schools sometimes seem reluctant or take long to refer such learners. The reasons for dragging the process are not clearly specified. This could imply the existence of a gap in the current research evidence as far as the rationale behind the slow referral process is concerned. This silence may have a bearing to schools' guidelines philosophy, policies and frameworks in making decision for referrals. However, this is a mere hypothesis and requires more research. However, literature (Luckasson, 2002) depicts the above as logic because intellectual challenge is viewed as a developmental disability, because of its onset during the developmental period (before the age 18), and can only be diagnosed if the limitations in human functioning manifest during the developmental period. Implications could be that, what might look as schools dragging behind to refer challenged learners could be in the nature of intellectual challenges that may be recognised at different times or levels of childhood development (Taub, 2006; UNCEF, 2012).

This study indicates that, failure of schools to identify intellectual challenges early and early referrals has brought some new insight in the processes of referrals. The failure of the schools to refer learners earlier makes it difficult for parents to accept referrals to special schools. This could be attributed to their children having spent a long time in the mainstream schools and hope was created by keeping such learners longer in the mainstream schools. However, this is just a supposition that might call for further research.

In this study, the silences of the voices of fathers could indicate the existence of a gap, because for the entire four focus groups that were conducted in four special schools only three (3) men participated. As such fathers' experiences of support cannot be fully accounted for, and this is also true for the ongoing need for support. This silence is also identified in the existing knowledge base and literature indicating that the support needs of fathers often go unrecognised in this field and as such they can be labelled as: 'hard to reach' (McConkey, 1994), 'invisible parent' (Ballard, Bray, Shelton & Clarkson (1997), or 'the peripheral parent', (SCIE 2005; Carpenter & Tower (2008). This calls for more research that includes fathers of learners who are facing intellectual challenges.

Even though health, educational, and governmental institutions are acknowledged as potential sources of support, data revealed that medical practitioners as the sources of support are inconsistent in the way they communicate or deliver diagnoses of intellectual challenges. Schools as sources of support typically lack provision of after school programmes for elderly learners who exit the system. The local government policies for accessing grants seemed to lack clear guidelines in terms of eligibility for accessing grants. This indicates some gaps within these sources of support. It has also emerged that despite the launch of the Department of Educations' National Strategy on screening, identification, assessment and support in 2008, which emphasized that all learners entering grade 1 are supposed to undergo an assessment of hearing, vision, speech and gross motor function, findings in this study indicate that for some children, intellectual disabilities will remain uncovered and un-identified until later in their formal schooling. It seems as if schools may be seen as reluctant or taking long to refer intellectually challenged learners to special schools.

New insights that stem from the study regarding the experiences of support, received by parents of learners who are faced with intellectual challenges in Soweto is two-fold. On one side data confirm the existence of support, received by the parents. On the other side no support has been experienced by other parents. The rationale behind these discrepancies may be attributed to the following key factors: visible signs indicative of intellectual challenges and the nature or type of disability. For, example a number of participants reported that they could not access governmental grant support because their children do not have visible signs of disabilities. At the level of psycho-social support and educational support, parents remain un-aware of other alternative support systems in Soweto. This situation suggests that families of learners with intellectual challenges in Soweto are not sufficiently aware of other available alternative support services (like non-governmental organisations) or that such services do not exist at all.

With regard to available support services, data also suggest that parents were not aware of any other services available to them in Soweto. Literature in this study highlights continuation of unawareness of other alternative support services by parents of learners with intellectual challenges. Most researches continue to indicate this lack of awareness without accounting for the rationale behind. This could mean that such services are not available in Soweto. Parents of learners in Soweto however seem to need support to be knowledgeable about raising a child who is facing Intellectual challenges, need ongoing support for elder learners who leave school, need for improved systems that have clear criteria for grant eligibility and a need for the process of assessment for eligibility to receive grants to be reviewed.

5.4 CONCLUSION

In this chapter I discussed the findings of the study according to the three themes that emerged with specific reference to correlations with existing literature, contradictions, silences and new insights that stem from the study. The findings regarding parents' experiences of the process of diagnosis, referral and support received, varied across families and seemed to be affected by the type/nature of the disability. This trend overlaps within the three themes that I identified.

The ongoing need for additional support by parents of learners who are facing intellectual challenges in Soweto is wide ranging and seems to replicate familiar experiences indicated by other studies. Findings indicated the parents' general needs to be knowledgeable about raising a child who is facing Intellectual challenges, a need for holistic support to families living with a child with intellectual challenges, ongoing support for elder learners who leave school, and access to financial support (Zhou, 2000, McConkey & Chang, 2008; Garan et al., 2012). In this respect, this study provides insight into the experiences of support received by families living with children who are facing intellectual challenges in Soweto.

In the next and final chapter I came to conclusion when revisiting the research questions I formulated in chapter 1. I summarise the potential contribution of this study, identify limitations and make recommendations for further research, training, practice and legislation.

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CHAPTER 6
FINAL CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

In chapter 5, I presented the main findings and my interpretation of the results according to the three themes I identified. In discussing the findings I referred to correlations with existing literature, contradictions, silences and new insights that stem from the study.

In this chapter I present a summary of the previous chapters. I then revisit the primary and secondary research questions that have guided this enquiry. I discuss limitations; provide recommendations and make some concluding remarks.

The purpose of this study was to explore and describe the experiences of support rendered to the parents of learners who face intellectual challenges. I aimed to gain an in-depth understanding of the processes of identification, diagnosis and referral of learners who face intellectual challenges as well as the interactional relationships between parents of learners who are intellectually challenged and professionals involved in rendering support to these parents. The socio-ecological systems and family systems theories guided me in viewing the experiences of support, in the context of mutual interaction and relationships with all agencies involved, and to link different levels in which support experiences take place.

6.2 SUMMARY OF PREVIOUS CHAPTERS

Chapter 1 provides an overview of the contextual background in which the research problem was formulated regarding experiences of support received by parents of learners with intellectual challenges. I presented the main research problem and subsequent questions, followed by the research purpose which was to explore the existence of the processes of support rendered to the parents of learners who face intellectual challenges and how these processes are experienced by those parents. The chapter proceeded with an explanation of the key concepts used in this research and how such concepts have been used and perceived in this study. I also briefly introduced the methodology of the study.

