



**University of Cape Town**

**Faculty of Health Sciences**

**An exploration of parents' experiences of the  
inclusion and retention of their disabled children in  
public schools in the Eastern Cape Province**

A thesis submitted in fulfilment of the PhD (in Disability Studies)

Department of Health and Rehabilitation Sciences, Faculty of Health Sciences

University of Cape Town

May 2014

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**Declaration**

I declare that this thesis titled; **“An exploration of parents' experiences of the inclusion and retention of their disabled children in public schools in the Eastern Cape Province”** is my own work. Sources that I have quoted have been acknowledged by means of references.

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February 2014

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**Abbreviations**

CBR: Community Based Rehabilitation

DBST: District Based Support Team

DoE: Department of Education

EFA: Education for All

EWP6: Education White Paper 6

IDEIA: Individuals with Disabilities Education Improvement Act

ILST: Institution Level Support Team

RDP: Reconstruction and Development Program

SSAIS: *Strategy for Screening, Identification, Assessment and Support.*

Stats SA: Statistics South Africa

UNESCO: United Nations Educational Scientific and Cultural Organization

WHO: World Health Organisation

## **Definition of Terms**

**Inclusive education:** Inclusive education is about accommodating all learners within the education system irrespective of race, culture or disability and ensuring that learners are retained and offered the support needed for them to succeed in their education. Emphasis is on providing opportunities for equal participation of disabled children whenever possible into public education. The South African government introduced White Paper 6, an inclusive education policy as a sign of commitment to the inclusion and participation of disabled children, parents and communities in schools. Inclusive education aims to address issues of social justice, inequality and human rights.

**Disability:** The International Classification of Functioning (ICF) defines disability as an umbrella term for impairments, activity limitations and participation restrictions, resulting to the negative interaction between an individual and his/her environment (World Health Organisation (WHO) and World Bank, 2011). This social model of disability differs to the medical model of disability in that an individual is always given a benefit of doubt to be able to achieve anything that the mind is set to achieve given support needed. The medical model seeks to find the problem within one's health.

**Impairment:** A defect or alteration in body functioning that tends to affect one's performance in any life activity such as hearing or communication.

**Transformational leadership:** in the context of this study, transformational leadership focuses on the act of empowering and supporting parents of disabled children to take on the lead in the process of ensuring that schools become inclusive sites for learning and that disabled children are accommodated retained and supported in their schools in order to succeed and become independent adults.

**Note:** The terms **role player / stakeholder** are used interchangeably referring to participants as outlined in the policy for inclusive education, White Paper 6 on inclusive education (Department of Education, 2001)

## **Abstract**

South African national policy on Inclusive Education, as expressed in White Paper 6 of 2001, regards the role of parents as key to making schools inclusive sites for learning. For parents who have been historically discouraged from participating in the education of their children, this is a challenging role. The aim of this study was to assemble data which would shed light on what parents of disabled children in public schools view as relevant support for them to actively participate in the process that ensures inclusion and retention of disabled children in schools.

In line with the social model of disability, this qualitative study follows a participatory action research design using critical theory as the lens through which the world of parents with disabled children was examined. Purposive sampling was used to select five parent participants in the study within a District Municipality (South Africa). They were all members of a support group of parents with disabled children. Parents were given a detailed outline of the study aims which were explained to them by the researcher at the outset and were informed that they could resign at any time without any implications thereof to their children and themselves.

Individual interviews with parents, school meetings involving parents, children and teachers, researcher personal journal, narrative and focus group sessions were used for data collection. A transformative paradigm informed the data collection procedures and interactions with parents. Data was analysed through content analysis of the full data set, including the researcher's reflective journal. Recurring patterns were identified, coded and then categorised according to similarities and meanings. Data management and analysis took place through an iterative process of selecting, simplifying and transforming raw data during and after meetings held with the assistant researcher after each meeting with the parents and in discussion with a research mentor.

**Four themes** were selected as representative of the main findings, namely: **growing up; stunted involvement of parents; inadequate awareness and information about the policy and we live busy demanding lives.** From this thematic description of the findings, the thesis development and recommendations drew out **four cross-cutting aspects** of parents' participation in the inclusion and retention of

disabled children in schools – the 4-Cs: **Constraints, Complexities, Capacity and Compassion.**

Although a qualitative approach enabled insight into the perceptions of participants and the meanings given to events, some nuances may have been lost in the process of translating interviews that were mainly conducted in isiXhosa. The conclusions to the study take account of these methodological limitations.

It was concluded that co-operation and support from schools, the Department of Education and employers can play major role toward active involvement of parents in the education of their children. A change of attitude towards disability issues need shifting from that of “an elephant in the room” to that which teachers, employers, and communities at larger would feel comfortable talking about. Thus a Transformational leadership program informed by Indigenous Knowledge Systems and Capabilities approach that is aimed at supporting and empowering parents to drive the process of inclusion is recommended. A Community Based Rehabilitation (CBR) Approach is further recommended as a vehicle that disability organisations in association with the Department of Education can use to facilitate discussions and awareness campaigns around disability and Inclusive Education. This way parents can be empowered to be assertive in relating to employers and teachers in addressing issues relating to their children.

**KEY WORDS:** inclusive education; social model of disability, active participation, empowerment, Ubuntu, resilience, indigenous knowledge, social cohesion, community based rehabilitation, agency

## **Acknowledgements**

Every moment and every single day of my life God designed my way before I was born. In his wisdom, I was able to overcome every challenge in the process of undertaking this study because God allowed a number of people to cross my path as I journeyed through to the end of this study. For this reason, I am grateful to God my creator for the following special people and institutions in my life.

My mom and dad, without you I would not be the person I am today. My late grandmother, Diana, stood by all of us, her grandchildren, to make sure that we were included and retained in our schools despite all odds. Mvuyi, you were my main source of inspiration and the reason I went through my early years at university. Rolf, when an opportunity for a PhD scholarship came up, you believed that I can and truly I did, thank you for believing in me.

My son, what a pleasure it was to juggle between parenthood and a student life. You are a real blessing a parent can ask for. My brother and sister (Nceba and Thandi) and all of my cousins, though we live distant apart, it is those phone calls and little times spent together that keep confirming to me why we had to share the same blood. I love you dearly!

Theresa, Shirley, Margaret and Roy you believed in my capabilities and made my study a pleasant experience to go through. I am grateful for your wise guidance, understanding, encouragement, patience and unwavering support. Sue Matthis and Jill Stevenson, your editing made this thesis all the more readable, thank you so much.

Parents and all research participants, without your co-operation this study would not have been possible. My colleagues and brothers at HSC Consulting, my 'sisters' (Nqa, Zukeka, Mbuyi, Priscilla, Eva, Sheryl, Pam, Dee, Chioma, Mamsi, Unathi, Rizaa, Yandi, Una, Thandi, Fundi, Andiswa and Rob) thank you for your love, prayers and support.

Thank you to Mam Gra and the support team at Canon Collins Trust, for the Graca Machel scholarship and for the special moments shared during the scholars' retreat sessions and for encouraging us to continue giving back to our communities for the benefit of future generation.

Thank you to NRF Thuthuka programme and Community Engagement Strategy for additional funding support.

## **The researcher**

Ntombekhaya Tshabalala is a 45 year-old single mother with an 18 year-old son. She lives in East London (Eastern Cape Province, South Africa). She is self-employed focusing on community development issues where she also supports parents of disabled children around the inclusion and retention in schools

## **Academic**

In 1993, Ntombekhaya completed her undergraduate degree at the University of Cape Town in Social Sciences majoring in Psychology. In 1999 she completed her MPhil in Housing Development and Management at the same university. As a community development facilitator, her interest in disability issues developed while she was involved as a project co-ordinator for the REHAB organisation, a disability Non-Governmental Organisation (NGO) in East London. REHAB was a pilot project for inclusive education within the Amathole District Municipality. This developed into her recent PhD study, which also focused on experiences of rural parents of disabled children regarding inclusion and retention of their children in public schools. During the period of her PhD study, Ntombekhaya was involved in a multi-institutional study focusing on how disabled youths sustain their livelihoods. She also became involved when the Disabled Youth Enabling Sustainable Livelihoods (DYESL) project was extended to the rural part of the Eastern Cape Province in Cofimvaba acting as one of the research team.

## **My role in this study**

My role in conducting this study has been that of a researcher. The experience gained from my day-to-day work as a development practitioner with a social work background has empowered me with necessary skills in the field of research. These skills have particularly helped me, as a researcher, to interview and relate with parents, teachers, children and every person at the time of conducting this study.

## **Preface    An opening: The symbol of an elephant**

The symbol of an elephant is strong for me, an African woman, born and raised in Africa. In presenting this study, I use the elephant as a fitting symbol for the life experiences of parents of disabled children, for my experiences in working with them, and for the manner in which people often deal with issues of disability and inclusion of disabled children.

As a symbol, the elephant is rich in associated meanings. Known for its size, strength and outstanding memory, the elephant is the subject of many idioms, several of which are especially pertinent to this study. I have discovered that the elephant has symbolic meanings across cultures. Amongst other attributes, these meanings are associated with strength, patience, power, reliability, caring, determination and loyalty. In African cultures the meaning is strongly associated with strength and determination. In some Asian cultures it is believed that a dream about an elephant is an indication that one is able to deal with any obstacle one might be faced with; it is also seen as an indication that “there is an elephant in the room” that needs to be attended to. Riding an elephant in a dream suggests leadership attributes and ability to carry those who might be heavily depending on you at that particular time in life. In Xhosa one might hear someone saying “*indlovu ayisindwa ngumboko wayo*”, meaning that long and big though the elephant’s nose is, the elephant never tires of carrying it wherever it goes because the trunk is part of the elephant. This idiom is often used to encourage parents who are faced with challenges in raising their children. As Chapters 5 and 6 of the study will show, the idiom has been embraced by parents of disabled children in dealing with challenges of raising a disabled child.

Determination and loyalty are among the other characteristics of elephants that are relevant to my symbolic use. In their natural habitat, elephants have been observed to demonstrate a strong tendency to be loyal, always standing up for others in their herd (Tshabalala, 2012; Ernst, 2007 and O’Connell, 2007.—This is nothing new in an African culture that puts emphasis on the value of *Ubuntu* (humanity), an observation made in my involvement with parents in the course of this study.

In an attempt to establish how elephants secure themselves against enemies and also manage to maintain the strong bond and commitment to one another, O'Connell (2007) discovered that elephants listen through their limbs. She observed that elephants appear to 'know' when it is time to move towards a different direction when an enemy approaches or when something bad is about to happen, while they tend to move towards a support system or friend in stressful and difficult circumstances. In working with parents of disabled children, I learnt that parents communicate more through their emotions than voicing or sharing their feelings, more especially when they are hurt or going through painful or difficult situations.

My own experiences in interacting with women in various aspects of my life have been a fascinating and eye-opening personal journey. Childhood memories that I have about my mother depict a loving, protecting go-getter, a hard-working, fearless, very strong and yet soft hearted person. I have similar memories of other women in the community where I grew up. Interactions with my peers, specifically women, have been no different. An opportunity to work with parents of disabled children, who mainly have been women and single parents, has taken my knowledge and experience of women's strength to another level, as I discuss in detail in Chapter 8.

Not only have the women I have met in my life and through this study exemplified the strengths of the elephant, but talking about disability in the context of inclusive education is a challenge equal to having an elephant in the living room. As obvious and big as these issues are, society keeps ignoring them, from generation to generation. This has become evident throughout the years of my involvement in this area of inclusion. Interesting to note though are the repercussions that we continue having to deal with because of our fear of talking about these issues. We are like a society conditioned to adopting a fire extinguisher approach in dealing with effects of silence than addressing its precursors rooted in our sub-conscious minds.

"An elephant in the room" is an idiom used to refer to a situation that people feel uncomfortable to talk about but yet so obvious and too big to ignore. According to the Heacock' *Cambridge Academic Content Dictionary* (2009), this idiom refers to an obvious truth that is being ignored or goes unaddressed: "It is based on the idea that an elephant in a room would be impossible to overlook, thus, people in the room who

pretend the elephant is not there have chosen to avoid dealing with the looming big issue” In the Eastern Cape, where I conducted this study, the status of inclusion in the education system is the elephant in the room. As clear as it is to everyone that the department is experiencing many challenges with management, this is the issue that no one wants to talk about. Once more parents and children become victims of the consequences of the elephant in the room. It seems we brush our concerns aside rather than address them.

As indicated in chapter 5 and 6 of this study, it became clear that it is the little things that parents do while working together that make a difference in the education of their children while in the process of doing so, they contribute towards making inclusive education a reality. As the saying goes about eating an elephant “one bite at a time”, so I believe participants did in this study.

For all these reasons, I have chosen the elephant as an emblem for this study. At different points throughout the theses I return to the elephant and its various symbolic meanings – to pay tribute to the parents, to enrich some of the chapter headings, to help me build the thesis and tell the stories that have played so vital a part in this study.

### **Structure of the study**

The chapters in this thesis are grouped together in four parts so as to clearly present the development of this study from inception to end.

Part 1, Problem Identification and Methodology encompasses Chapters 1, 2, 3 and 4. Chapter 1 and 2 present the background and the purpose for the study. Chapter 3 focuses on literature review. Chapter 4 concludes with an outline of the research design and methodology including key concepts used in the context of the study.

Part 2, Findings: Themes and discussion, comprises Chapters 5 and 6 which take us through the world of research participants and the discussion of findings.

Part 3, Thesis Building, covers Chapters 7 and 8. Chapter 7 focuses on thesis building while the significance and limitations of this study including the role played

by the researcher are detailed in Chapter 8. In this section, I acknowledge that writing and research can never be a neutral exercise where the participant observer does not hold cultural biases and personal reference points (Artiles, 1998).

Part 4, Conclusion and Recommendations, covers Chapter 9 where I present my conclusion and recommendations based on personal experiences and information gathered in the process of conducting this study while being mindful of lessons from previous researchers in the field of disability.

## **Part 1 Problem identification and methodology**

This section gives the background and purpose of this study, relevant literature, and concludes with an outline of the research design and methodology.



*Picture from website, [www.itsnature.org](http://www.itsnature.org)*

# **Chapter 1: There's An Elephant in the Room: Introduction and background to the study**

## **1.1 Focus of the study**

The focus of this study is upon a group of parents who, like elephants, remain strong-willed and resilient in dealing with challenges regarding the education of their disabled children. All the parents were participants in a project in the Eastern Cape Province of South Africa that aimed to address the gap between the rights of disabled children and their access to education. In 2006, parents' commitment to the REHAB project resulted in their children's admission to their local schools, both mainstream and special schools. Detailed information on REHAB in relation to this study is presented in the next Chapter 2. Currently, these parents find themselves faced with the challenge of playing a leading role in making inclusive education a reality (McKenzie, Tshabalala and Mpurhwana, 2008).

Other studies have shown that the capacity of parents to understand or to gain access to their rights is still influenced by socio-economic status and their ability to exercise individual and collective power (McKenzie and Loebenstein, 2006). Parents of disabled children who require additional support still experience difficulties gaining access for their children to schools and those who do manage to get their children admitted in mainstream schools, still struggle to have them retained in those schools. "Disabled children are still to some extent in the mainstream on sufferance", (Engelbrecht, Oswald, Swart, Kitching and Eloff (2005:192).

In the light of this situation, if parents are to play a leading role in making inclusive education a reality, there is clearly a need to facilitate, support and empower them to take on the role proactively. The ultimate purpose of this participatory action research study is to contribute to meeting this need, through a deeper understanding of the experiences of parents with disabled children and of their requirements for support. On this basis, the study will suggest strategies for inclusive education policy implementation that pays due regard to the role of parents.

## 1.2 The importance of this study (Rationale)

The importance of this study, and the rationale for the research, should be understood in relation to South Africa's policy for inclusion and the challenges of implementing policy to achieve the ideal of an inclusive society.

Disabled learners have experienced great difficulty in gaining access to education in South Africa. The legacy of apartheid still remains where there is inequality of resources. Segregation is perpetuated by the continued categorisation of learners according to disability, race and language. A recent study conducted amongst disabled and non-disabled youth in rural and semi-rural parts in South Africa indicated that disabled children are still excluded within the education system compared to non-disabled children (Cramm, Nieboer, Finkenflügel and Lorenzo 2013). Despite the lower number of disabled youth who were registered in school at the time of the research, findings revealed a large difference between the two groups in terms of accessing education. About 99.3% of non-disabled participants were attending school and 82.4% of disabled youth were attending school. Findings revealed *lack of access to information, distance, difficult admission systems, and physical access or as major barriers to accessing education for disabled youth* (Cramm et al., 2013). While this study mainly involved youth between 18 and 35 years, findings raise concern in terms of the inclusion and retention of disabled learners in schools. This exclusion is in contradiction to our human rights based constitution, which promotes education for all. Implementation of inclusive education requires more than the right of access to school, but it challenges every South African to make it work (Soodak, 2004). This again shows the challenge that parents as social agents and in their agentive role are faced with as their children solely rely on them as main advocates in their lives.

Various policies and legislation, such as the South African Schools Act and the Integrated National Disability Strategy (1997) inform Education White Paper 6 (EWP6): Building an Inclusive Education and Training System (2001). These policies promote the recognition of all people and an inclusive society.

EWP6 seeks to redress the inequalities and exclusion of disabled children from education and promotes accessible and quality education for all children through the

development of appropriate assessment and support systems. Polat (2011) maintains that the principles of inclusive education require all schools to be open to all children and to seek to respond to diversity. She further argued that access without quality leaves the education system vulnerable, as this tends negatively to affect access and achievement as well as failing to meet the goals of equity and justice (Polat, 2011: 53). Ainscow and Miles (2009), further raised concern about the short supply of relevant curriculum material that is crucial for teacher training in the light of the fact that they are expected to teach inclusively. The points raised by Ainscow and Miles (2009) and Polat (2011) on diversity and relevance in the field of education and learning confirm the need to incorporate indigenous knowledge in curricula development so as to include all children, irrespective of the context in which they live (United Nations, 2000). This is the area that needs further interrogation where the role of parents in the learning and development of children is often missed.

The policy on screening and assessment (SSIAS) informed by EWP6, acknowledges the central role played by parents in implementing inclusive education. The policy emphasises the social model of disability and accessibility of curriculum in ensuring that areas of learning become inclusive. Equal participation of parents, educators and learners is encouraged. Two critical structures entrusted with making sure that the policy is implemented in schools (with preference to learners accessing their local schools) are the Institution Level-Support Teams (ILST) and the District Based Support Teams (DBST), (Department of Education, 2008). It is important to note that, although the ILST plays a key role in making sure that the processes of assessment and support take place in a school environment with the support from the DBST, no decision can be taken without the consent of the parent in the process. Thus this study focuses on the participation of parents in the education of their children. It seeks to explore experiences of parents with disabled children with regards their participation in the process of including and retaining their children in schools. The study, however, argues that parents still experience barriers to fulfilling their role as equal partners in this process (McKenzie et al., 2006).

If, as this study argues, a paradigm shift is paramount in effecting progress in the field of inclusive education, then the issue of disability needs not to be seen as an

“elephant in the room” when it comes to addressing challenges around admissions and retention of disabled learners in schools. Educators and parents should feel comfortable in engaging in discussions regarding matters affecting role players in the process of implementing inclusive education.

Like all children, disabled and vulnerable children have the right to learn and develop in a structured and supportive school environment. Education is vitally important for them as it is an effective way of redressing the inequalities in our society (Department of Education, 2001; World Bank, 2002; Lewis, 2009). From my experience as a facilitator supporting parents and educators around issues of disability and inclusion of disabled learners in schools, I am aware that for many educators in the Eastern Cape East London area, it is challenging and overwhelming for them to work with disabled learners. However, in line with the policy of Education For All (UN, 1989), the Convention on the Rights of the Child (UN, 2006) and White Paper 6 on inclusive education (Department of Education, 2001), educators should help disabled children to become productive members of society by providing them with quality education, referring them to appropriate schools when necessary, taking care of them and providing them with a safe and healthy environment.

While the Special School Resource Centres are expected to support and train educators in mainstream schools, co-operation between parents and educators can play a vital role and make this task easier to accomplish (IDEIA) (Indiana Protection and Advocacy Services Commission (IPAS), 2004; Department of Education, 2001 and UN, 2006)). In addition, educators may require guidance in dealing with issues such as confidentiality and identifying and making better use of resources outside educational institutions. These include medical, psychological, social and other services. Therefore, for any learning site to be inclusive and supportive, co-operation between parents and educators becomes vital. It is important to recognise parents as key partners in the education, care and support of disabled and vulnerable children. They can offer valuable support for educators to be able to deal with challenges emanating from the needs of this specific group of children. Parents need to be part of the identifying of and of the solution, since they are key role players.

Clearly, therefore, there is an urgent need for parents actively to take on this challenge and to claim their space in the process of making inclusive education a reality. However, I would argue that parents are not informed about the current policy and what it expects from them as role players in the process of implementing inclusive education. Thus, this study seeks to address the problem regarding appropriate support in the process of empowering parents of disabled children so that they can actively participate in the inclusion of their children in education. This study engages parents of disabled children, disabled children and their educators using a participatory narrative approach in analysing their views and experiences, particularly those of parents, as key informants. It seeks to explore the nature of parents' relationships with teachers. I consider parents of disabled children as marginalised because they have been excluded from participation in policy implementation and monitoring that will inform decision-making related to issues of education which affects children's lives. Their voice is therefore crucial in forging ways for an inclusive education system. Engaging with them, in their settings as this qualitative study set out to achieve, provides first hand experiences of parents and their children regarding the effective implementation of inclusive education system, so that the child's right to education is promoted. Driven by the desire to support parents, I acknowledge that parents themselves are the best source of information as to the nature of support they need and how this support can be made available. For this reason focus is on the parents of disabled children. The study will establish a platform for parents to share their stories about the education of their disabled children. Focus will be on what parents view as necessary in different situations, so that they can fully participate in matters relating to the education of their children. By addressing these needs, parents will be able to take their children to school, to confront challenges hindering their admission in schools, and to actively participate as role players in the implementation of inclusive education. Ultimately the findings that will emerge from this research will inform and support inclusive initiatives and strategies and the development of inclusive sites for learning, an index for inclusion (Booth et al., 2000; 2006).

### **1.3 Research Questions, Aims, Objectives**

In designing the research questions, I acknowledge the importance of incorporating the positive and negative aspects of the research question in order to provide a link

between the findings of the study and possibilities for social transformation (Mertens, 2003). There were two main *research questions*, clearly linked to the research objectives, namely:

- What experiences do parents of disabled children have with regard to the education of their children?
- How can parents of disabled children be supported to facilitate their active participation in the inclusion and retention of their children in public schools?

The *research aim* was to explore the experiences of parents with disabled children, in order to understand their needs and to identify appropriate support in the process of engaging these parents in the inclusion and retention of their children in public schools.

The specific objectives were:

- Investigate the experiences and needs of parents with regard to their disabled children with a specific focus on the challenges they face,
- Explore ways in which parents of disabled children can be supported to facilitate their active participation in the inclusion and retention of their children in public schools.

#### **1.4 Study Area**

South Africa has a population of about 50.6 million with estimated disability prevalence at 5% (Stats SA, 2001- 2011). According to the Census information, the highest prevalence of disability is amongst Black Africans who make up the majority of the Eastern Cape population (Stats SA, 2011). The Eastern Cape, with an estimated population of 6.8 million (third largest after Gauteng with 11.3 million and KwaZulu Natal with 10.8 million), is regarded as the second poorest province in the country after KwaZulu Natal (Stats SA, 2011). Thus children in the Eastern Cape are disadvantaged through poverty and unemployment of their parents, (McKenzie et.al., 2008). The province is largely rural with the majority of its inhabitants relying on farming. Prior to 1994, the Eastern Cape was categorised as a Black Homeland, As a result, the province remained behind in terms of its development. The province is rated as having the largest outflow as regards migration streams (SA Stats, 2006-

2011). This can be attributed to the fact that people move to bigger cities, the Western Cape or Gauteng to find work. The language used by the majority isiXhosa.

All except one of the parent participants in this study reside in informal settlement areas. One of these parents lives in an established area near East London in the Eastern Cape Province (See figure 1 and 2).

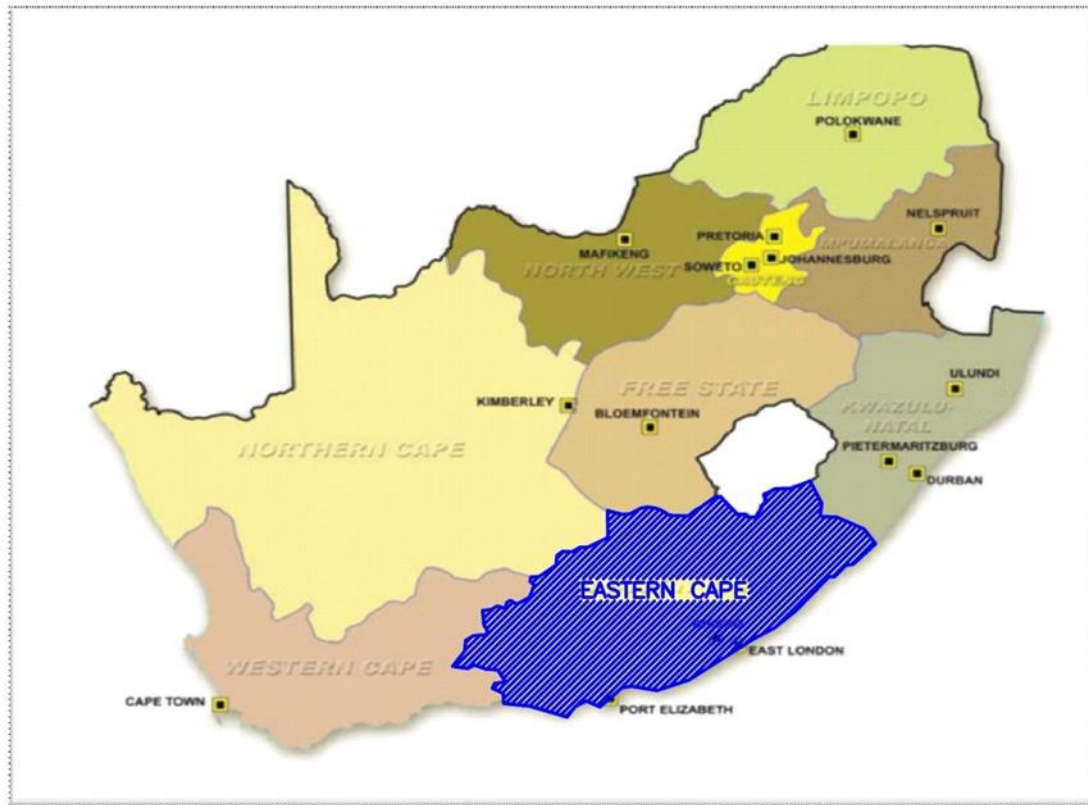


Figure 1: Area of Study (the shaded section indicates the province)

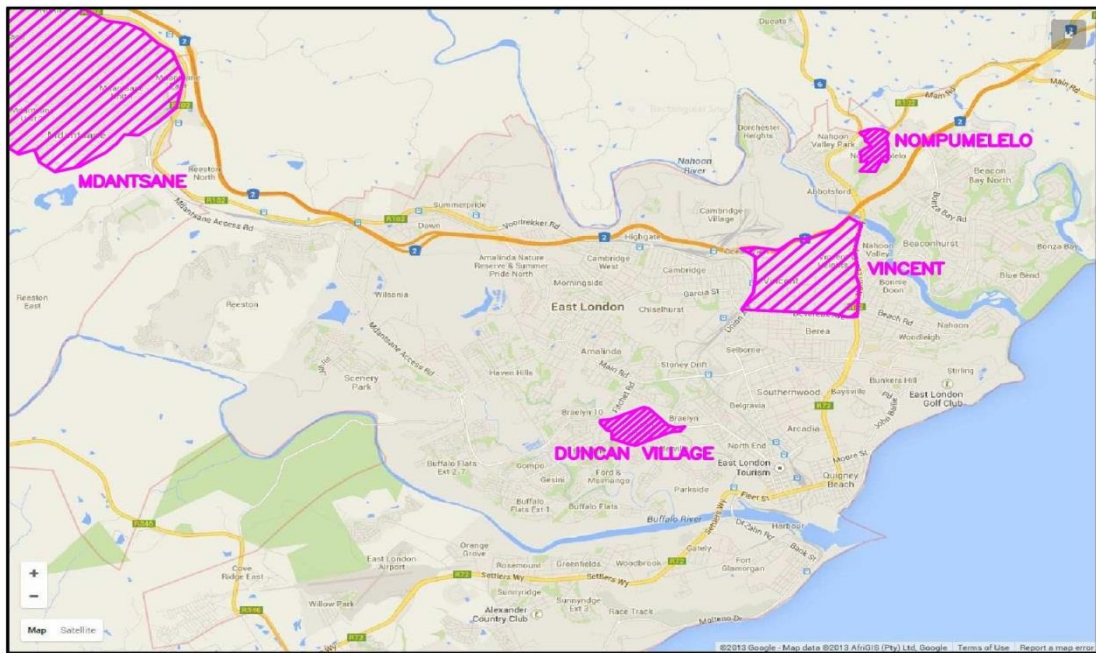


Figure 2: Map of East London and the sites of the study (the shaded sections indicate the four sites of the study)

## 1.5 The Researcher

In this section, I outline my experiences growing up, highlighting lessons that have shaped the person I have become, as well as my interest in this research topic and my decision to take a qualitative, participatory approach to the study.

### 1.5.1 Upbringing

Having mentioned some of the important attributes of the elephant, I will now relate the aspect of “strength” to women, including participants in this study, who have impacted on the kind of person I am. I was born in Cape Town and my family moved to Stutterheim, a small town in the Eastern Cape between East London and Queenstown. I come from a very small family of four. I was very close to my mother while my brother was close to my father when we were growing up. My mother was like a sister to me, and I still relate to her as if she were my sister. I think this relationship and my experiences observing how she strove to make life the best for the family have had an effect on the way I relate to other women. This, with due respect to the love my father gave to us, his children, too. Although we didn’t have everything in our family, we were part of a very wealthy community and I credit that to the ability of the entire community to uphold the value of Ubuntu. This meant that if

a neighbour could afford to have a plate of food, the person next door would never go to bed on an empty stomach. The section below further explains the relevance of my life in this study and the links with the symbol of the elephant.

My upbringing had a great influence in shaping my career path. Growing up in a rural and previously disadvantaged Xhosa community, I observed how parents, in particular women, tried to ensure that their children had access to education. I remember the long distances our mothers used to walk to and from work. They spent most of the time away from their children, driven by the desire to secure a better future for them. One of the memories that comes to mind are the days when I would boldly take the risk of walking in the dark from home so that I could meet my mother half way fearing for her safety as she walked a distance of about 5km or more to and from her place of work. She and some of my friends' parents from the same neighbourhood would get home very late at night and still help us with school work, whilst preparing evening meals and breakfasts, as by the time we woke up the following day they would have left for work. I have to mention again here that for me it is difficult to imagine what life might have been without the lessons I gained at that time and I credit this to the values of Ubuntu. I find these experiences to have developed some resilience in the person I am.