Chapter 2 presents a literature review with specific focus on parents' knowledge and understanding of intellectual challenges, parents' need for support, parents' experiences of support and their interaction with professionals who diagnose their children. In addition, I discussed support services already offered both locally and internationally. I concluded the chapter with an explanation of socio-ecological and family systems theories, forming the theoretical framework of the study.

Chapter 3 presents the procedural aspects of the research process. I explained how the research design and methodology were selected and used, to guide this study on the experiences of support received by the parents of learners who face intellectual challenges. I also explained how data were collected and documented using focus group discussions, field notes and observations.

In chapter 4, I presented the results of the study, based on the data I gathered from four focus group discussions which involved parents of learners who face intellectual challenges in Soweto. I discussed analysis of data as I identified recurrent themes.

In chapter 5, I discussed the findings of the study by interpreting the results in terms of existing literature. I presented the findings with specific reference to correlations with existing literature, contradictions, silences and new insights that stem from this study.

6.3 CONCLUSIONS

In this section I come to conclusions, based on the findings presented in chapter 5, and by revisiting the secondary research questions formulated in chapter 1.

6.3.1 SECONDARY RESEARCH QUESTION 1

Which processes are involved in the identification, diagnosis and referral of learners with intellectual challenges?

Based on the findings I obtained in this study, the experiences of the processes involved in the identification, diagnosis and referral of learners who are facing intellectual challenges seemingly vary across parents and families. This variation can be attributed to the type/nature of the disability, noticeable signs of the disability and severity of the disability. These findings suggest that the type of disability and its severity may influence the processes involved in the identification, diagnosis and referral of learners who face intellectual challenges.

Parents of children who are born with (immediately apparent at birth) intellectual challenges are prone to experience all the processes involved in the identification, diagnosis and referral of learners who face intellectual challenges, following the birth of their children. Parents of such children are thus more liable to early identification, diagnosis, guidance, and early referrals. For example, parents of children who are diagnosed with cerebral palsy and/or Down syndrome will typically become aware of their children's intellectual disability at birth. In this regard, medical specialists such as doctors and paediatricians are often involved in making diagnoses and confirming and informing parents about the result of a diagnosis.

With regard to the parents of children whose intellectual challenges appear only later during the developmental periods following school entrance, findings indicate that the processes involved in identification, diagnosis and referrals, are characterised by parents witnessing their children failing at school, and children not meeting academic expectations and not reaching developmental milestones. As a result, parents tend to deny, and not accept the diagnoses and referrals imposed on their children. It is against this background that I posit that the processes involved in identifying, diagnosis, and referring of children experiencing intellectual challenges are complex, wide ranging and seem to be informed by whether or not a child is born with a disability and the type of disability identified. This implies that, before these learners are identified, they may experience a series of failures at their respective mainstream schools.

6.3.2 SECONDARY RESEARCH QUESTION 2

What are parents' levels of knowledge and understanding of intellectual challenges, including its implications in terms of academic development?

Findings of this study indicate that parents' level of knowledge and understanding of intellectual challenges, including its implications on their children's academic development ranges from no knowledge, shallow knowledge to deeper knowledge. These discrepancies can be attributed to the following factors. Firstly, data suggest that most parents of learners who were born without visible signs of disabilities showed lack of knowledge and understanding of the implication of intellectual challenges towards the academic development of their children. This lack of understanding can be attributed to the following factors: parents of such learners did not have the opportunity to receive counselling and guidance; their children's challenges were identified long after they started schooling and as such they found it challenging to understand the professionals explaining the diagnosis to them ,they reacted with hostility when their children were later diagnosed as facing intellectual disabilities.

On the other side, data suggest that both parents of learners who were born with and without visible signs of disabilities showed shallow knowledge and understanding at the initial stages of diagnosis. This could be attributed to the following factors: parents found it challenging to understand the professionals and medical practitioners explaining the diagnosis to them, data revealed that these professionals were inconsistent in the way they communicate or delivered diagnoses of intellectual challenges. As such, some of these parents sought further clarity about their children's health status after initial diagnosis, followed by confirmation from different agencies involved in supporting people who face intellectual challenges. As a result parents gradually developed realisation and understanding of the implications of the intellectual challenges their children faced.

On another side parents of learners who were born with disabilities that are apparent and have obvious signs of intellectual challenges like cerebral palsy and Down syndrome received counselling, guidance and support services shortly after birth. These parents also seemed satisfied with the way in which diagnoses were explained to them which resulted in them developing deeper knowledge and understanding the implication of intellectual challenges towards the academic development of their children.

I found that most parents in this study are in need of knowledge on raising a child who faces Intellectual challenges. The apparent lack of knowledge is embedded in the fact that parents may perceive doctors and other related professionals as discounting to support them shortly after the diagnosis had been presented. This leaves parents with little information regarding the adjustments that need to be taken in the following developmental stages of their children. I also found that few parents do posses knowledge on managing their intellectually challenged children, but that such knowledge resides with them and does not prevail to the entire family as a whole. This often results in non-supportive attitudes and lack of holistic participation by other persons in the family as a result of being not knowledgeable about caring for the disabled child in the house.

Allied to the lack of holistic knowledge about raising a child who is facing intellectual challenges was a lack of knowledge about what to do with older learners who exit the school system. This may indicate that services offered will potentially lack continual support. This could have a bearing on parents' levels of anxiety and fears emanating from not being knowledgeable about the future of their children. Given the above mentioned findings, I conclude that parents of learners who are facing intellectual challenges in Soweto show a lack of knowledge and information on how to support their children who face intellectual and developmental challenges more specifically with older children. This could in turn imply that support services available for children facing intellectual challenges may lack continuity that could support learners and their parents beyond school going age. Furthermore this could potentially imply lack of understanding in terms of academic development of the older learners.

6.3.3 SECONDARY RESEARCH QUESTION 3

How can support services affect parents' perceptions and expectations about the academic development of their children who have intellectual challenges?