A traditional idiom - "*Indlovu ayisindwa ngumboko wayo*" – depicts the possibility of courage in difficult times. The idiom, literally translated, means no matter how big an elephant's trunk, the owner never feels its weight. At times when I am faced with difficult situations, I find the courage to press on when I recall childhood situations when life didn't seem easy and yet I managed to achieve valuable things despite the difficult challenges. My own childhood experiences meant that I could relate very well when listening to the stories of the parents' growing up and how they had found hope in knowing that they had conquered so many problems/challenges and were able to find strength in dealing with challenges pertaining to their disabled children, in particular to schooling.

### 1.5.2 Education

During my schooling, teachers used to visit parents in the late hours of the day to report challenges to children at school. Despite the fact that these parents were not educated, they arranged extra support for their children. This resulted in the initiation of a study group for children identified as slow learners with the support from the teacher residing in my community. When considering the hectic schedule of our parents' lives, one can imagine how much more hectic the schedule of a parent with a disabled child would have been in the same situation. Looking back, I realise the important role played by parents in the education of their children. They might not have been physically available to assist with school work because of their socio-economic circumstances and illiteracy; however, they made sure that additional support was provided for their children. For me, a career in community development was the key to change the situation in my community for the better, and this is what gives me fulfilment in my career

### 1.5.3 Adulthood

As a community development worker in adulthood, I have worked with women in various community projects. These projects included income generating projects, the provision of infrastructure and low cost housing focusing on self-help and intensive labour, establishing support systems for and with victims of domestic violence, HIV/AIDS and inclusive education. I have spent the past three years facilitating a program that aimed at addressing the gap between the rights of children and their access to education.

My personal and cultural beliefs were constantly challenged in my attempt to establish how these parents influenced the education of their children. I struggled to understand why a child would be denied admission in a local school mainly because the child uses a wheel chair whilst the same child is told not to meet the criteria for admission in a special school (McKenzie et.al. 2008). When the person responsible for admission was a woman, and from the same culture, but showing no sense of 'Ubuntu'<sup>1</sup> to this uneducated and desperate fellow woman and parent (McKenzie

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<sup>1</sup> **Ubuntu (humanity)** is a Xhosa word generally meaning "kindness" or the ability to accommodate and live peacefully with others. In other words, my ability becomes limited when on my own than

et.al, 2008), then suddenly reality would hit, and I would be reminded of where I had come from and this would help me understand the parent better.

The example above from experiences of a parent confirms the challenges that parents experience when we focus attention on impairments and not the person when it comes to relating to disabled children. Once more, the symbol of “an elephant in the room” is evident as the source of the problem here as the parent and the school do not openly talk about concerns and fears resulting in the rejection of the child at school. The section that follows, reports on the REHAB project in which parents in this study participated. As the facilitator who worked closely with these parents, I shared their experiences and the challenges they had been through while linking these to the stories shared during this study. It is apparent that, without perseverance, hope, humility and resilience’ parents could have long given up the hope that their children’s lives would have changed for the better.

## **1.6 Cultural considerations**

My position as a researcher has been shaped by the values and practices of community and ‘Ubuntu’ that have been so much part of my own life experience. The notions of community and ‘Ubuntu’, and other related notions, form an important backdrop and cultural context to the study. For this reason, I include a brief discussion of them here.

I consider myself a development facilitator, daughter and granddaughter, niece, mother, woman, wife and a Black African who, as a young girl grew up in a family and a rural community characterised by a number of social ills and poverty yet with warmth and love. In an African rural culture, community holds much value. I concur with Dlamini (2008) that ‘community’ is a rich and multidimensional term that in some can stir emotions while others might view it as just an area of residence. In an African rural culture, community defines who the person is while offering a sense of belonging. It has the power to shape and inform one’s thinking and actions both

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when I am with others. I might be able to do but I cannot be without another person in life. **Also see 1.5 “umntu ngumntu ngabantu”.**

consciously and unconsciously. It is known as “*Ubuntu*” and seen as a resource to tap into when times are difficult.

### 1.6.1 The concept of Ubuntu

My discussion here on Ubuntu takes a view that the concept of Ubuntu is mainly used by people in Southern Africa however, what it refers to is not restricted to the African context but rather a tradition shared by a large majority of the African people through which research on African philosophy, non-Africans became aware and adopted (Ramose, 2002; Bell and Metz, 2012). In support of this view Gianan (2011:64) citing Ramose states that Ubuntu philosophy is manifested in other cultures and in various forms exemplified in European and Asian philosophies, making it “universal and universalisable”.

Several writers agree that Ubuntu as a concept embraces unity and in particular, a sense of ‘community’ thereby promoting the spirit of oneness, sharing and empathy towards one another which all in turn enhance human value, trust and dignity (Mbigi and Maree, 1995; Venter, 2004; Khoza; 2005 Mabovula, 2011; Bell and Metz, 2012; Letseka, 2011 and Sedibe, 2013). Sedibe (2013), quoting Mandela, defines Ubuntu from an African point of view as the social currency of an African and the Reconstruction and Development Program (RDP) of the soul. Earlier, Mbigi and Maree (1995) defined Ubuntu concept as the collective solidarity of the poor with regard to survival issues adding to their definition: conformity, respect, human dignity and unity as the key values of Ubuntu. Highlighting the aspect of oneness and unity that Ubuntu embraces, Khoza (2005:266) associates Ubuntu with communalism which he defines as “a concept that views humanity in terms of collective existence and inter-subjectivity, serving as the basis for supportiveness, cooperation, collaboration and solidarity”. People view themselves and what they do as equally good to others as to themselves (Mabovula, 2011:39).

This sense of unity is embraced almost in all levels of African society. In politics, one would say *an injury to one is an injury to all*, with this implying that if you hurt one of us, every one of us feels the pain and therefore expected to combine our efforts to support or comfort the person that has been injured. This slogan was used by Black

communities in South Africa during the time of uprisings against the apartheid laws as a call for organised revenge or firing back by throwing stones to soldiers when one within the crowds might have been shot by the soldiers.

Disciplining a child is viewed as a community rather than just a family effort. as a result the entire community is expected to share the blame when a child tends out to fall on the bad side when it comes to adapting to social norms and values or ill disciplined. Older people are expected to say something when they see younger ones doing something wrong and not just leave as if nothing has happened, although things are slowly beginning to change with people fearing their safety intervene in other people' s "businesses" as it is often said in our days. The majority of communities especially in rural communities still hold on to the saying and belief that *"it takes a community to raise a child"* or *"umntu ngumntu ngabantu"* meaning you are what you are because of others.

In his novel about the history and the lives of rural people in the Eastern Cape (South Africa), Mda (2000) uses the term, "the heart of redness", depicting the power and importance of culture to Black African people. The term implies the ability to trust and to hold onto something that one believes in. Africans have a strong sense of interdependence which again shows the solidarity amongst them. This becomes evident as extended families hold gatherings at times of mourning, weddings, and when the both families from the husband and the wife meet to find solution when marital problems are experienced. Ramose in Mabovula (2011) explains the notion of connectedness amongst African communities as a "moral view point". Indicating therefore that in African communities, Ubuntu is their way of life and just the right thing to do.

According to Venter (2004), Ubuntu is a concrete manifestation of the interconnectedness of human beings and the embodiment of African culture and life style. Mabovula (2011:41) captures the views of different authors on Ubuntu well when she notes that "by perceiving the individual as being in the centre of this greater whole, the philosophy of Ubuntu may perhaps be described as African humanism." Resulting to social harmony and cohesion within the families and impacting communities globally.

Fukuyama (1999), writing about social cohesion as a cultural component of modern society, argues that social cohesion is not an asset that can easily be created. The connotation here is the importance of knowing who you are; the process which, in an African community, becomes impossible when one doesn't know where one comes from and can only be achieved in relation to others. This knowing is implicit in the African expression of togetherness, "*umntu ngumntu ngabantu*" ("we need each other"). In my work-related interactions with women in rural communities, I find that women have an ability to rely on and to trust one another; and this is very powerful in challenging times.

History tells us how African people have, for a long time, managed to keep their heads high even in the darkest times of their lives mainly because they maintained an awareness of who they were. Obama describes Mandela as: "a man who was willing to risk his own life for what he believed in, and worked hard to lead the kind of life that would make the world a better place" cited in (Mandela, 2010: xiii).

Despite the positive and the good view on Ubuntu that I have mainly focused my argument, the concept or practice has been criticised of being susceptible to abuse by others with wrong intention. Gouws and van Zyl in Reddy, Meyer, Shefer and Meyiwa (2014) criticised the concept of promoting social hierarchy thereby abused by some in order to gain control over others. Gouws and van Zyl (2014) claim that the promise of equality in Ubuntu has been appropriated into the services of heteropatriarchy and therefore in need of gender reform (Gouws and van Zyl in Reddy et al., 2014). The point of concern here is about the abuse of power with intention to advance one's own interest. An example in an African tradition is that of an uneducated/ uninformed women who feels she has to show respect because "traditionally" a wife is expected to show "intlonipho" (respect). Mbeki (1999) also expressed concerns and took initiative to see Ubuntu values reclaimed in African communities. In his efforts to revive the spirit of Ubuntu, which he refers to as African Renaissance, Mbeki (1999) adds an important value on Ubuntu, the aspect of *selflessness*. The concept of African Renaissance encourages one to look beyond the present to a better future (Mbeki, 1999). Mbeki (1999) relates the aspect of selflessness to the effort that people made sacrificing their lives to see freedom and

democracy achieved. He further reminds us Africans that for any initiative to be sustainable, we need to be holistic in our approach. Our morals, attitudes and values count the most (Mbeki, 1999). As Africans, we are encouraged to keep cognizant of who we are and where we come from – a reminder that there are those who sacrificed their lives for the better life we have today, something that we too owe to the future generation, and indeed a true indication of Ubuntu. Gianan (2011) also relates Ubuntu to selflessness noting in his definition of the concept of philosophy calls on everyone to responsibly act towards the humanization and attainment of peace with and for oneself, the other and the world.

## **1.7 Conclusion**

In this first chapter, the rationale, focal research questions and the objectives of this study have been presented. A holistic presentation of my background detailing my life growing up, cultural considerations which have impacted my focus on the study and my specific role (as 4.2.3, and p. xi-xvii further expands) in this study have all been outlined. The maps indicating the study area are also included.

The next chapter provides a brief overview of the REHAB project from which this study arose. It also describes the situational context within which the study took place.

## **Chapter 2: Project and Research Background to the Study**

### **2.1 Introduction**

The concept of an elephant here talks to the challenges faced by parents of disabled children in the context of inclusive education. It acknowledges that making schools inclusive sites for learning is a process that requires patience, co-operation and the understanding that we are all different and that, given a chance, we can learn from each other's experiences as participants in the process.

My interest in the field of inclusive education and parent participation dates back to the period of my involvement in the REHAB project. Ever since then, it has been my desire to see the White Paper 6 on inclusive education being successfully implemented. In carrying out qualitative research, one needs to determine whether or not findings from the research support, refute or supplement existing beliefs about the topic being researched (Creswell, 2005). It is necessary to read existing literature relevant to the research topic as widely as possible. Reading widely provides a framework and a context for qualitative research.

A comprehensive and a well-integrated literature review is important because it is an excellent source for selecting and focusing on a research topic. It provides the researcher with a good understanding of the issues and debates in the area in which he/she is working. It also gives the researcher an understanding of current and historical theoretical thinking and definitions, studies and their results (Mouton, 2001).

In this research, the literature study was conducted to form a firm theoretical framework for the study, to substantiate the orientation and the rationale for this study, to justify the research design and methodology, and to compare the research results of this study with previous studies in the field (Creswell, 2005). I thoroughly searched for useful and relevant information pertaining to the study, with the aim of gaining knowledge and ideas for other research. I also used documents and records because they are useful sources of information, as they are always available, stable, cost effective and relevant and could contribute to this study (Lincoln and Guba 1985; Leedy and Ormrod, 2001). Having said that, I do acknowledge the challenges

involved and view this work as a process with goals that can only be accomplished when we, as the citizens of this country, can work together within the values of Ubuntu.

## **2.2 Background information to REHAB in the context of this study**

This chapter focuses mainly on a project that was conducted by REHAB, a non-government disability organisation in the Eastern Cape province of South Africa. The project which took place from the years 2006 to 2008 was initiated by the Nelson Mandela Children's Fund Program (NMCF) with the aim of supporting local government's plan to pilot inclusive education in the one of the districts (McKenzie, et al., 2008). The main reason for the NMCF to engage REHAB, to work hand-in-hand with government, specifically the Department of Education, in the process of piloting inclusive education was due to the experience of REHAB in the field of disability.

For this assignment, REHAB had to play a neutral role assisting the schools to put systems in place for the implementation of inclusive education. It also supported parents who were experiencing difficulty getting their disabled children admitted in local schools according to the policy. I was then employed by REHAB as the project facilitator and became involved as a researcher for the NMCF research project from 2006 to completion in 2008. The study conducted by REHAB, influenced my focus in this study.

During the period of my involvement with the REHAB study, my interest towards inclusive education and the involvement of parents in particular grew. I saw a need to understand how parents themselves viewed the process on inclusive education and their involvement as the inclusive education policy puts emphasis on the participation of parents in the process of making schools inclusive sites for learning.

## **2.3 Background of REHAB**

REHAB was founded in 1997, as a joint venture program of the Societies for Mental Health, Physical Disability and the Blind. The program aims at extending services to disabled people in rural areas of the Eastern Cape Province in South Africa. Although services are directed at all disabled people, the primary target group is young children and newly disabled adults.

### **2.3.1 The Project**

The Nelson Mandela Children's Fund project was one of the projects within the REHAB program and the particular project that is referred to here was initiated in 2006 with the support of the Nelson Mandela Children's Fund. The project aimed at addressing the gap between the rights of children and their access to education. The research team in 2006 was made up of five people, a research leader who was responsible for the overall management of the project, myself as research co-ordinator who worked with the research leader and was specifically the liaison person between parents, schools and REHAB. The REHAB director also worked with the research team as she was the one who made decisions on behalf of the organisation when necessary. In addition, two of the REHAB fieldworkers assisted the researchers during focus groups. The focus groups were made up of ten children and their parents who were clients at REHAB.

At the time of my involvement as the co-ordinator at REHAB (2006-2008), I became acutely aware of the anecdotal evidence, as revealed through parents of disabled children, of the challenges and barriers faced by these parents. The project also provided support to educators and parents in addressing barriers preventing children from being fully included. Amongst others, the following were key focus areas:

- Awareness-raising within communities and parents around the importance of early stimulation, education and the right of vulnerable children to education.
- Empowerment of parents through informing them of the relevant policies and the need to actively lobby on behalf of their children. They were also engaged in developing individual, education plans for their children at school and addressing the concerns of the school regarding resources and support for the child.

- An action learning research approach to continuously ensure that lessons learnt assisted parents to ensure the on-going support of their children as they progressed through the education system.
- Workshops for parents and educators to address attitudes towards disability within the targeted schools.
- Support to the educators and parents to address the barriers preventing the child from being fully included.
- Facilitation of a support network of parents to assist them in their efforts to access and maintain their children in the education system through quarterly meetings to evaluate the children's progress. We encouraged parents to be closely involved in their children's schools in order to be proactive in addressing the needs as they arose.

### 2.3.2 Research Process

The approach taken was a qualitative one where parents were supported to deal with challenges they were experiencing in schools where their children were enrolled. Parents were encouraged to address problems involving educators, their children and, in some cases, engaging Department officials where it was deemed necessary.