Findings in this study indicate that parents' perceptions and expectations about the academic development of their children who face intellectual challenges can potentially be affected positively if relevant support services are rendered. Data indicate that being knowledgeable about raising a child who is faced with Intellectual challenges will assist parents to discover the difficulties experienced by their children during the process of teaching and learning. Holistic support services rendered to families of a child who is facing intellectual challenges can help the entire family to be informed about the disability and be able to know and understand the characteristics and possibilities that can be expected of a person facing intellectual challenges. This could lead to realistic expectations about what these learners could do and achieve.

Findings also revealed that parents, who have received support from relevant professionals, are better adjusted to the developmental progress of their children than without any support. They have learnt to understand, accept and adjust to their children's abilities and functionality. Findings indicate that, the majority of parents appreciated and valued the support they receive from stakeholders as this has helped them to understand their children better. It is against this background that I conclude that, given the necessary and relevant support, parents of learners who are facing intellectually challenges can develop positive perceptions and realistic expectations about the academic development of their children.

6.3.4 SECONDARY RESEARCH QUESTION 4

What is the nature of interactional relationships between parents and professionals involved in supporting parents of learners who are facing intellectual challenges in Soweto?

Findings of this study indicate that the nature of interactional relationships between parents and professionals varied across parents and families. This difference can be attributed to the nature, severity, and type of disability. Data suggests that the experiences of interactional relationships between parents and professionals are three-fold. There are those parents whose interactional relationship with professionals has long been active since the birth of their children, those who did not have any interaction, and those who partly interacted with the interaction ending prematurely after the diagnosis has been presented.

Findings therefore indicate an association between the visibility of intellectual disability, type of disability identified and the succeeding interaction that take place between parents and professionals. For example, most parents who claimed that their children did not have any visible signs of disabilities reported that they did not have any interaction with the professionals. Parents of children whose intellectual challenges were visible at birth (like cerebral palsy and Down syndrome) indicated that they have interacted with professionals on a regular basis. This seems to imply that, to some degree the experiences of interactional relationships between parents of learners who face intellectual challenges and professionals rendering support, depends on the visible signs, types and severity of the disability. Furthermore, data also suggest a deficiency in the quality of the parent-professional relationship which indicate that the support relationship between doctors and parents of children with intellectual challenges tend to end immediately after the diagnosis has been presented.

6.3.5 SECONDARY RESEARCH QUESTION 5

How are the roles of the various stakeholders involved in the diagnosis and referral of children who have intellectual challenges synchronised to effectively support parents?

Based on the findings I obtained regarding effective synchronisation of the roles of various stakeholders, data indicate that such roles are often not well coordinated, and that lack of coordination may be located within the three identified sources of support which are health, schools, and government grant institutions. The process of identification and referrals in health institutions may lack coordination especially in the ways in which diagnoses are communicated. This process still produces high levels of dissatisfaction, and thus results in a number of parents complaining about insufficient support. Findings also reveal that professionals still tend to work with the individual with intellectual challenges in isolation from the family, with little attention to how they feel and the fact that their lives are intimately intertwined**.** Findings stress the tendency of certain medical practitioners still not wanting to tell the parents that their children were diagnosed with intellectual disability. However, this lack of informing parents early about diagnoses may be strategic and intentional from practitioners' perspectives. However, this is a mere speculation that deserves further investigation.

Educational institutions were found to be lacking well coordinated referral systems. This is evident in the way that referrals of learners with intellectual challenges to special schools and other institutions are handled at mainstream schools. Data indicate that schools sometimes seem to take long to refer learners, and the reasons for such behaviour are not clearly defined. Data also revealed that support services rendered by schools do not always offer continual support that fit with individual child life after school. For example, schools may not assist parents with information about other external existing support services or recommend aftercare programmes for older learners who are exiting the school system.

This could imply that special schools lack information to guide parents and their children beyond the school system. In addition, data indicate that special schools still do not have all relevant professionals available that could help facilitate well coordinated support systems. For example, it is rare that one would find a special school that has an occupational therapist, a physiotherapist, speech therapist and, a professional nurse in one school. There is often a shortage of such professionals in special schools. Hence the Department of Education still refers to this profession as essential and scarce skills within the educational sector. This scarcity of professionals in the special schools needs to be investigated further.

At the level of government as a source of support, findings suggest that many parents still primarily rely on informal support from their families as support services because community resources for children who are facing intellectual challenges are not well coordinated. For example, many parents reported that they did not know of other support services that the government provides for these children, except the school. Another deficiency that is levelled against the government is a lack of well coordinated criteria for eligibility to access government grants or financial support. The study found that the benefits of disability grants are not objectively evaluated as the eligibility to access financial support still tends to be ability oriented, to the neglect of others whose intellectual disabilities are not so apparent.

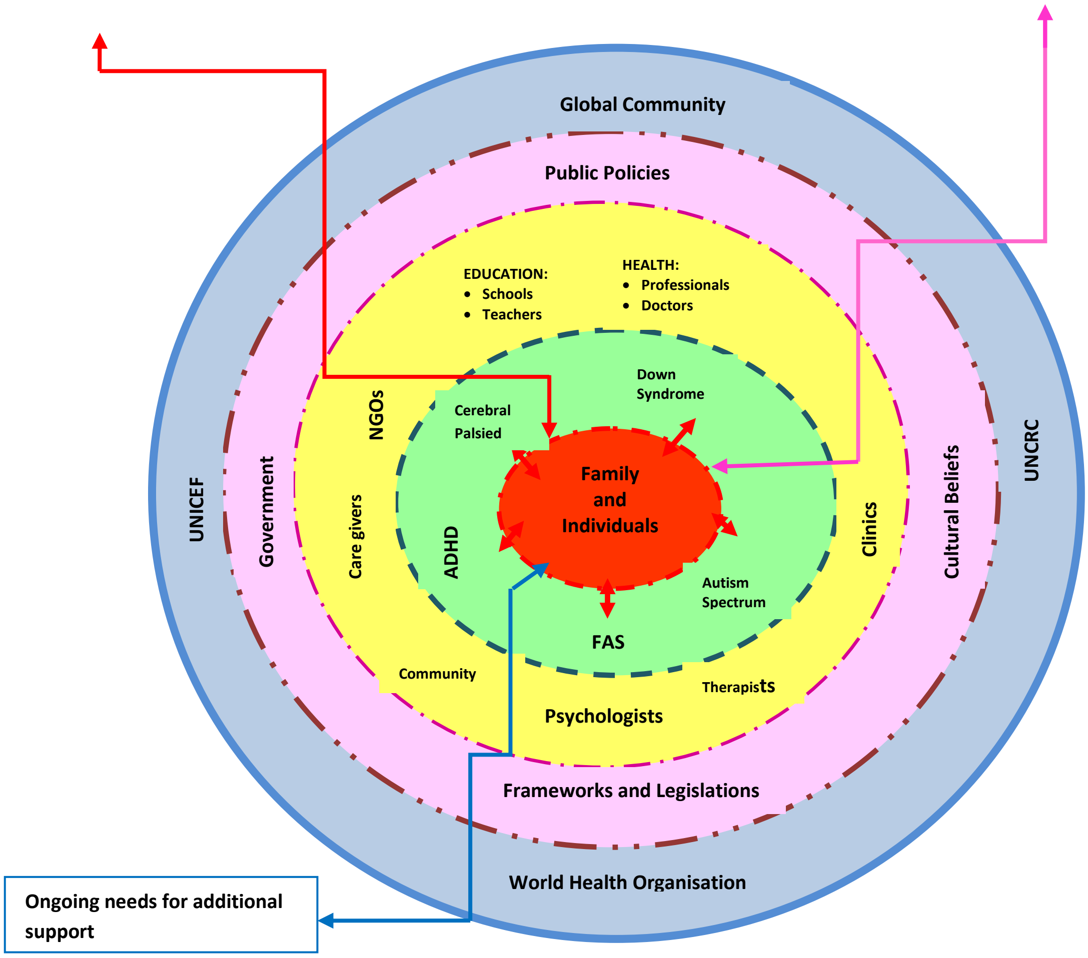
6.4 PRIMARY RESEARCH QUESTION

6.4.1 USING A UNIFIED MODEL OF ECOLOGICAL AND FAMILY SYSTEMS THEORY TO ANSWER THE RESEARCH QUESTION

In this section I conclude by answering the primary research question using a unified model of ecological and family systems theory to describe the experiences of support services by participants mentioned in the primary research question below.

> ***How do parents of learners who are facing intellectual challenges experience support services offered to them in schools in Soweto?***

In figure 6.1., I demonstrate how I used the theoretical framework to answer the research question according to the three themes that emerged from the study.



LEGEND

Colours	Layers/system
🟥	Micro-system
🟨	Meso-system
🟩	Types of disabilities
🟪	Macro-system
🟦	Exo-system

Figure 6.1: A unified model of ecological and family systems theory

Drawing from a systemic mode of thinking, figure 6.1 indicates that experiences of support services received by parents of learners with intellectual challenges occur within the three themes that were identified in this study, which are the process of diagnosis and referral; support received by parents; and the ongoing need for additional support.

a) The process of diagnosis and referral

The findings of this study indicate that the experiences of support services, received by parents of learners who are facing intellectual challenges in schools in Soweto seemed to be generally valued, helpful, and reliable. From a systemic mode of thinking and with regard to the different layers from which support services take place, schools are experienced as being at the forefront in identifying intellectual challenges and remain at the fore-front in offering support to many parents. As such, educators and grade-R practitioners are portrayed by the parents as the ones who initially identified their children as experiencing intellectual challenges. Such identification thus, often resulting in referrals by schools for formal assessments and screening process in order to confirm the schools' identification of intellectual challenges.

A number of valued experiences of support received from schools and teachers are the educational support, the advisory role that schools fulfilled which helped the majority of parents on accepting the diagnosis and on ways that the school could benefit the child. However, findings also reveal gaps in the processes of referrals of learners who are facing intellectual challenges in schools in Soweto. Referral processes are experienced by many parents as lengthy and tiring. Parents were of the opinion that mainstream schools often tend to keep learners in schools for too long before they would refer them. This lengthy keeping of learners in schools contributes towards parents' hostile reactions to the diagnosis and referrals.

(b) Support received by parents

Findings in this study indicate that a number of valued experiences of support received by parents came from schools and teachers. According to the data support services received from schools and teachers are the educational support, the advisory role that schools fulfilled which helped the majority of parents on accepting the diagnosis and on ways that the school could benefit the child. From a systemic epistemology the types of support received by parents make sense, if we consider them in their relationship with the type of services offered by schools. This implies that the interaction networks between parents and schools are to a certain degree structured to elicit performance competence. However, findings also indicate that such performance competence is experienced as not enough by some parents of learners who are facing intellectual challenges in Soweto.

Even though there is enough evidence that schools still remain at the fore-front in offering support to the parents of learners who are facing intellectual challenges, findings also reveal that schools are also under-resourced and do not have all the support services needed by parents. From a systemic epistemology, this could imply that the various roles of stakeholders and agencies involved in supporting parents of learners who are facing intellectual challenges do not complement each other through various layers of support. To this end, some schools were experienced as lacking in other support services from professionals like the social workers, Speech therapists, Occupational therapists and other relevant agencies involved in diagnoses and supporting parents. In addition, schools were also found to be lacking in offering parents with an ongoing and additional support especially for older learners who are exiting the school system.

(c) Ongoing need for additional support

What has also emerged from the findings is that, even though schools may still remain at the fore-front in offering support to the parents of learners who are facing intellectual challenges, there is also enough evidence to show that some schools are under-resourced and do not have all the support services needed by parents, such as the services of Occupational therapists, Speech therapists, Social workers and other related special services required by special schools. At the level of systems theory such lack in other core aspects of performance competences compromise the system’s ability to offer support from a holistic approach. From this perspective, the two theories call for examination of multiperson systems not limited to a single system and aspects of the environment beyond the immediate professional staff establishment that schools have.