The research was integrated with project activities in an action research (AR) framework, which Welman and Kruger (2001) define as an attempt to find a solution to a practical problem rather than testing or developing a theory. Our theoretical model was based on a systemic view of educational failure within a social model of disability. In line with Booth and Ainscow (2002), researchers took the view that their discriminatory attitudes, actions, cultures, policies and institutional practices are disabling to students with impairments or chronic illness and that schools themselves can do a lot to ensure their accessibility and learner participation.

While the project aimed at supporting parents as they were directly affected by the challenges of exclusion of their disabled children from schools, the research team acknowledged that every role player had to be involved in the process of addressing these challenges, hence the involvement of schools and Department officials.

A support network of parents that worked together in their efforts to access education for their children was established. Quarterly meetings with the schools and parents aimed at evaluating children's progress were facilitated. Some of the schools were assisted in setting up support structures i.e. Institution Level Support Teams (ILST) and in reviewing their current policies (e.g. admission policy) to ensure an inclusive ethos existed. Lessons learnt in the process were shared with the relevant stakeholders i.e. families, educators, department officials and specialists supporting children experiencing barriers to learning.

As the project progressed, it became apparent that many parents were faced with the challenge of getting their children admitted and retained in mainstream schools due to their impairments. The situation worsened to such an extent that an element of excluding children on the basis of impairment became evident, even in special school resource centres. For parents and disabled children, ensuring admission and retention in the education system became a situation of the survival of the fittest. It was also noted that sometimes parents got tired of the struggle to keep their child in the mainstream and opted for a special school as this was perceived to be an easier option. The desire was see empowered parents acting as a resource and advocates in the community, rather than the general feeling of dependency on REHAB which was evident amongst them. It was considered important by the research team to look at ways they were relating and working with parents and therefore questioned whether they were creating dependency.

Challenges were also noted in the process of working with the District Based Support Team (DBST). The DBST is a Departmental structure that is mandated to oversee the delivery of support to learners in the district and to ensure that all learners are accommodated within the education system. The relationship between REHAB and the DBST was not always straightforward or positive, which was largely due to a lack of clarity and sometimes capacity in the delivery of support. On the one hand, REHAB felt that they were doing the work of government and on the other some members of the Department of Education felt that they were overstepping the mark at times. However, the DBST had a limited capacity to cope with the number of

schools in the district and they were not able to get to the schools that were desperate for support. This limitation resulted in some teachers relying on REHAB to provide support. Consequently, the concept of inclusion was seen as a REHAB programme rather than a Departmental policy where REHAB was playing a facilitative role.

Problems around the referral to special schools were also noted since they took a very long time to be acted upon. This delay frustrated parents so much that they resorted to approaching special schools directly as the process of applying for admission through local mainstream schools was seen as too challenging and lengthy. In trying to intervene, REHAB had difficulty knowing who to contact and how they had to work with the DBST but this improved as a result of discussions. Educators seemed to need practical support but were not sure who to approach for this support. They understood that the DBST should be responsible for training the institution-based learning support teams (ILSTs) but the reality was that they were not able to meet that requirement. REHAB stepped in to some extent but they also did not have the capacity to provide on-going support especially in technical educational matters such as curriculum adaptation. This confusion resulted in parents losing confidence and doubting whether teachers to whom they were entrusting the education of their children knew what to do.

Generally, the project was hampered by a fear of the unknown and a reluctance to change old ways of doing things. When teachers began to change and do things differently they were not necessarily supported by the management of the school. This response became clear in cases where it was difficult to accommodate changes to time tabling in order to accommodate ILST meetings in schools.

There was some tension between parents and teachers. Parents became empowered to take their children to school but teachers frequently did not want disabled children in their classrooms. They felt that this was someone else's responsibility, possibly because they felt that it required special training and extra time. Teachers also had to deal with large numbers in the classroom and felt that they were not supported. They were often reluctant to approach the parents as

problems surfaced and as a result the problems became more entrenched. This reluctance was perceived as fear of taking responsibility in the absence of support from the Department. The same attitude was perceived during meetings between parents and teachers where teachers would blame the child for their poor performance, rather than reflecting on their own teaching skills.

In the midst of these challenges, parents suffered the most as time was wasted with disabled children remaining out of school while waiting for admission. In addition, their children were allowed to proceed from grade to grade in order to keep them at the same grade level as their peers if they were not placed in special schools, instead of the local schools adapting to accommodate their needs..

## **2.4 Lessons from REHAB Project**

Through the process of gaining admission and providing support for disabled children in mainstream schools, the following questions believed to be key to the process were examined:

- What changes in the school eco-system would be necessary to support the admission and retention of disabled learners in mainstream schools?
- In what ways can the process support the empowerment of parents?
- In what ways can the process assist schools to become inclusive sites of learning?
- How does the support of individual learners mesh with the support structures mandated in EWP6 to provide optimal support?

### **2.4.1 Changes in the School Eco-system supporting Disabled Learners**

Schools were best able to change where there was support from DBST in terms of referrals and the training of ILST and educators in curriculum adaptations, with clear consistent messages from all role players i.e., DBST, NGOs and CBOs. In this case, the school management showed the same commitment to inclusive education as that shown by teachers in the classroom who were implementing inclusive education.

The role of REHAB was seen as a sensitive one in this respect since the school was bound by Departmental policies and procedures. This gave researchers insight into the role a disability NGO could play in monitoring and linking rather than working directly with the school structures in the implementation of overall policies (McKenzie, Tshabalala and Mpurwana, 2008). REHAB has a role in supporting schools to admit and retain learners by assisting the Department with early identification of learners who will be entering the formal education system, disability awareness education and issues of physical and intellectual accessibility. The DBST has the responsibility for the development and training of the ILST which would cover familiarity with inclusive education procedures, administration and referral structures. Teacher training, especially in disability awareness and curriculum adaptation, is essential.

#### 2.4.3 Assisting Schools to become Inclusive Sites of Learning

An organization such as REHAB can assist with identifying disabled children in the community and guiding them through the correct referral process to the local school. Once admitted, they can identify adaptations that need to be made to make the school more accessible, both physically and intellectually. They can also assist schools by linking the school to support structures e.g. DBST, Special School Resource Centres (SSRC) and in assisting in the development of links between these structures themselves. This strategy would include links to training opportunities and shifting attitudes to a commitment to children of the community, regardless of whether they have a disability or not.

#### 2.4.4 Supporting Individual Learners according to EWP6

Schools must be encouraged and, indeed, expected, to make use of the Departmental procedures for screening, identification, assessment and support. To support this, the DBST should be well trained and consistent in the application of the referral processes for disabled children. REHAB has a role to play in ensuring that DBSTs, parents, educators and other role players are well-informed about education policy with regard to disabled learners and to assist in educating their partners in this policy. By so doing, REHAB could act as a vehicle used by parents in changing perceptions around disability being seen as “an elephant in the room” when it comes

to adhering to admission of disabled learners and facilitating the process for the retention of disabled learners in schools.

It became evident that an NGO, such as REHAB (that parents of disabled children find easy to relate to and to call on for support), has an important role to play in supporting the implementation of inclusive education policy for disabled learners. The critical element of this role is the partnership with the Department of Education in order to work hand in hand with District Based Support Teams (DBSTs).

The outline of the REHAB project shows that, while the focus of the project was on the children through the support given to parents, nothing was done to look at experiences of parents and their views on how they could be supported. South Africa's White Paper-6 policy on inclusive education is considered amongst the best in the world (Mail and Guardian, 2006). For this policy not to become a "white elephant" to the citizens whom it is meant to serve, we need to start interrogating our actions in the process of making it work for us. It was for this reason that I decided to focus my research study on the experiences of parents with disabled children.

## **2.5 Summary**

This chapter focused on the REHAB project as the background context of the study. The description of the organisation was presented to highlight the context in which the organisation operates. It described the challenges and lessons learnt from the REHAB project as contributing factors to the initiation of this study. It highlighted challenges that parents of disabled children face in engaging in the education of their children, indicating that inclusive education is a process achievable over time.

Chapter 3 expands on the policy of inclusive education and reviews a selection of national and international research literature on inclusive education and parent participation in the education of their disabled children. It further provides a theoretical framework for the study and its recommendations for approaches to parental support.

## Chapter 3: Literature Review

### 3.1 Introduction

In carrying out qualitative research, one needs to determine whether or not findings from the research support, refute or supplement existing beliefs about the topic being researched (Creswell, 2005). It is necessary to read existing literature relevant to the research topic as widely as possible. Reading widely provides a framework and a context for qualitative research.

A comprehensive and a well-integrated literature review is important because it is an excellent source for selecting and focusing on a research topic. It provides the researcher with a good understanding of the issues and debates in the area in which he/she is working. It also gives the researcher an understanding of current and historical theoretical thinking and definitions, studies and their results (Mouton, 2001).

In this research, the literature study was conducted to form a firm theoretical framework for the study, to substantiate the orientation and the rationale for this study, to justify the research design and methodology, and to compare the research results of this study with previous studies in the field (Creswell, 2005). I thoroughly searched for useful and relevant information pertaining to the study, with the aim of gaining knowledge and ideas for other research. I also used documents and records because they are useful sources of information, as they are always available, stable, cost effective and relevant and could contribute to this study (Lincoln and Guba 1985; Leedy and Ormrod, 2001).

A newspaper article published in *The Mercury* (June 13, 2012) outlined a case of a mother of a disabled child who decided to challenge her employer in court for making her work long hours resulting in her not having time to attend to the needs of her disabled child. As a result of this, the child missed out on therapy sessions from which she could have benefited towards improving her speech development. Instead her condition was found to have deteriorated over that period of time. This article indicates two significant changes, firstly, the decision taken by the parent to

challenge the employer indicates a paradigm shift in the way parents view their relationship with employers and the awareness of their rights as employees and parents. Secondly, the court's ruling on this case indicates a level of commitment and a paradigm shift in government policies as the information from policies, previous and recent research studies in this chapter will outline.

As the article noted here above indicates, this study is positioned where communities, organisations, government officials, learners, parents and educators grapple with the notion of ensuring inclusive education for all and where the concept of disability remains "an elephant in the room" when it comes to addressing challenges in this process. In particular, this chapter explores and interrogates literature relating to inclusive education and parent participation. The purpose is to make it easy for the reader to view this study in the context of the works of others. As this study revolves around the inclusion of disabled children within the education system and the involvement of their parents in the process, I focus on White Paper 6 as a policy on which this study is based.

Although this study focuses on a group of parents who are based in a specific area in South Africa, the move towards an inclusive education system needs to be seen as a worldwide move from a mainly medical view of disability to a rather more eco-systemic model. Hence, both national and international experiences around inclusive education and parent participation, as well as the focus on the social model of disability, are encapsulated in this chapter. The process of supporting parents is viewed alongside the concepts of empowerment, transformation and participation with the understanding that, given some level of support, one gains more power to do things one would not have been able to do in the absence of support. It is against this background that the Transformative Paradigm outlined in this chapter, forms the basis for a theoretical framework on which this study is based. The sequence of this chapter is as follows:

- Shift from exclusion to inclusion: South African perspective
- Policy on inclusive education and previous studies conducted relating to parent participation in the education of their children
- Identified needs of parents.

- Concepts of empowerment, transformation, participation and Community Based Organisation (CBR)

Literature presented in this chapter will assist the reader to locate this study in relation to the works of others in the field of inclusive education and parent participation. Welman and Kruger (2001) mention that by exploring previous work related to the topic of discussion, researchers may become aware of inconsistencies and gaps that may point to further research. This approach also holds true with regard to what this chapter hopes to achieve.

A number of researchers across the world agree that the move from special to inclusive education is a challenge not only facing South Africa. It is a global challenge that education systems are faced with (see, for example, Lomofsky and Lazarus, 2001; Nussbaum, 2006 and Engelbrecht et al., 2006). However, the countries that seem to be most challenged by this move to inclusive education are the African countries because of their low-income levels (Engelbrecht et al., 2006). Nussbaum's (2006) view of disability indicates that the process of inclusion involves not just placing disabled learners in a mainstream school, but also the changing of policies and infrastructure. This focus on changing policies and infrastructure seems to be the major challenge that the African countries are facing as the process is very costly.

Using a human rights perspective, Booth (2005) argues that more than anything else, inclusion involves changing values and attitudes in society and education by minimising exclusionary and discriminatory practices. This view is affirmed by the Universal Declaration of Human Rights (Article 26, United Nations, 1948); the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Education for All (EFA) flagship (UNESCO, 2010).

### **3.2 Shifts from Exclusion to Inclusion: A South African Perspective**

As the concept implies, inclusive education is concerned about the admission, inclusion and retention of disabled learners in schools. Rooted in the social model of disability, inclusive education is regarded as a process of bringing about change with

specific reference to attitudes, practices, policies, environment and resources in the education system, by identifying and solving barriers to full participation by every learner within mainstream settings (Lewis, 2009). Note that the focus and emphasis is on barriers within the education system rather than on barriers within the child. This focus is what basically distinguishes the social from the medical model of disability. South Africa shares this approach with Zambia in its current application of inclusive education in that special education is still administered in parallel to the mainstream school system (Miles, 2009). The definition by Miles (2000) that inclusive education is the process of increasing the presence, participation and achievement of all students in their local schools and the disabled students in particular, talks to what the White Paper 6 on inclusive education seeks to achieve through its processes and procedures for the admission of disabled learners in schools. Central and key to this process is the involvement of parents, a vital yet challenging, aspect that this study sets to interrogate.

Discussions around the need for an inclusive education system date back to as early as the 1970s when most modern or developed countries started realising the impact caused by a segregated education system in their countries (Ainscow, 1999; Heung, 2006; Opretti and Belalcazar, 2008) . In the USA, findings from research undertaken in the early '70s indicated that children had learned some academic skills before they started school and that this had led to the introduction of training programs focusing on parents as teachers (Shapiro and Forbes, 1981).Such developments were then legally enforced through the Public Law 94-142 of 1975 (amended in 1997 to the Individuals with Disabilities Education Act (IDEA). This policy stated that parents need to be involved in decision making around the education of their disabled children (Public Law, 1975; Shapiro and Forbes, 1981). Initially, and in South Africa in particular, concern was mainly about the admission of disabled children to special schools. This concern resulted in the gradual move from the mere placement of disabled children in special schools and special classes within mainstream schools to the admission and retention of disabled learners in local schools with the support and co-operation of educators, parents and the Department of Education.

South Africa is signatory to a number of international agreements dealing with education and the protection of the rights of children. Among these are the

Convention on the Rights of the Child (United Nations, 1989); Standard Rules on the Equality of Opportunities for Persons with Disabilities (UN, 1993); the Salamanca agreement (UNESCO, 1994); the Dakar Framework for Action (United Nations Educational, Scientific and Cultural Organisation / Ministry of Education and Science, Spain, 1994) and the Dakar Framework for Action (Education For All Forum UNESCO/EFA, 2000), to mention but a few. At a local level, the South African Schools Act (RSA, 1996) and the White paper on An Integrated National Disability Strategy (ODP, 1997) both informed the Education White Paper 6 (EWP6). Building an Inclusive Education and Training System (Department of Education, 2001) was introduced to promote the recognition of all people (including the disabled) and an inclusive society. As a sign of commitment to protecting the rights of its disabled citizens, South Africa further ratified the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006). This commitment included the upholding of the principles outlined within the inclusive education policy (Department of Education, 2001).

EWP6 seeks to address the inequalities and exclusion of disabled children from education and promotes accessible and quality education for all children through the development of appropriate assessment and support systems. The policy acknowledges that all children can learn and that they differ in ways in which they learn. Despite the acknowledgement of the different ways in which children learn, our system of education still remains silent about the aspect of Indigenous Knowledge and the crucial role it plays in the learning and development of people. Miles (2009) correctly suggested a need for teachers to get access to contextually relevant information as a means of empowering them with knowledge and the skills to teach inclusively. Focus needs to be on individual strengths without overlooking the context in which the child lives in order to maximise participation and minimise barriers to learning (Department of Education 2001; Ogot, McKenzie and Dube 2008; Pillay and Di Terlizzi 2009). The policy further acknowledges the vital role of parents in the process of creating inclusive sites for learning.

Parents, therefore, have a right to place their disabled children in local schools just as children have a right to gain access to local schools. It is for this reason that White Paper 6 on inclusive education encourages parent participation, the

establishment of resource centres and District Based and Institutional Learning Support Teams in promoting an inclusive education system (Department of Education, 2009). A number of previous researchers argued in support of active parent and family participation within the education sector, but there have been some who approached such developments with reservations (Engelbrecht, 2003; Dunst, Bruder, Trivette and Hamby, 2006; Turnbull, Summers, Turnbull *et al.* 2007).

Swart, Engelbrecht, Eloff, Pettipher and Oswald, (2004) argued that “parent-school partnerships that allow parents to become active collaborators rather than passive observers of their children’s education need to be fostered”. While earlier, Kalyanpur *et al.*, (2000) viewed the move towards parent participation as an attempt to adjust the lack of parental involvement and the balance of power between professionals and parents that has historically been skewed in favour of professionals. Interestingly Lundeby and Tossebro (2008) observed parent representation in groups of professionals and found that in cases where parents were in disagreement with professionals’ view point, they were then regarded as problematic. This suggests the need to build equal and respectful parent professional relationships as when there are conflicting points of view, the child suffers. (McKenzie *et al.*, 2008; Lundeby and Tossebro, 2008).

Twelve years after the policy on inclusive education was introduced, disabled children still experience difficulty in gaining access to education in South Africa. According to available information, only 20% of disabled children are accommodated in Special Schools. It is estimated that there are presently 250,000 disabled children excluded from education in South Africa (Statistics South Africa, 2011). This finding is in contradiction to our rights-based constitution, which promotes education for all. Highlighting its vision for the year 2025, the Department of Basic Education (DBE) commits to ensuring that parents are kept well informed about school matters and about their children’s performance while authorities will ensure that parents are listened to in the process (Department of Basic Education, 2011). This intention shows commitment by government to ensure that parents and educators work together. It also implies that parents need to be prepared to face and deal with the challenges in the process of engaging with different professionals.

While this study aims to establish relevant support needed by parents in the process of engaging in their children's education, it also acknowledges the need for the department to identify other structures in which parent participation can be accommodated rather than the School Governing Bodies, the only structure through which South African Schools Act allows for parents' participation (RSA, 1996).

### **3.3 Policy on inclusive education and previous studies conducted relating to parent participation in the education of their children**

Presenting the first draft of the Education White Paper 6: Building an Inclusive Education and Training System (Department of Education, 2001), the then Minister of Education, late Prof Kader Asmal, called on all members of the public, social partners and interested organisations to join in building an inclusive education system.

"I hold out great hope that we will be able to convince thousands of mothers and fathers of some 250,000 disabled children, younger than 18 years who are not in schools that their place is not in isolation in dark backrooms and sheds, but with their peers in schools" (Department of Education, 2001:4).

This study argues that the concept of disability remains "an elephant in the room" as people feel uncomfortable about raising their views and concerns around this topic. It is from this angle that I base my views throughout this study, arguing that with the attitude that we have towards disability issues, Asmal's call above is doomed to fail. Holistically, inclusive education according to Lene (2012) is a process whereby the school systems, strategic plans, and policies adapt and change to include teaching strategies for a wider more diverse range of children and their families. Interesting to note in this definition is the emphasis it puts on school systems rather than the child weaknesses. Practically in a classroom setting, this requires identification of a learner's learning style and adaptation of the classroom and teaching strategies to ensure high quality learning outcomes for all members of the class (Lene, 2012).

For me the issue of the disabled child, parent participation with equal partnership and a mutual relationship amongst role players is vitally important in the process of making schools inclusive sites for learning. Engelbrecht et al. (2008) noted key

aspects that are very crucial in an 'equal partnership': mutual respect, support, trust, open communication, consensual decision-making and joint ownership, while Henley, Ramsey and Algozzine (2006) added that success or failure of such relationships mainly depends on trust, mutual respect, and co-operation. I find these aspects relevant in ensuring successful partnerships and co-operation amongst participants in creating inclusive sites for learning. Studies from other countries show that there is a lot that can be achieved through our inclusive education policy when our actions become accommodating towards the disabled children and their parents.

### 3.3.1 United Kingdom

In the UK, greater assertiveness and unity amongst the disabled preceded and accompanied changes in the education policy in the construction of a strong civil movement based on a socio-cultural view of disability (Shakespeare and Watson, 2002). Tregaskis (2006) suggested that professionals need to adopt an understanding that disability is an aspect of the mainstream continuum of human diversity rather than a negative determinant in the life of the learner and his/her family.

From what has happened in the UK, South Africa could learn that with relevant support, parents and the NGO sector can play a major role in developing an inclusive strong, assertive and united society. It follows, therefore, that the realisation of an inclusive education system requires restructuring of society, change in attitudes and active participation of role players, with parents taking a leading role in the process of establishing an inclusive education system. The manner in which schools used to be positioned historically as institutions separate from the community and parents of learners, together with the traditional way in which teachers were trained to distance themselves from communities, pose a major challenge to parents in their new role.

The policy on inclusive education, EWP6 (Department of Education, 2001) based on a human rights approach to disability, acknowledges that parents are the best source of information when it comes to their children and therefore they play a critical role in implementing processes and procedures for inclusive education. Consequently, this

study aims at achieving that objective, by exploring experiences of parents in order to identify their needs to ensure effective participation.

### 3.3.2 Lesotho

One other country close to home, Lesotho, seems to have adopted a similar approach to ours in promoting inclusive education. Key issues highlighted in their policy statement as published by the Lesotho Ministry of Education (1989) are the integration of disabled learners into mainstream schools, the establishment of resource centres and the formation of support teams within the schools to help support schools to become inclusive sites for learning that would support educators working with disabled learners.

However, in Lesotho unlike South Africa, teacher training took into consideration the empowerment and training of educators around their policy on inclusive education. South Africa has not yet undertaken this training. The Lesotho government took another major step when they introduced a pilot project in 1993 which emphasised changing attitudes of teachers and parents, in service training of teachers and parental training and involvement. When this program was evaluated in 2007, Urwick and Elliot (2010) criticised the program on the basis that it did not cater for the severely disabled children as more emphasis was put on the closure of special schools rather than on alternatives for severely disabled learners (Urwick, 2007). Despite the initial success of this program, Urwick (2010) criticised the Basotho Department of Education for failing to allocate funds in order to sustain the program. Similarly, this gap seems to be one of the challenges facing South African Schools when it comes to the implementation of inclusive education policy. While the policy stipulates that there should be teacher assistants and other professional support specialists, learners in need of such services often end up missing a day of school waiting in hospital queues to be seen by practitioners. As a strategy to address this challenge, I tend to concur with Taylor (2001) who supports the view that regional centres need to provide the kind of services that can only be provided by professionals/ specialists like physiotherapists, speech therapists etc. for the benefit of learners, in addition to other teacher support initiatives. This is what the Full

Service Schools in South Africa purposed to do though this has not materialised in practice.

### 3.3.3 Uganda

A community-based rehabilitation approach to implementing inclusive education proved a successful working model in Uganda. While these two interrelated concepts both value diversity and inclusion, they also aim to ensure that disabled people gain equal access to the services that are available to other people in the community, such as education and employment (Coleridge, 2006). Uganda is considered one of the first African countries to introduce an inclusive education system. As early as 1997, teacher training colleges in Uganda introduced Special Needs Education courses targeting primary school teachers who were encouraged to remain in their local mainstream schools (Millward et al., 2005). As a result of initiatives that encouraged an inclusive society, Uganda is now considered one of the advanced countries using a community-based approach in implementing inclusive education. In addition, there is strong unity and co-operation between families, government and private and non-government sectors towards supporting families of disabled children to ensure that they participate and benefit from the education system of that country (Millward et al, 2005).

McKenzie et al. (2008) and Coleridge (2006) noted a number of similarities in the context in which South Africa, Uganda and Kenya have been challenged to implement an inclusive education system. They identified accessible school environments, lack of support systems (like trained personnel and resources), large classes and negative attitudes as key issues.

### 3.3.4 India

In their attempts to make education accessible in rural India, the Indian Institute of Education (IIE) took it on themselves to support community initiatives that sought to promote recognition of Indigenous Knowledge. What stands out the most in IIE approach is their willingness and commitment to work hand in hand with non-formal education sectors in promoting sustainable development. PROPEL, a model which the IIE has adopted in promoting Primary and Elementary Education, emphasizes

learning while playing. The main target group was children and rural women. The IIE considered their model of inclusive education to be an appropriate replicable alternative for reaching out to all children through primary education, irrespective of community lifestyles and expectations (UNESCO, 2011). The bottom-up approach adopted by IIE through PROPEL encouraged communities at grass roots level to take ownership of their own development thereby seeing themselves as equal partners with education authorities. This bridged the gap between formal and non-formal education centres. This is an ideal situation from which South Africa can learn in an attempt to develop working relations and co-operation between communities and schools.

### **3.4 Identified Needs of Parents**

The findings of the study conducted by Dembinski and Mauser in 1997 (republished in 2001) outlined very interesting issues that I found extremely relevant to this study and the context in which attempts are made to create working relationships between parents and educators. I do acknowledge the fact that the study was conducted very long ago and in a different context from South Africa. However, as so much relates to my study there is much to learn from the conclusions outlined below.

The study specifically focused on information that parents of disabled learners needed to learn from the educators and health practitioners they worked with in the process of supporting their children with their schooling. The Information below was drawn from findings as being crucial to parents' needs, which were:

- Copies of reports about their children
- Reading material containing *information about the diagnosis* or impairment in *simple language*
- *Time to interact with professional and to ask questions about the diagnosis* rather than just receiving information from the professional
- *Interdisciplinary communication* about the child rather than the reliance on parents' passing information from one professional to another *especially regarding side effects of medication that might affect child's performance at school*

- Immediate rather than long term *advice on supporting the child in dealing with challenges and in working co-operatively with the teacher*
- *Information on both social and academic* aspects of the child's behaviour
- An honest evaluation of the child's problem *and capabilities*, rather than blaming the parents for learner's poor performance, so that they can confront and address the issues head on
- Training programs for teachers, physicians and therapists should include *skills on interacting with parents of learning-disabled children* (Lemmer and van Wyk, 2004). .

Dembinski and Mauser (1977) argued that developing education and disability policies in a more culturally appropriate way might make them easier to understand, accept and implement. International movements such as Education for All are discussed, highlighting their weaknesses around disability issues and the effect this has on national education policy. Findings from both Dembinski and Mauser (1977); Lemmer and Van Wyk (2004) confirmed that parents had clearer expectations of teachers' roles and responsibilities than those of physicians and therapists. The conclusion also suggests that parents can facilitate the process of meeting professionals halfway by organising themselves, accessing learning material and discussing ways in which they can develop their skills.

As my study focuses on parents of disabled children and their involvement in schools, I find relevance in findings from Dembinski and Mauser (1977) in that it challenges me at the same time preparing me to approach my study with more information thereby helping me to be open in thinking, planning and tackling questions as I interact with parents and teachers. As Anderson and Arsenault (2004) and Neuman (2006) note, findings from Dembinski' study have widened my view around my research topic more specifically as it touched on parent, child and teacher issues, the main interest and focus of my study.

Similar findings were also noted from studies conducted in Zambia and South Africa on inclusive education where teachers regarded inclusive education as a specialist issue with nothing to do with them. The teachers believed it was important for a

teacher to get special training to be able to teach a disabled child (McKenzie et al., 2008; Miles, 2009). In South Africa, teachers separated the role of mainstream teachers from that of teachers in a special school setting (McKenzie et al., 2008). From the REHAB study (McKenzie et al., 2008), it appeared that the general trend in teachers and parents is that many schools in rural areas, and some in urban areas, seem to manage teaching a number of learners with 50 to 60 (plus) in one classroom. There is no doubt that such learners are at different academic development levels. Teachers in such circumstances tend to manage well, until such time that one brings up the concept of “inclusion / inclusive education” (McKenzie et al., 2008). Noted also was that teachers associated the concept of “inclusive education” with REHAB rather than seeing it as something they could initiate and take responsibility for (McKenzie et al., 2008). This suggests teachers’ resistance to change and fear of the unknown.

In South Africa, the involvement and participation of parents in the education of their children has traditionally not been recognised and their involvement in the education sphere, where it was allowed, was mainly in the area of fundraising (Van der Westhuizen and Mosage, 2001). Despite lack of recognition, parents continue to play a tremendous role in fighting for their recognition in the development of better and more inclusive education systems worldwide. Lemmer and Van Wyk (2004) argued that parent participation in school activities depends solely on the extent to which schools communicate with parents. Yssel, Engelbrecht, Oswald, Eloff, and Swart (2007) findings corroborated with Van der Westhuizen and Mosage (2001) and Dembinski and Mauser (1977) in that parents felt not cared by the way professionals treated them and their children with for in situations. A Participants who were school managers in their research study confirmed that was easier for parents to engage in school matters when a welcoming environment was created by teachers and frontline personnel (Lemmer and Van Wyk, 2004)

In the United States, parents have been credited for the role they have played in advocating for the inclusion of disabled children in the education sector. This action saw the birth of the Education for all Handicapped Children Act of 1975 and the Individuals with Disabilities Education Act (IDEA) of 1997 (Duhanney et. al., 2000).

As a result, in the USA, recognition of parents and their contribution to decisions pertaining to their children is enforced across sectors (Kalyanpur et al., 2000).

South Africa seems to have followed the same pattern with regard to the role parents continue to play in the development of an inclusive education system with specific reference to the role played by parents of children with Down Syndrome (Schoeman, 2000 and McKenzie et al, 2008). Despite a number of challenges in the process of implementing an inclusive education system, current policies as discussed in the previous section, are a result of advocacy actions by parents of disabled children for an inclusive education system. Today there are some of the disabled children who benefited from REHAB program enrolled in mainstream schools.

There has not been much research done in South Africa that specifically looks at the role, participation or the involvement of parents in the process of implementing inclusive education. Some of the studies by Engelbrecht (2005; 2008) focus on strategies to promote recognition of parents and their involvement in the education of their children through parent-school partnerships. In their study, Engelbrecht et al. (2005) looked at parents' understanding of their rights in the implementation of inclusive education in South Africa. The findings revealed that parents experience inclusive education as a major challenge for everyone involved in the process, starting from the moment a parent has to make a decision to place the child in mainstream school. A further recommendation towards an effective collaboration and partnership is to investigate how parents see themselves as experts about their children as the current policy on inclusive education acknowledges (Engelbrecht et al. 2008).

The REHAB study, aimed at addressing the gap between the rights of children and their access to education, notes that parents agreed that it is the right of any child to go to school (McKenzie, Tshabalala and Mpurwana, 2008). Parents felt that they needed to be involved in the child's future. However, they noted that it is often difficult to send their children to mainstream schools as they are discriminated against. Parents believed that inclusive education could break the isolation of the child with a disability. As the EWP6 outlines a system of support for inclusive

education, the REHAB program proved that a disability organisation has an important part to play in providing this support.

Although much emphasis has been put on the role of parents “as collaborative rather than passive observers of their children’s education” (Engelbrecht and Green, 2006:200), not much has been done in terms of engaging parents’ views as to where they need support for their empowerment, to take on their role actively. The study of Engelbrecht et al. (2005) supports the view that when professionals and communities at large are informed of how parents want to be supported in their participation in inclusive education, they will in turn get to know parent expertise from parents’ point of view.