In addition, findings reveal that support offered by the schools did not cater for the developmental changes that a child with disability undergoes. Most support that has been offered at schools seemed to end, immediately after the child has left the schooling system and they lack an ongoing additional support, especially ongoing support for older learners who leave school. From a systemic epistemology, this could imply that the link between the different levels and roles of various agencies involved in supporting the parents of children who face intellectual challenges lack mutual interactional relationships that can effectively produce the smooth synchronisation of their roles.

Data also suggest that some parents of learners with visible signs and severe intellectual challenges do experience ongoing additional support, and the opposite occurs to those whose children do not have visible signs of intellectual challenges. At the level of ecological and family systems theory the above mentioned pattern of experiences seems logic if considered within the context of its relationship with the nature, type, and severity of the intellectual challenges that learners face. Findings indicate discrepancies in the way in which support services are experienced by parents of learners who are facing intellectual challenges. Some parents experience being sufficiently supported while other seemingly receives little or no support at all. From a systemic epistemology these discrepancies make sense, if we consider them in their relationship with the type of disability, obvious signs of disability and severity thereof. This also indicates that support needed by parents does not require one programme to operate every type of service which might be needed by parents and families, but calls for examination of multiperson systems not limited to a single support system and aspects of environment beyond the immediate setting.

6.5 CONTRIBUTION OF THE STUDY

In this section I provide the potential contribution and areas in which this study may add value. Such contributions lie in the possibility that this study may offer new knowledge to literature on parents' needs for support in Soweto, more specifically in dealing with children who face intellectual challenges. This could potentially be escalated to broader South Africa.

This study could thus contribute towards establishing a framework for coordinated support from various agencies involved in supporting parents' of learners who face intellectual challenges. Such a framework should cater for the developmental changes that a child with disability undergoes. This framework calls for interdepartmental collaborations between schools, health, and social development department to form a multi-disciplinary approach that will synchronise roles and expertise around support needs of parents. Lastly, this could contribute towards a strategic framework for identification, diagnosis, referrals and provision of quality information to the parents.

Regarding the shortage of other professional people (like the occupational therapists, social workers, psychologists etc) that existed, a framework for such policy could potentially inform the staff establishment in special schools and for effective recruitment of professionals who possess skills which could add value to the special schools. Furthermore, the advantages and weaknesses identified in the processes of support rendered to parents, may inform the revision of existing policy guidelines and legislations.

6.6 RECOMMENDATIONS

In this section I provide the following recommendations: for further research; training of professionals involved in rendering support to parents of children who face intellectual challenges; for local government, and professional practice.

6.6.1 RECOMMENDATIONS FOR FURTHER RESEARCH

One area of extreme significance in upcoming research should be around the support needs of fathers of children with intellectual disabilities and to increase their involvement in this field. I recommend that future studies must strive to incorporate the viewpoints of such fathers. By the same token, the right to be heard of learners with intellectual challenges themselves is missing from literature on the support needs of person with intellectual challenges. Such research is eminent. An exploration into the experiences/perceptions of the professionals and other agencies involved in support of parents of learners with intellectual challenges would be another significant avenue for future research. Based on the findings of this study I recommend further research of the following nature:

- A case study on the support needs of fathers of children who face intellectual challenges

- A comparative study on experiences of support from the perspective of both mothers and fathers of children who face intellectual challenges.
- A descriptive study on experiences of support from the perspective of children who face intellectual challenges

6.6.2 RECOMMENDATIONS FOR TRAINING OF PROFESSIONALS, TEACHERS AND COMMUNITY

There is a need to provide health professionals, educators and communities with training and experience in family-based support services. Health professionals need to be empowered to be able to deliver diagnosis of intellectual challenges to the parents without fear and doubt, so that families can be set realistic goals for their children who are facing intellectual challenges. Regarding teachers' development I recommend that they should be trained on how to identify intellectual challenges earlier. Teachers should know when the right time to refer a learner is, they should be knowledgeable about the types of intellectual disabilities and how to identify them. An advocacy to make communities to be knowledgeable about intellectual challenges is eminent, in order create an environment that is conducive to offer support to the parents of learners with intellectual challenges holistically and around the whole family system.

6.6.3 RECOMMENDATIONS FOR LOCAL GOVERNMENT

It would seem sensible and essential for the government, especially the South African Social Security Agency (SASSA) as a financial source of support (for people with disabilities) to create a system that has clear stipulation in terms of accessing grants so that no disability is left unattended. Doctors at SASSA seem to focus on physical disabilities as a catalyst to access social grants and as a result mental, cognitive and intellectual disabilities are overlooked as conditions that meet the criteria for accessing social grants. With regard to the ongoing need for support for elder learners who leave school, sheltered employment and protective workshops were established more than 60 years ago. Their status quo and accessibility needs further investigation (DWCPD, 2012).

6.6.4 RECOMMENDATION FOR PRACTICE

In this section I provide the following recommendations for professional practice in terms of health professionals, schools, family and friends.

❖ Health professionals

Professionals must provide parents with the necessary knowledge about the nature of the child's disability, information on how to help their children including knowledge about the problems that a child might go through and help the families throughout all the developmental stages of the child. They should create an effective framework for delivering the diagnosis and continuous support beyond diagnosis. In this context, professionals who are involved in diagnoses and supporting learners who are facing intellectual challenges will have to make systemic adjustments to this problem, such taking into consideration of the nature, type, and severity of the intellectual challenges

❖ Schools

Impression has been made to convey the notion that most parents of learners with intellectual challenges relied on the schools and teachers as their primary support providers in many aspects of their support needs. This in return calls for teachers to be trained in skills that can address the overwhelming support needs of the parents. In this training a special teacher should be more than just a teacher and more than a counsellor, but, becoming teacher-counsellor. In actual sense all teachers should be special educators through a variety of courses and service in learning experiences, in the curriculum that train future teachers to more effectively work with and support the parents of learners with intellectual challenges.