**The following section examines parents of disabled children in relation to the context from which they operate**

### **3.5 Exploring Agency, Empowerment and Resilience of parents**

It was noted earlier in my discussion that the characteristics of the individuals, as well as structural factors such as organisation of services, distribution of power, economic or personal resources and time limits, may act as supports to or constraints against parents working with professionals. Engelbrecht et al. (2005) note that, in South Africa, the medical deficit approach has led to labelling and discriminatory criteria for service delivery resulting in the exclusion of environmentally and economically disadvantaged learners who equally share the right to available support.

In reality, engaging parents in the process of including disabled children within the education system translate to engaging them in a process that has been driven largely by those with a medical training and therefore a world with systems of which are still dominated by a medical approach. This, on one side presents a challenge to parents as social agents whose parenting skills are already shaped and influenced by their own “self-generated intentions” and cultures (Bruner 1996, 16) and an area which for a long time excluded them to participate. These are change dynamics that suggest possible resistance by professionals on the other hand, to allowing their well-earned “professional” knowledge conform to basic societal norms and standards

which they learned to see at two different worlds. This confirms need for strategies that allow equal participation of role players and in particular, allowing space for parent participation with understanding that the implementation of an inclusive education is a process that requires perseverance in order to break through challenges in the journey.

This section focuses on three key concepts for parent participation in schools; **parental agency, empowerment and resilience**. I argue that the issue of education and schooling in particular is an area which by its norms and culture has excluded parents from participating in. As the current policy on inclusive education calls for participation of parents in the education of their children, there needs to be willingness for teachers and other professional role players to accommodate parents (Department of Education, 2006). Parents in their role as social agents need more than willingness but rather a radical shift out of their comfort zones to being able to share with professionals their wealth of knowledge about their children so as to create better understanding of children by those working with them.

Here I use the term “radical” with the understanding that in their agentic role as parents, parents find themselves playing a number of roles in response to their personal experience of the situation while at the same time thinking of how to protect their children from hurts that they might have experienced. Adding to the complex agentic role of parents’, resistance on the side of professionals to allow parents the opportunity to be directly involved in issues and decisions about their children would require more effort by parents to gain control of such situations, an experience that would be frustrating and exhausting for parents.

Hitlin and Elder (2007:172) define agency as a temporally constructed engagement by different people in a temporal-relational contexts of action which, through the interplay of habit, imagination and judgement, reproduces and transforms those structures in interactive response to the problems posed by changing historical situations. In a simplest form, Ahearn (2001:112) defines agency as “the socio-culturally mediated capacity to act.” In his definition of the term, Bandura (2001) identifies four aspects of agency namely, *intentionality*, *forethought*, *self-reactiveness (self-regulation)*, and *self-reflectiveness (beliefs of efficacy)*. Bruner (1996) notes that

people have a conceptual system that organizes a 'record of agentive encounters that can be related to the past and the future. As a parent the possible self sees a future with the child that is based upon the childhood the parent experienced and subsequent agentive encounters. However, the study by Rix and Paige-Smith (2008) found that for a parent of a disabled child the 'possible self is likely to be displaced as soon as the label is applied to the child, either before or after birth. Substantiating this argument Rix and Paige-Smith (2008) mention that Hornby' (1995) recorded fathers talking about the initial trauma they experienced following diagnosis of their child, while Bridle and Mann (2000: 11) noted parents being left *feeling very inadequate and desperately in need of some direction*.

In the context of agentive parenting, implication is that in relating to their children, parents tend to allow or use their own life experiences guiding their children that they may learn ways of avoiding experiencing difficult/bad situations they might have gone through with the desire for them to experience best things in life. This is what I would refer to as a naturally inclined desire every parent possess.

A study conducted by Rix and Page-Smith (2008) on parental agency and early intervention reported that discussions with parents about relevant support for their children were framed by the initial aims and focus of the medical practitioners. Parents could only comment on the model that was presented to them. McKenzie and Muller (2006) agree that the professionalization of support to parents of disabled children is disempowering experience for parents. While a parent with a disabled child needs support, it is important that practitioners working with them should listen to parents so that they become aware of necessary support parents need (McKenzie and Muller, 2006). Parents need to be directly involved in decision making about their children and not be consulted mainly to get their views on decisions made (Department of Education, 2006). Mahoney and Wheedon (1997) suggested that parents need to have a sense of control over their family life and to recognize that effective intervention strategies result from their own actions, strengths and capabilities. This indicates parental agentive challenges consciously and unconsciously at play that parents can become susceptible to when their parental role becomes undermined.

I discuss the concept of empowerment adopting Nussbaum's (2006) capability viewpoint and argue that parents of disabled children are capable of engaging and working with professionals in schools and those offering professional support when needed, however parents need to be empowered to, and supported in dealing with challenges in the process and that parents should always be involved in decisions around relevant support to supporting them.

According to Askheim (2003), empowerment basically deals with giving the users of the welfare services some degree of influence and control over the services they receive. Empowerment is seen as goal and as means, as ideology and methodical approach, fighting oppression against individuals and social groups (Askheim, 2003). From a Community Based Rehabilitation (CBR) perspective, Okune (2008) defines empowerment as "a process to make CBR truly community and a people-centred programme. Both Askheim (2003) and Okune (2008) acknowledge the importance of community empowerment as a means to ensure active participation of individuals in their own development. In parent-professional relationships, empowerment is often seen as a process where families with disabled children could be offered knowledge, skills, and resources in order to gain positive control over their own life situations (Dempsey and Dunst 2004).

As parents are expected to be seen as active participants in the process of inclusive education (Education Department, 2001), it is important to support and empower them to play this role. For me, the concept of empowerment also requires talking about transformation, for, in order for one to be empowered, there needs to be change in the way of doing or seeing things by the person being empowered. Considering empowerment as a process, it can take time for change or transformation to happen. Therefore, the quality of resilience is also important. This means that individuals need to persevere beyond the challenges that might be encountered in the process of change. When the desired change happens, the empowered person will then be able to lead others to deal with the challenges s/he has experienced. This holds true in ensuring that relationships between parents, professionals and other stakeholders in the process of implementing inclusive education, become beneficial to all and that negative attitudes towards disability are eradicated.

The concept of CBR was developed by the World Health Organisation (WHO) out of the realisation that a bottom up approach to community upliftment produces more effective and sustainable results than a top down approach. CBR involves working closely with disabled persons and their families to overcome barriers within their communities through a holistic approach in the areas of health, education, livelihood, social inclusion, skill development and empowerment (CBM, 2009). Most important, as a context based approach to rehabilitation, CBR acknowledges the importance of social dynamics which through engagement we constitute and out of which we are constituted (Rix and Paige-Smith 2008).

Alick et al., (2006) noted the key aspects that link CBR and inclusive education making the two paradigms possibilities in encouraging parent participation and creating working relationships between parents and professionals. While both strategies aim to address issues and challenges affecting disabled people and their families, professional and community attitudes are challenged in the process. The value the parents of disabled children and their participation is recognised since parents are regarded as first-hand key informants and support to professionals working with disabled children (Alick et al., 2006, in Hartley 2006).

With its main focus on bettering the lives of disabled people, the shaping of CBR has undergone a number of stages in ensuring an inclusive and human rights approach towards developing the lives of disabled people. These developments culminated in the publication of a set of 36 CBR manuals titled: "Training in the Community for People with Disabilities" (WHO, 1989). The "Training in the Community for People with Disability" manuals were developed as a guide and skills development manual for professionals working with disabled people at grass roots level. These manuals had a huge impact in reshaping health professional approach from a medical view to a social human rights model in working with disabled people. The manuals were later reviewed leading to the joint position papers about CBR by WHO, International Labour Organisation (ILO) and United Nations Educational Scientific and Cultural Organisation (UNESCO), in 1994 and 2004. The joint international position paper of 2004 saw the introduction of a CBR Matrix, a multi sectorial programme for CBR managers acknowledging the importance of empowering disabled people, their

families and communities as a way to achieve equal rights and opportunities for disabled people in their communities (Okune, 2008 also Ref. 3.5). The CBR Matrix was developed further into the CBR Guidelines (WHO, 2010) and acknowledges that community needs differ from community to community and therefore implementation needs to be cognisant of the sectorial aspect under review. For example, the Education Component focuses on early childhood development, non-formal, formal (primary), secondary (including higher) and life-long learning. Based on the community situation and its needs, an education development project needs to be appropriate and relevant to the needs of each community.

Resilience is a result of the interaction between an individual and ecology that provides needed resources, and opportunities to access these resources in a culturally acceptable way (Hoohlo, 2012). I like the way Hoohlo (2012) talks about resilience: “we all come with a reservoir of strength that can withstand severe psycho-emotional, physical and mental storm, however, this reservoir is something not innate, for if it was, we all would not flounder at the site of adversity” (Hoohlo, 2012: 136). Masoga (2012) believes that resilience is a combination of skill and attitude. We learn through hardships to draw out resilience when situations call for it and by so doing our skills become sharpened. According to Fergus and Zimmerman (2005), Cameron, Ungar and Liebenberg (2007) and Ungar (2008), being proud of one’s culture and adherence to cultural norms and practices makes an individual feel grounded. This in turn helps to enhance an individual’s resilience and fosters a sense of belonging and resilience.

Culture defines the way that people from a given community live their lives. This includes family life, behaviour patterns, beliefs and language (Reber and Reber, 2001; McCubbin and McCubbin, 2005; Robinson, 2007). Ungar, Brown, Liebenberg, Cheung and Levine (2008) add that adhering to cultural traditions contributes to an individual’s sense of purpose, aspirations, beliefs and values, as well as spiritual and religious identification (Ungar et al., 2008). Cultural heritage also encourages a collective identity and sense of belonging, both important factors for developing resilience (McCubbin and McCubbin, 2005).

Dass-Brailsford (2005) further adds that spiritual and religious practices help to build resilience and that it is this spiritual connection that helps to build commitment to serving others. In identifying qualities of a good leader, Ebersohn (2011) notes that good leaders tend to be resilient, strong and always displaying a can-do- attitude. The section that follows explores the concept of transformational leadership and significance thereof in the context of inclusive education.

### **3.6 Transformational Leadership**

The concept of leadership focuses on the roles expected from different stakeholders in an inclusive education setting. Horth (2002, cited in Ebersohn, 2011), states that leadership is reciprocal process. In order for progress to happen, it becomes each member's responsibility to ensure that issues that others are not well informed of and those that directly affect each individual, are attended to. As a long-ignored aspect of social justice and a topic that people still feel uncomfortable to engage in discussion, the aspect of disability and inclusion poses a challenge to parents. Progress towards an inclusive education system requires parents to take the lead in ensuring that disabled children are included and that attitudes allow for this to happen.

Recognising that the concept of leadership involves more than just interaction between leader and follower, Bass and Riggo (2006) and Leigh and Maynard (2011) note the following as crucial components in transformation leadership:

- The transformational leader is an effective listener. He recognizes and is accepting of other members' individual differences. S/he recognizes and is accepting of other people's individual differences. In an inclusive education setup, while teaching and assessing learners, educators can make a meaningful contribution towards learner support where they have to take cognisance of each learner's level of thinking and abilities. Learners are monitored to determine whether they need additional direction or support and to assess progress. However, they do not feel frightened about being observed or monitored, thereby encouraging independent thinking, learning and creativity (Bass and Riggo, 2006).

Similarly, parent teacher relationships can be encouraged and strengthened when teachers and parents listen and accept each other while working together

in schools. Transformational leaders encourage innovation and creativity by questioning assumptions, reframing problems, and approaching old situations in new ways, thereby creating independent thinking, learning and creativity. The approach can benefit role players in the process of awareness-raising and stimulating discussions and conversations on disability and inclusive education. When supported, parents can also benefit by developing and strengthening their skills to be proactive in playing a role in inclusive education.

- Transformational leaders are seen as doers who inspire those around them by providing meaning and challenge to the work of those around them. The proactivity of parents can be seen when parents continue to approach teachers regarding areas of support for their children, identifying areas presenting as challenges to them in assisting their children with school work and confronting schools on exclusion practices.
- Their resilient natures, willingness to take risks not being intimidated by change, persistence, and determination earns them the credibility they need to become role models that are admired, respected, and trusted by those they work with.

### **3.7 Summary of Literature Review**

Previous studies on parent professional relationships indicate that strong dissatisfaction by parents when it comes to involvement around issues of decision seeking and decision making about diagnosis of their children. General themes from the studies conducted show that:

- Mainstream schools are discriminating to disabled children.
- Role players do not understand inclusive education policy
- Parent participation in schools depend on school's willingness to accommodate them
- Professionals often do not involve parents in decision-making around their children, when they do they do not take parents' views into consideration when theirs differ from those of parents
- Parents need to hear about strengths of disabled children which they do not get from professionals' reports

- There is a need to create reciprocal relationships between teachers and parents.

### **3.8 Summary**

This chapter has outlined perspectives underpinning my approach in engaging with participants and data for analysis. It confirms that research is an important component of meaningful development with emphasis on understanding, learning, empowering and being empowered as I discovered in the process of engaging with participants in this study.

The next Chapter gives a preliminary overview of the rationale for the choice of methodology and design. It focuses on the methodology and the theoretical framework for engaging with parents of disabled children in my attempts to explore their world.

## Chapter 4: Methodology

“We conduct qualitative research when we want to empower individuals to share their stories, hear their voices and minimize power relationships that often exist between a researcher and the participants in the study “(Creswell, 2007).

### 4.1 Introduction

The ultimate and critical aim of this study is the active involvement of parents in the inclusion and retention of their children in public schools. This study acknowledges the need to support parents in this process as they have been, for a long time, excluded through policies and socio-cultural practices and beliefs from participating in this field. With parents being the key focus of this study, it is crucial to make sure that the support becomes relevant to them, hence they are considered key informants in this study. It is against this background that a qualitative research has been decided upon as the relevant approach. There is no better way of putting what I want to say and how I set out to do this study than the citation from Creswell (2007) above.

A qualitative approach allows one to assess peoples’ knowledge, attitudes, beliefs and behaviour in a natural setting making it easier for one to understand *why* people behave as they do, which is relevant to the objectives of this study (Denzin and Lincoln, 2005; Moss, 2006; Creswell, 2007). A qualitative approach also allows the subject being studied to give much richer answers to questions put to them by the researcher, and may also give valuable insights that may have been missed by any other method (Cohen et al., 2000).

In this chapter, I set out the research paradigm and design and a description of procedures used in interviewing participants. Theoretical frameworks and an account of methods used to analyse, order and understand data are also given, providing justification for methods of data gathering and the subsequent analysis employed. I begin by reiterating the research purpose, objectives and questions which I set out in Chapter 1.

## **The purpose**

To gain insight into the experiences of parents with disabled children in basic education in schools in East London with regard to their children's admission, education and retention in schools in order to identify appropriate support in the process of engaging parents in the inclusion of their children in public schools.

The research questions are:

- What experiences do parents of disabled children have with regard to the education of their children?
- How can parents of disabled children be supported to facilitate their active participation in the inclusion and retention of their children in public schools?

**The specific objectives** informed by a Participatory Action Research are to:

- Investigate the experiences and needs of parents with regard to their disabled children with a specific focus on the challenges they face,
- Explore ways in which parents of disabled children can be supported to facilitate their active participation in the inclusion and retention of their children in public schools.

## **4.2 Theoretical Frameworks**

According to Newman (2006), three main influential paradigms underpin the research design, the positivist, interpretive, and the critical approaches. In each one of these theories, it is important to determine the ontological, the epistemological and the methodological bases. Ontology specifies nature and characteristics of reality (Creswell, 2007); epistemology refers to how the creation of knowledge is theorized; methodology specifies how the researchers practically go about studying whatever they believe can be known (Babbie and Mouton, 2001).