❖ Family and friends

At the level of families, friends and community, I would like to draw on the African proverb that says 'it takes the whole village to raise a child'. The responsibility for the wellbeing of individuals with intellectual disabilities lies on the shoulders of the entire society as a whole. All citizens in society should be more concerned with the support needs of parents and families who are raising individuals with intellectual disabilities. I therefore recall for African model of support that was characterised by a conscious emphasis on people, their dignity, collectiveness, solidarity, teamwork, interdependency and brotherhood of mankind called ubuntu to be implemented. There seems to be a need for families to be supported and socialised around the disability as a unit**,** however families also need to be proactive and take responsibility in formalising their own support systems that facilitate sharing of expertise and advocates to lessen challenges due to intellectual disabilities. In addition, such support systems should be characterised by specific strategies, procedures and activities that increases the full participation of fathers.

6.7 LIMITATIONS OF THE STUDY

The four focus groups discussions involved only three (3) male participants resulting in the question as to what extent the views of fathers' experiences of support is included in the data and subsequently in the findings of the study. Limited representation of fathers might results in certain perspectives that may not be representative of fathers' views. In addressing the limited voices of the fathers, I relied on the fact that this study was focusing on the merit of the case study and not the representation thereof.

Another threat and challenge I was facing during the focus groups is that some parents' functionality could also be limited and when recruiting participants the invitation requested for parents of learners with intellectual challenges. Therefore it could have been unethical and difficult to include such exceptions when recruiting participants. Another limitation in the study was the fact that I played a dual role as a principal and the researcher in this study. I had to keep a balance and guard against influencing participating parents.

6.8 CONCLUDING REMARKS

In conclusion to the answer on “How do parents of learners who are intellectually challenged experience support services offered to them in Soweto?” findings in this study indicate that amongst the crucial support needs of parents of learners with intellectual challenges are the dire need to be knowledgeable about raising a child who is facing intellectual challenges. The need for holistic support to families living with a child with intellectual challenges, and the desire to receive ongoing support for elder learners who leave school seem evident.

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ANNEXURES

ANNEXURE 1

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no. D2014/008

GDE RESEARCH APPROVAL LETTER

Date:	**18 April 2013**
Validity of Research Approval:	**18 April 2013 to 20 September 2013**
Name of Researcher:	**Lushozi B.B.**
Address of Researcher:	**P.O. Box 601**
	Kwa-Xuma
	Soweto
	1867
Telephone Number:	**011 939 2454 / 072 294 2968**
Fax Number:	**011 939 2548**
Email address:	**bernard@albertinasisulucentre.co.za**
Research Topic:	**How parents of intellectually challenged learners experience support, guidance and counselling services rendered to them**
Number and type of schools:	**FOUR LSEN schools**
District/s/HO	**Gauteng West; Johannesburg North and Johannesburg South**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

2013/04/18

The following conditions apply to GDE research. The researcher may proceed with the

above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

....

Dr David Makhado
Director: Knowledge Management and Research

DATE: 2013/04/18

Office of the Director: Knowledge Management and Research
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za

ANNEXURE 2

University of Pretoria
Department of Educational Psychology
Faculty of Education
September 2013

Dear Principal,

My name is Bongani Bernard Lushozi. I am currently studying for a master's degree in education at the University of Pretoria. I would like to request for your permission to conduct my research at your school. My research question is '**How can the experience of support, guidance and counselling assist parents of learners with intellectual challenges in understanding the implications of these challenges for academic achievement?**' The purpose of this study is to explore the processes involved in support, guidance and counselling rendered to the parents of intellectually challenged learners in Soweto.

If you give me permission, I will conduct focus group discussions of not more than six (6) parents. The focus group discussions will not interfere with school activities and will not take longer than ninety (90) minutes a session.

The focus group discussions will be audio and video recorded for accurate data collection. I ask your permission to record the sessions. All the information gathered from the participants will be used solely for research purposes and will be treated confidentially. Participants will be identified through pseudonyms which they will choose before the session begins. Participation is voluntary and there will be no payment for sharing views, however there will be transport allowance for parents using public transport for coming to the sessions. During the discussions, participants will be free to withdraw anytime when they want without any negative consequences.

If you have any questions, please do not hesitate to contact my supervisor or me at the numbers given below

B.B. Lushozi (student)

B.B. Lushozi
Tel 011 9392454

Cell 072 294 2968

M.M. Sefotho (Supervisor)

Maximus Monaheng Sefotho
Department of Educational Psychology
University of Pretoria
Groenkloof Campus
Tel: 0124202772
Cell: 0726380868

If you accept this request, please sign the attached form and give it back to the researcher.

CONSENT FORM TO BE SIGNED BY PRINCIPAL

PRINCIPAL'S CONSENT FORM TO ACCEPT REQUEST TO CONDUCT RESEARCH AT HIS/ HER SCHOOL

This is to confirm that I, ______________________________(your name), principal of __________________ (name of school) have read and understood the information about the study. I give/do not give (delete what is not applicable) permission to Mr. B.B. Lushozi to conduct his study at my school. I also give/ do not give (delete what is not applicable) him permission to audio and video record the focus group session and I as part of data collection.

____________________	____________________	__________
Principal's name	Principal's signature	Date
_____________________	_____________________	____________
Researcher's name	Researcher's signature	Date

ANNEXURE 3

University of Pretoria

Department of Educational Psychology
Faculty of Education
September 2013

Parent invitation to participate in focus group discussions

Dear Parent,

My name is Bongani Bernard Lushozi. I am currently studying for a master's degree in education at the University of Pretoria. I would like to invite you to participate in my study during focus group discussions. My research question is '**How can the experience of support, guidance and counselling assist parents of learners with intellectual challenges in understanding the implications of these challenges for academic achievement?**'. The purpose of this study is to explore the processes involved in support, guidance and counselling rendered to the parents of intellectually challenged learners in Soweto.

If you accept this invitation, you will kindly be expected to participate in the focus group discussions of not more than six (6) parents at your child's school. The focus group discussions will not interfere with school activities and will not take longer than ninety (90) minutes a session.

The focus group discussions will be audio and video recorded for accurate data collection. I ask your permission to record the sessions. All the information gathered from the participants will be used solely for research purposes and will be treated confidentially. Participants will be identified through pseudonyms which they will choose before the session begins. Participation is voluntary and there will be no payment for sharing views, however there will be transport allowance for parents using public transport for coming to the sessions. During the discussions, you will be free to withdraw anytime when you want without any negative consequences.

If you have any questions, please do not hesitate to contact my supervisor or me at the numbers given below

B.B. Lushozi (student)	M.M. Sefotho (Supervisor)
	MMSefotho.
B.B. Lushozi	Maximus Monaheng Sefotho
Tel 011 9392454	Department of Educational Psychology
	University of Pretoria
	Groenkloof Campus
	Tel: 0124202772
Cell 072 294 2968	Cell: 0726380868

If you accept this invitation, please sign the attached form and give it back to the school principal at your child's school.

CONSENT SLIP TO BE SIGNED BY PARENTS

PARENTS CONSENT FORM TO PARTICIPATE IN FOCUS GROUP DISCUSSIONS

This is to confirm that I, ___________________________ (your name), parent at this school have read and understood the information about the study. I accept/do not accept (delete what is not applicable) the invitation to participate in the study. I also give/ do not give (delete what is not applicable) permission to audio and video record the focus group sessions.

____________________	____________________	__________
Parent's name	Parent's signature	Date
____________________	____________________	____________
Researcher's name	Researcher's signature	Date

ANNEXURE 4

FOCUS GROUP DISCUSSION GUIDE

Thank you for taking time to participate in this study. Our topic is “How parents of intellectually challenged learners experience support guidance and counselling” This study aims to “explore the processes involved in support, guidance and counselling rendered to the parents of intellectually challenged learners in Soweto.” My name is Bongani Lushozi, I am studying towards Masters Degree in learning, support, guidance and counselling at the University of Pretoria. I am here with my colleague who will assist to interpret Tsonga and Venda.

You are invited to participate in this research study because of your knowledge about the question at hand and as such you could provide invaluable information in this study. I If you choose to withdraw from participating in this study please you are allowed to do so.

There are no right or wrong answers to the questions I am about to ask, but all answers are important. The session will be audio-video recorded because I do not want to miss any of your comments.

Feel free to have conversation with one another and to share your view even if it differs from what others have said;

If you want to follow up on something that someone has said, and may be you want to agree, disagree or give an example, you are allowed to do that. However, I may request you to make a comment if you are not saying much. However, I may also ask you to give others a chance if you are talking a lot.

Before we resume with the discussions I would like you to provide me with your biographical information to allow the study to have relevant details about yourself and your child.

BIOGRAPHICAL DATA

What is your relationship to the child?	**Please tick appropriately below**
Mother	
Father	
Adoptive parent	
Foster parents	
Guardians	
What language do you speak at home?	
How many children are under your care?	
How long have you been raising a child with intellectual disability?	
Which clinic/hospital do you normally take the child for attention?	
What is your highest level of education? (Choose ONE)	**Please tick appropriately below**
Junior primary	
Senior primary	
Secondary	
High school	
Post high school	

ANNEXURE 5

(Focus Group 1)

Verbatim transcripts of focus group conducted at Pumelela Special School - 16 September 2013

Question one:

Let's begin by having each person in the room tell us about when and how did you discover or learn about your child's intellectual challenge

P (e)

I started to notice that Sipho was not developing like other children of his age because when he was two years old he was not crawling like other children of his age. This worried me and tempted me to take him to the clinic to find out about this problem. At the clinic a doctor performed a mini assessment on him and thereafter without saying anything, referred us to take him to Baragwaneth hospital (Bara). At Bara I was sent to a psychiatric department where the doctors called me after their examination on my son and told me that my son has a mental problem." I was not sure what they meant by that. As this to me it meant that my son was crazy" I sought for clarity from the doctor, and the doctor said to me your son shows signs of potential developmental delays which means he will always lag behind in physical development, speech, and language acquisition and in other areas of development.

Not reaching developmental milestone (Motor development)

Referral following medical assessment.

Confirmation after psychiatric assessmen and Uncertainty of exact meaning of mental problem

P (c)

When my son was 3 years old I noticed that he was not active like any child of his age, however I told myself that perhaps this is because he is a sweet child and even in the streets people confirm this by echoing my belief that he is a sweet child. This has been happening for some time until one day my Aunt (his granny) said to me your child needs a little smacking, slapping, or spanking so that we can hear him talk, make noise and be active like other children of his age. This comment prompted me to take my child to a local clinic for developmental evaluation where I was referred to Bara and Leratong hospital respectively where I was told that my son is normal, and he will be fine. There was never any improvement as he started schooling at the mainstream and I was told by the teachers that he is not coping academically and I must get him a space in the nearest special school. Hence, I am here.

Not reaching the developmental milestone (physical)

Lack of understanding and empathy by others

Medical assessment

Poor academic performance in school.

Referral to special school by teachers

P (d)

When my daughter was in grade R, I noticed that she was playing with children far younger than her and she was 6 years old. I thought this was just a passing phase as she was still at the pre- school level. However, when this behaviour persisted when she was now at a grade 1 in the school, this worried me and this prompted me to see the teachers at the school just to find out as to what was going on with my daughter. The class teacher echoed my observation as well, and told me that my daughter was not coping satisfactory at the school.

Delayed social development

Seeking guidance from the school.

However, she suggested that we must give her a chance and see how she progresses. She was highly active at the school and likes playing around to such an extent that you might mistake her for an intelligent person, but at the same time she could not cope with academic work, as she was forgetful. You can teach her something now and when you request her to repeat what was taught after two hours she has forgotten. As a result I began to smack her because I thought she was too playful and did not take serious of her school work. My mother reprimanded me against smacking her and suggested I go to see the teacher again. The teacher referred me to Baragwaneth Hospital (Bara) for assessment. The diagnosis confirmed that she was a slow learner and needs to be taken to the special school.

Poor academic performance at school. Forgetfulness.