In this study two theoretical approaches are adopted. The Critical Theory (transformative paradigm) is the lens through which the data is analysed. The developmental paradigm informed by the Afrocentric Owusu-Ansah and Mji (2013)

and the Capabilities Approaches (Nussbaum, 2006), is a conceptual framework that informs my approach to data gathering.

To explore the world of parents with disabled children, with the intention of empowering a group that has been marginalised, requires a framework that is appropriate in guiding the research process. Such a framework should respect experiences of the group as individuals. In addition, it should allow for proper examination of societal forces that are capable of reforming and / or transforming attitudes and practices. According to Babbie and Mouton (2001), Critical Theory focuses on a critical understanding of the situation or practice being researched in order to plan for transformative action. Since it provides enlightenment, it is said to be emancipatory or empowering. This is in line with my ontological and epistemological belief that parents need to be encouraged and supported to face the “elephant in the room” that is hindering progress for their disabled children with regard to education. The “elephant” in this case refers to the assumptions made about their disabled children by educators and decision- makers in schools. Parents need to be part of and to understand the process of decision-making that impacts the future of their children.

Critical Theory has been chosen to examine the world of these parents. According to this theory, there is no way that knowledge can be separated from everyday life. Social circumstances play a major role in determining what people do and how they do things. People are far more influenced by the society in which they live than they realise. The very structure of thinking processes is the result of the social forces which, over centuries and decades, have moulded people (Higgs and Smith, 2008:69).

The Developmental Paradigm, and in particular Nussbaum’s Capability Approach (2006) in which she adopts the social model of disability viewpoint, was the basis guiding my approach in my interactions with parents of disabled children in this study. The Capabilities Approach is a political doctrine about *basic entitlements for a decent society* (Nussbaum, 2011). It critically focuses on the interaction between the person (inner world) and external conditions with its values based on humanity. External conditions refer to the social, political and economic environment. The view

is that every person is born capable of *being* and *doing* something in life. However, external conditions play a major role in determining what the person does or becomes. As a political doctrine, the Capabilities Approach is a relevant tool in policy making as it focuses on ensuring that opportunities are provided for citizens to at least live basic and dignified lives. As this study intends to enable parents of disabled children (a group that has been marginalised both socially and politically) to participate in the implementation of Inclusive Education Policy, I regard the Capabilities Approach a perfect fit. Furthermore, this paradigm goes hand in hand with the qualitative nature of this study in that both put emphasis on the subjectivity of participants, the context in which the person lives and flexibility of the process as Taylor puts it:

...we intervene into the development processes of the people themselves, working facilitatively alongside them so that they may enlarge themselves and gain their own capacity to exert authority over their own lives and futures, to make their own choices (Taylor, Marais and Kaplan, 2008:2).

#### 4.2.1 The Transformative Paradigm

Mertens and McLaughlin (2004:3) consider the Transformative Paradigm as emerging in concert with the socio-cultural view of disability. They describe it as being an umbrella term that incorporates other paradigmatic perspectives which include emancipatory, participatory and critical approaches. It is made most articulate in the work of writers such as particular feminists, disabled people and their advocates, and others who represent marginalised groups like racial/ethnic minorities (Mertens, 2003:93). Transformative Theory places central importance on the lives and experiences of marginalised groups. As Mertens notes:

Transformative scholar's work assumes that knowledge is not neutral but rather directly influenced by human interests and values. All knowledge is a reflection of the power and various social relationships within society. Therefore, a fundamental intention of knowledge construction should be to assist people to improve society (Mertens, 2003:139).

The Transformative Paradigm allows for an examination of the dilemmas present in the contemporary South African educational and social landscape which hinder parent involvement. In addition, this will highlight the influences of our history of segregation, values and culture. It may ultimately unleash the potential to actively take on the challenge of making inclusive education a reality.

## The ontological assumption of the Transformative Paradigm

... holds that there are diversities of viewpoints with regard to many social realities but that those viewpoints need to be placed within political, cultural, historical, and economic value systems to understand the basis for the differences (Mertens, 2003b:140).

The degree of active participation, reciprocity and negotiation within an action reflection research cycle is considered to be integral to the transformative paradigm. This process necessitates the involvement of the researcher in the communities participants come from to the degree to which deep understanding can be gained (Mertens, 2003b:141).

### 4.2.2 Models of Disability

The Medical Model of Disability views disability as a condition to be cured (Penn, 2005, Thurgate and Warner, 2005; Burke, 2008). This connotation then objectifies a disabled person into someone needing “treatment”. This idea takes focus away from the individual’s sense of being and he becomes a condition needing treatment. Finkelstein (2005) further argues that the medical model promotes inhumane and abusive practices such by systematically shunting disabled people into apartheid-like facilities such as homes and institutions that marginalise them from society (Finkelstein, 2005). The emphasis that the medical model puts on treatment makes it difficult to incorporate other issues like socio-economic conditions that might impact on individuals with an impairment.

In its attempt to be holistic in its classification of disability, the International Classification Of Functioning, Disability And Health (ICF) (World Health Organisation (WHO), 2001) adopted the Bio-Psychosocial Model of Disability as a framework for describing and analysing interactions between one’s health condition and the context in which one operates (Schneider et al., 2003). However, the ICF has been widely criticized for being disabling (Thomas, 2004) and for neglecting the environmental and social impact in the process of disablement (Bickenbach et al., 1999 and Imrie, 2004).

In this study issues faced by parents of disabled children in early childhood development within the context of inclusive education were examined from an assets perspective supported by the Social Model of Disability. The Social Model is viewed as a social construction with the overarching need to do something to support parents, ensuring that systems in schools do not jeopardise their disabled children but instead create an inclusive environment for learning. Burke (2008) takes this point further and argues that disability need not be seen as the only defining element of an individual who should define him/herself and be accepted in his/her entirety.

The research puts emphasis on the socio-cultural view of disability (Mertens and McLaughlin, 2004) which dislodges the location of the 'problem' of disability from being within an individual to the responses of the environment to disability (Oliver, 1996). While seeking to represent the needs of parents and the feelings of the learners themselves, this research places an even greater emphasis on initiating and maintaining relationships between educators, parents and learners on one hand, and parent support groups on the other. The explicit intention of this will be to effect social transformation where parents will be able to challenge and ensure commitment to the policy on matters of inclusive education.

This study is in line with the Social Model of Disability. In referring to disabled children, the study takes the view that children with impairments are disabled by the society around them. Parents, families, educators and the community at large can play a role in enabling a disabled child to function to his/her best ability. According to Barnes and Mercer (2004), disability can be viewed as 'social exclusion on the grounds of impairment'. Barnes and Mercer (2004) further defined impairment as the medical or professional determination of a bio-physical limitation. In other words, a physical or intellectual difficulty rather than a limitation imposed by an external source as might be experienced in a social setting.

The study takes the view that disabilities are barriers to participation for students with impairments or chronic illness (Booth, et al., 2000). Disabilities are created by the interaction of discriminatory attitudes, actions, cultures, policies and institutional practices. Therefore, parents and educators can play a major role in improving access and participation for disabled children in learning.

According to Thurgate and Warner (2005), individuals exist beyond the limitations of their diagnosed medical conditions. By recognising that sphere of relationship the individual's sense of self-worth can be recognised in the process of identifying a problem. It is this light that disabled people challenged the medical model of disability calling for their full participation in society when they formed the Union of the Physically Impaired Against Segregation (UPIAS, 1974). Based on the Social Model of Disability, both UPIAS and Disabled People's International (DPI, 1982) put emphasis on the separation of disability from impairment. Disability can be viewed as the limitation imposed by social experiences and opportunities that restrict an individual's ability to engage with others or to access specific locations (Burke, 2008:12).

According to Swain et al. (2004) the Social Model of Disability indicates that disability is exacerbated by environmental factors and consequently the context of disability extends beyond the individual. Contributing factors here are physical and social barriers. Burke (2008) adds that the Social Model encourages changes to be made to social settings for a disabled individual not to be disadvantaged by situational, emotional or physical barriers to access. Interesting to note as regards inclusive education, Goodley (2000:36) proposes an inclusive Social Model of Disability which, in relation to learning difficulties, recognises the social origins of challenges to learning and difference as indicating attitudinal reactions. He further suggests that whatever the cause of such difference, distinctions are not necessarily made in all cultures. In the process of engaging parents to share their experiences in this study, it is hoped that teachers will get to understand more about specific children whose parents are participating in this study and will gain an understanding of how the socio-cultural and economic issues affect the children's performance at school. The research will also be alert to both the constraints and possibilities regarding support for these parents. The paradigm which best accommodates both of these individual and institutional variables is that which the Transformative Theory provides.

#### **4.3 Qualitative Methodology, Critical and Afrocentric Theory, Participatory Action Research**

Here, I define the qualitative paradigm that I use in this study, and then the approach and finally the research design and the methods used. I also explain why I consider the choice of paradigm appropriate to this study.

#### 4.3.1 The paradigm: Critical, Developmental and Afrocentric Theory

Three paradigms that guided this study are the Critical, Afrocentric and Developmental Theories. The Critical and Afrocentric Theories are the lens through which the world of parents with disabled children (and teachers) was examined while the Developmental Paradigm (Capabilities Approach) guided my interactions with participants.

Babbie and Mouton (2001) hold the view that a paradigm is a model or framework for observation and understanding, which shapes both what we see and how we understand it. A paradigm may be viewed as a set of basic beliefs or a worldview that defines how one views the world and one's relationship with it (Guba and Lincoln, 2000; Creswell, 2007). It follows, therefore, that in order for one to carry out research one has to place it within a paradigm, as it is the paradigm that will largely determine the research design chosen and the methodology used in gathering and analysing research data.

According to Babbie and Mouton (2001), Critical Theory focuses on a critical understanding of the situation being researched in order to plan for transformative action. Since it provides enlightenment, it is said to be emancipatory or empowering. This is in line with my ontological and epistemological beliefs (Table 4), that parents have to be supported to participate actively in the education of their children in order to ensure admission and retention of disabled children in schools. Owusu-Ansah and Mji (2013) defined Afrocentricity as a paradigm with its core values rooted, centred and located in the African culture. It recognises the African voice and reaffirms the centrality of cultural experience, which is what informs the choice of this approach to research (Mkabela, 2005 cited in Owusu-Ansah and Mji, 2013). The participatory approach to this study and my personal experiences as an African woman living and working in rural Eastern Cape made it easier for me to relate with some level of understanding to the parents whose culture I share. The opportunity to spend time

with them and to listen to stories shared by parents about their lives (Chapter 5 and 6) all confirms the Afrocentricity of this study. The Critical Paradigm allowed me to dig deeper into the world of parents with disabled children while the Afrocentric nature of my interrogation of their situations reminded me to be non-judgemental in my interaction with them and to be sensitive to the context from which parents came.

*Table 1: Theoretical paradigms adopted in this study*

<b>Theoretical paradigm</b>	<b>Ontology</b>	<b>Epistemology</b>	<b>Methodology</b>
Critical, Afrocentric & Developmental (Capabilities Approach)	Governed by structures that can be questioned, Reconstructed through intentional critical reflection. People are agents of their own change. External conditions have power to enable or disable people.	Knowledge is constructed by questioning existing power relationships within social, economic, political structures in order to distribute that power justifiably	Participatory methodologies; values are explicit and located in the African Culture; researcher is facilitator to encourage dialogue and raise critical consciousness in a non-judgemental manner.

Different forms of qualitative research have been presented by various writers on qualitative research. Amongst others, Patton (2002) presented ten orientations of qualitative research according to different kinds of questions that researchers from different disciplines might ask. Creswell (2005) identified five traditions, namely biography, phenomenology, grounded theory, ethnography, and the case study. In this study I use an ethnographic approach in the Participatory Action Research.

It is apparent that qualitative research designs share similar features. They share a detailed engagement with the object of study; they select a small number of cases to be studied; they use a multi-method approach; and they are also flexible in that they allow the researcher to adapt and make changes to the study, where and when necessary (Babbie and Mouton, 2001; Leedy and Ormrod, 2001). The researcher's choices and actions determine the design. For example, during the research process, the researcher can create strategies suitable for his/her research.

Creswell (2005) states that qualitative research has an emerging research design, meaning that the design plans can change as the data is collected, analysed and understood. He takes this definition further and points out that the process begins with assumptions, a world view, possible use of a theoretical lens and the study of research problems inquiring into the meaning participants ascribe to a social or human problem (Creswell, 2007:37). Burns (2000) and Denzin and Lincoln (2005) further contend that qualitative research is an inquiry approach useful for exploring and understanding a central phenomenon. It is an effort to understand situations in their uniqueness as part of a particular context and the interactions thereof. It is therefore an umbrella covering several forms of inquiries that help us to understand and explain the meaning of social phenomena with as little disruption to the natural setting as possible (Patton, 2002).

In this study, I opted for a qualitative approach as it would allow better understanding of the world of parents with disabled children. It would also take into consideration their own perspective in order to identify relevant support needed for them to engage actively in the education of their children.

#### 4.3.2 Key characteristics of qualitative design

Patton (2002) and Creswell (2007) outline nine characteristics of a qualitative research, the key components which I outline in Table 4.2 below. Here I discuss only those that I find relevant to this study and those which I regard as cutting across various critical and transformative research designs as outlined in the works of Struwig and Stead (2001), Patton (2002), Welman and Kruger (2001) Denzin and Lincoln (2005) and Creswell (2007). Emphasis is put on meaning and interpretation constructed by people about their world and their experiences, the role played by the researcher as primary instrument for data collection and analysis and the inductive nature of a qualitative research.

#### **Qualitative Research Follows an Inductive Process**

Qualitative research cannot be neatly fitted into well-planned phases which must be engaged in from inception to the end of the study, as every step becomes executed

side-by-side with the next one. It is an evolving process. This means that in qualitative research the study approach and design is also naturalistic and participant oriented.

*Table 2 Key characteristics of a Qualitative Design (Creswell, 2007)*

<b>Key characteristic</b>	<b>Explanation</b>
<b>1.</b> The researcher operates in a natural setting	Direct contact between the participants and me in a natural setting
<b>2.</b> Researcher is key instrument	Although researchers do use other instruments for collecting data, in qualitative research, researchers become key instruments for collecting data
<b>3.</b> Inductive nature	Data analysis is inductive in approach. In other words, patterns, categories and themes are developed or generated by organizing data from simple to more abstract units of information
<b>4.</b> Use of multiple sources of data	Qualitative researchers use multiple sources of data unlike quantitative research that can simply rely on questionnaires
<b>5.</b> An attempt is made to understand people from their own frame of reference	Meanings assigned by participants to issues or problems investigated is vital
<b>6.</b> Use of a theoretical lens	Qualitative researchers use a theoretical lens in viewing their studies
<b>7.</b> Emergent design	The design is unpredictable (emergent) and allows for flexibility during data collection
<b>8.</b> Interpretive nature of inquiry	It is interpretive in nature and acknowledges the researchers own experiences, history and context
<b>9.</b> Every detail counts	Qualitative researchers identify the complex interaction of factors in any given situation.

### 4.3.3 The Approach to the Study

“Working developmentally means that we intervene, working facilitatively alongside people, so that they may enlarge themselves and gain their own capacity to exert authority over their own lives and futures, to make their own choices” (Taylor et al, 2008:2).

This quote talks to the approach I have used when working with parents of disabled children during the process of this study as outlined by the following section.