Problem with memorising

Punishment for poor performance by parent

Seeking guidance from teachers/school.

Referral to hospital by the teacher/school. Developmental delays (academically). Referral to special school by the hospital

P (h)

I am a foster parent to Fatima, Fatima's mother passed away when Fatima was 1 year six months old. She was born normal and looked like any other child. When she was two years she fell on her head and fainted. She was taken to hospital. We thought maybe this could be because her mother was epileptic. After she was discharged from the hospital we noticed that she was regressing developmentally as she started drooling saliva outside the mouth. There was a sudden excess of saliva production and inability to retain saliva within the mouth. We took her back to the hospital where she was diagnosed with cerebral palsied as a result of head

Child in foster due to parents' death

Physical injury (head) at young age.

Developmental delays (physical).

Diagnosis by hospital (cerebral palsy) injuries.

We were also advised to be patient with her as she will develop slowly and we were also promised that she will improve as she get older. The doctors then told us that when she reaches school going age we must take her to a special school.

Referral to special school by doctor.

P (j)

I am James 'father, James was born short sighted but we took him to a normal public school. When he was 7 years old in grade 1 I was called to the school by the teacher to say that James was not coping well with school work, he was always lagging behind and they were suspecting that he was an LSEN candidate. As a result they referred him to a special school. He is able to do some few things as we are assisting him at home

Born with special need (short-sighted)

Normal school despite special need.

Referral to special school by teacher/school.

P (a)

I am Karabo Molefe's Mom and I was born with a disability as a result of post polio, I was wheel chair bound until the age of ten. I attended a special school until I finish my matriculation. Karabo was born in 1998 and I asked myself a question that because I am a disabled person, is it possible that I can have a "normal" child. The doctor told me that I can have a normal child. After given birth I was reassured that my child was fine. As such my child attended normal school. However, during those school years my child has been repeating grades and the principal was

Mother born with disability

Mother attended special school

Poor academic performance and failure at school.

refusing to let him go to a special school until he was 12 years and still in grade 2.

Principal not supportive for special school/school taking long to refer to a special school

It was then that my child was referred to the department of education district office for assessment after which, we were referred to a special school as she could not cope in the mainstream school.

Referral to Department of Education (DoE) for assessment. Referral to special school by DoE after assessment.

P (i)

I m Ezekiel's parent, Ezekiel was born with birth defects or disabled as he did not look like other children, he had problems with body movement and posture as his neck was as if it was loose and could not stay upright. His body was floppy. After I had spent sometime in the hospital, they discharged us to go home. After I was discharged, the doctor asked me if I was aware of the condition of my child. I told him I was aware that he does not look like other children that I had before. He then said to me "I was afraid and thought that you will runaway and leave your child behind." Some years passed by as I continued taking my son to the hospital as per doctor's requests, when he was about seven I was given a referral letter to the special school.

Born with disability (physical and motor development)

Early identification communicated by doctor

Not easy for doctors to communicate diagnosis

Referral to special school by doctor

Question Two:

What was your understanding of the diagnosis given by the professional(s)?

(How did the information help you to understand intellectual challenges and its implication towards academic development?

ANNEXURE 6

Pg
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QUESTION FOUR:

Let us discuss the support services you received regarding your child.

P(a)

RESPONSES	OBSERVATION
did u receive (What kind of support, guidance & counselling regar managing the devlpmt of your intell challgd child)	
> No Counselling'	Parent was
> relying on my personal experience	showing Anger
>	& Pain feelings
	of betrayal
(who would you say are the key people involved in supporting you & what makes u say that?)	
> No support for me because I	
> was also not accepted by my family	
>	
(Describe your relationship and interaction with the professionals involved in supporting You)	
> no relationship - with the Doctor	
>	
>	
(How satisfied are you with the support You received from the professionals who diagnosed Your child'	
> I did not receive any support	
>	
>	

QUESTION ONE

Each person in the group telling the others about their first discovery that their child is intellectually challenged.

P	RESPONSES	OBSERVATION
P(a)	@ birth my child was left behind ~~a~~ my son stayed at bara for a month - he was digonsd to be hydro ~~cep~~ cephelling = water in the heah he walked @ 4yrs. Hydrocephalus is a medical condition in which there is abnormal accumulation of fluid in the head. As a result my child stayed @ the hospital for a month - after his birth - There-after I was called to be formally told about the health condition of my son - and the develop-mental implication's.	
P(b)	Cerebral palsied was diagnosed. But I took him to attend a Creche/ECD as per a request from a grade R- practitioner. My son was thin and underweight afte 1½ years and I had to take him back to hospital - where some tests were made and I was refered to a speech therapist, phisio and others. * The problem started from birth as he did not cry @ birth. @ six months he regressed. When [illegible] I took	There was an indication that a parent tend to blame the people who assisted during delivery (midwives). "She was suicidal" she had to be shown other worse

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QUESTION FIVE

Φ Is there anything you would like to say about support you received in general.

\$ What is your view of support services for the parents of learners with intellectual challenges?

△ What suggestions do you have to improve the support rendered.?

P	RESPONSES	OBSERVATION
(a)	Φ Information on managing the child with a disability is needed \$ mostly \$ △ Parents to form support groups.	
(b)	Φ I would like to know more abt my child's need - because sometimes I don't understand or know what to do and how to help him \$ we need to build one another as parents before we can seek support outside - I think we need to come together △ Let us form parents support groups so that we can speak as one voice to seek assistance from the	

QUESTION FOUR·

Let us discuss the support services you have received regarding your child.

P	RESPONSES	OBSERVATION
(a) (1)	(what kind of S,G &C did you receive from the professionals regarding managing development/achievement of your intellectually challenged child	
	> The only support I know is the > one I'm receiving from the > school·	
2	(who would you say are the key people involved in supporting you and what makes you say that?	
	> Family & school > > >	
3	(Describe your relationship & interaction with the professional involved in supporting you	
	> Unfortunately I have never ever > interacted with any other > Professionals·	
4	(How satisfied are you with the support you received from the professionals who diagnosed your child·)	
	> like I've just said I do not > have experience with the > professionals· >	