Within the ethnographic tradition, the approach that I took in this study was that of Participatory Action Research (PAR) as it was considered to best suit the research problem and questions. Reason and McArdely (2003) describe PAR as an orientation towards research, while Hilsen (2006) denotes the concept of action research as to what research does. I tend to resonate with Meyer’s definition that PAR is more of an outcome-based approach, meaning that success can often be viewed in relation to what has been learnt from the experience of undertaking the work (Meyer, 2000 cited in Ladkin, 2004:180).

As mentioned earlier, my background, which is deeply rooted in community development, has also had a strong influence on the choice of approach which I consider to be developmental and that which PAR enables.

Thus, in this study I engaged with parents during interviews, focus group sessions in their own communities where they shared experiences and lessons as parents with disabled children, and during school meetings where they discussed challenges and identified areas for support together with educators and children in schools. This was an opportunity for them to put into practice lessons learnt during focus group sessions.

Participatory Action Research is a research design in which researchers and participants are equally involved in the research process and take equal responsibility for the outcome of the research (Mouton, 2001; Creswell, 2005). The focus is on the involvement of all role players and includes participatory involvement, action and change, encounter and dialectic dialogue (Kemmis and McTaggart, 2000;

Strydom, 2005; Herr and Anderson, 2005). Hence, the research and the solutions to concrete problems occur simultaneously.

This research resonates with Lorenzo's view that Participatory Action Research helps research participants to move beyond the narrow view of thinking and the culture of silence, towards an informed knowledge, based on their needs and lived experiences (Lorenzo, 2005:41). The main reason/motivation for using a participatory approach is to allow for active participation of parents throughout the research process. This approach affords parents of disabled children an opportunity to express themselves, to share their experiences and to analyse their life experiences, conditions and to focus on areas for change (Turmusani, 2004). In this study, the participants were led by me and through their own discussions and action in a participatory way, to take action which drew them out of the 'culture of silence' and into a transforming role as parents of disabled children.

Park (2001) suggests three important activities involved in participatory action: inquiring into the nature of the problem, establishing ties to work together and mobilising for action. He defines PAR as a process through which a group identifies a problem, collects and analyses information and then acts in order to build a better, freer society. I tend to agree more with Reason and Bradbury (2006) in that,

...primarily action research aims at producing knowledge useful to peoples' everyday conduct of their lives while this in turn can contribute knowledge to the increased economic, political and psychological well-being of communities and a more equitable and sustainable relationship with the wider ecology (Reason and Bradbury, 2006:2).

The emphasis is on the researcher's creativity in capturing what will happen during the research process. With specific reference to this study, Patton (2002) defines this process as an applied form of social inquiry that aims at gathering information, generating and sharing findings, which can be of use. Based on Heron and Reason's (2001) definition of knowledge, the approach will put much emphasis on four types of knowledge in engaging participants: Firstly, experiential knowledge, a result of direct encounter; secondly, presentational knowledge, the product of experiential knowledge; thirdly, proportional knowledge which is often expressed through ideas and, fourthly, practical knowledge which is often expressed through a skill or

competence. The approach will help stimulate and allow equal participation for parents to share their experiences and be able to plan meaningful and relevant actions together.

#### 4.3.4 The Research Design

A research design is a plan or a structured framework of how the researcher intends to conduct the research process in order to solve the research problem or question (Babbie and Mouton, 2001; Neuman, 2006). The research design therefore describes the nature and the pattern that the research intends to follow and should include aspects such as the research and methods and techniques (Creswell, 2007). The research design is firmly based in this study, upon the Qualitative Paradigm and Ethnographic Approach to transformation through PAR.

The purpose of the research design is to plan and structure a research project in such a manner that the eventual validity of the research findings is maximised (Denzin and Lincoln, 2005). It is therefore important for a researcher when developing a research design to make a series of decisions along the following four dimensions: Firstly, he/she must take into account the purpose of the research; secondly, the theoretical paradigm informing the research; thirdly, the context within which the research is to be carried out; and finally, the research techniques employed to collect and analyse data (Mouton, 2001). Research design includes the statement of the problem presented to the researcher, the purpose and objectives of the study, the research questions and the context in which the questions are asked (for example, participants, geographical and historical).

According to Leedy and Ormrod (2001), Marshal and Rossman (2006) and Creswell (2007), a qualitative research process is inductive in its approach, which results in the generation of new hypotheses and theories. Qualitative researchers do not search out data or evidence to prove or disprove hypotheses they hold before entering the study; rather, the abstractions are built as the particulars that have been gathered, are grouped together. Theory developed in this way emerges from the bottom up rather than from the top down. This involves researchers working back and forth between the themes while interactively engaging participants with the aim

of shaping themes that keep emerging in the process until a comprehensive set of themes is established (Creswell, 2007). In this research, data collected was analysed, themes and sub-themes were identified, discussed and supported with relevant literature. I visited participants in their communities and interview sessions and meetings were conducted in home settings and schools where appropriate. In order to accommodate its unfolding nature, the design was an emergent one.

Research design therefore includes the research question, the purpose of the study, what context will answer the research question, strategies appropriate for obtaining it, as well as the philosophical foundation on which it is based (Denzin and Lincoln, 2005).

Because my research was based on an action learning approach, I was not tied down by any rigid rules in the process of collecting data, but decisions on action were based on problems as they arose in the field. This meant that I could be flexible and open to possibilities and changes during the process of data gathering (Patton, 2002).

Creswell (2007) notes that qualitative research is necessitated by the desire to empower individuals to share their stories, to hear their voices and to minimize the power relationships that often exist between a researcher and the participants in the study (Creswell, 2007). Working within a qualitative design enabled me to participate in the world of the parents and to explore the meanings parents gave to participation and support and their interpretation of their experiences (Merriam et al., 2002; Morse and Richards, 2002). Research questions were mainly used as a guide to facilitate discussion that led to more questions about the process of support for parents and ultimately answers to such questions. The qualitative emergent nature of this research allowed flexibility and adaptation of plans to circumstances that arose in the process and also allowed for full participation of parents from the planning phase to the final stage of the research.

Merriam (1998) sums this up succinctly when she notes that:

Qualitative research is an effort to reveal how different parts of the system come together to work as a whole as such researchers attempt to understand the

phenomenon being studied from the participants' point of view. The researchers are the tools for data collection and analysis (Merriam1998:103).

The design was also qualitative and interpretive which allowed interactions between different participants to be captured, interpreted and portrayed in words. “Qualitative methods provide researchers with a certain kind of knowledge and with tools to organise and make sense of messy data” (Eloff, Engelbrecht, Oswald, Pettipher and Swart, 2002:84). A qualitative design also allowed for rich descriptions of the recurrent themes that emerged in response to the research questions and the political, economic and social factors that impacted upon the study (Patton and Potter, 2002)

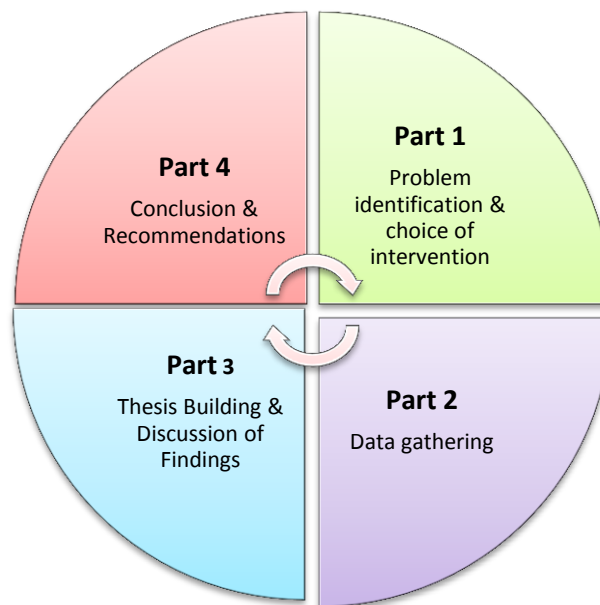


Figure 3: Action Research Design

#### 4.3.4.1 *Sampling*

Before I determined the sampling strategies, I considered the four key factors in sampling, namely the sample size, the representativeness and parameters of the sample, the access to the sample and the sampling strategy to be used (Cohen et al., 2000; Struwig and Stead, 2001). I did not gather data from the whole population of parents with disabled children and the results from this research do not claim to be representative of the larger population; neither does it aim to generalise about the larger population. I chose the sample mainly because of the convenience of doing so. For example, financial constraints, accessibility and time considerations greatly determined the size of the sample, its representativeness, parameters and the sampling strategies used.

Lincoln and Guba (1985), Patton (2002), Creswell (2005) and Neuman (2006) describe purposive sampling as a method in which the researcher uses a wide range of methods to locate all possible cases of a highly specific and difficult-to-reach population. Cohen, et al., (2000) contend that purposive sampling is the dominant sampling strategy in qualitative research because qualitative research seeks to understand the meaning of phenomena from the perspective of the participants. It is therefore important for the researcher to select a sample from which the most can be learned and that the qualitative research focuses on information-rich cases, which can be studied in depth. In this way, the researcher manages to build a sample that is appropriate to his/her needs.

Purposive sampling is undertaken with deliberate aims in mind (Leedy and Ormrod, 2001; Creswell, 2005). In purposive sampling, the variability common in any social phenomenon is represented in data. This is unlike random sampling, which tries to achieve variation through the use of random selection and a large sample size. Cases and sites are selected with certain criteria in mind.

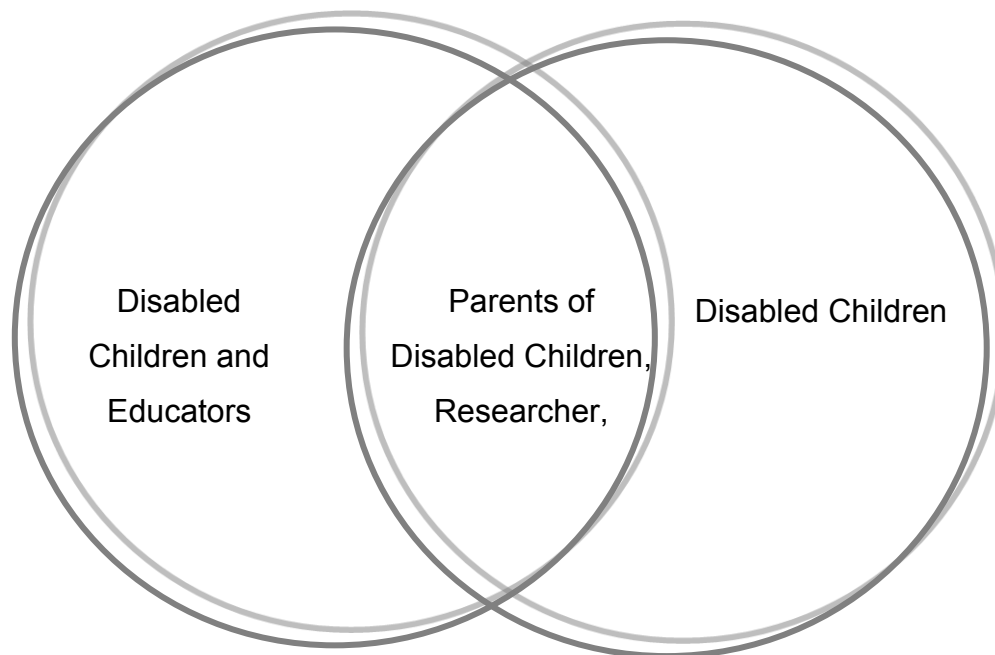
In this study, I used a purposive sampling strategy to select the participants. My sample consisted of rural parents who have disabled children in public schools. I invited 5 of the parents and their children to participate. A parent with no disabled child and those with disabled children that had already gone pass basic education

were excluded from the study. Participating parents had a heterogeneous background in that though they all had a disabled child in basic education, one of them had a completely different background from the rest of participants. The non-random method of purposive sampling is the method that was used in accessing participants (De Vos, 2002). All parents had participated in the REHAB project that I had previously facilitated. The research adopts the view that good informants are those that know the required information and that are willing and have time to participate and share information (Spradley, 1972 in Morse and Richards, 2002). Participants in this study were parents who had experienced challenges in getting access to (and ensuring their children were retained in) the education system.

Participants in the study were five parents with disabled children in public schools, their disabled children and each child's class educator. For the purpose of this study, "parent" implies a biological parent of the child or the person taking care of the child and playing the role of parent to a child. Only one parent participant was not the biological parent. However, the parent had been taking care of the child since the child was born, when the mother became ill after birth. Children and their educators only participated in school progress meetings. As the study was directed at parents of disabled children in public schools, each of the five participants had a child with impairment. The children were aged between 6 and 12 years. The reason for this particular age group was that these are the ages where children begin their pre-school and primary school levels. There was no exclusion with regard to impairment category of the child as the main focus of the study was on experiences of parents in accessing education for their disabled children. However, all children were registered in mainstream and a special school resource centre.

Three of the five participants were single parents and the two who were married considered themselves the ones who were directly involved in the education of their disabled children. Two of the parents were unemployed. It is important to note that during the initial phase of the study, I requested that partners of participants and fathers of their disabled children also participate in the study. These attempts failed, however, and participating parents decided it was better for them to participate together as mothers (women). In addition, they saw the benefit in their participating

in the study as there were challenges in the schools that they were dealing with at the time this study was introduced.



*Figure: 4 Research Participants*

For the purpose of this research, disabled children and their educators were both regarded as potential participants in the research process. Therefore, two heterogeneous and overlapping groups were formed (Figure 4). One group (core team) consisted of 5 parents, 1 researcher and a research assistant. This team was responsible for the on-going planning and monitoring of the research process. The second group consisted of the 5 disabled children of the participants and their educators who helped by providing feedback on the progress of the children at school, the involvement in and support of the parents to the school. Parents, as members of the community that the research was targeting participated frequently within the two teams (Mertens, 2001). This way, parents had an opportunity to share their views and thoughts with the school. In addition, they had an opportunity to share experiences amongst themselves during the focus group sessions.

#### 4.5.1 Data Presentation

In portraying both the “expected” (as I share the same “Xhosa” culture with the parents) and the “anticipated surprise” (Denzin and Lincoln, 2003) while I engaged in the world of the parents of the disabled children, an ethnographic approach was

adopted as the means by which I opened up the world of these parents for better understanding by others. Creswell (2008) describes ethnography as writing about people in a way that paints the social structure and world view of a group. The inclusion of examples of raw data and original discourse in presenting data involves organising these into readable, narrative descriptions with major themes, categories and illustrative case examples in data analysis. Denzin and Lincoln (2003) add that ethnography depicts experiences, responses and feelings at play as we become conscious of (or confronted by) the cultural, personal and social issues in our lives. Emphasis is on how these issues impact on the other (Denzin and Lincoln, 2003).

Denzin defines this concept so well when he says:

Ethnography is a therapeutic, allegorical and moral project that allows the researcher to step into the shoes of the participant and build transformative, connectedness, participatory and empowering relationships with the ones being studied (Denzin, 1997 cited in Mauthner et al., 2008: 24, 26).

Note the transformative, participatory and empowering elements which this study emphasises. In this study, narratives in different styles of writing are used to show that which was observed in the field. These styles include issues that presented challenges to the researcher in this study.

In this study, an ethnographic approach was followed as a means to illustrate and to substantiate assertions made. An attempt is made to support issues, inferences and tentative conclusions by means of reference to one or more extracts from participants' contributions and responses during interviews, meetings and focus group sessions.

#### 4.3.5 The Process of Participatory Action Research (PAR)

Action Research is a cyclical process of reflecting, planning, acting and observing (Kemmis and McTaggart, 2000). According to Babbie and Mouton (2001), it proceeds through repeated cycles in which researchers and the participants start with the identification of the major issues, concerns and problems, initiate research, originate action, learn about this action and then proceed to a new research action cycle. The cyclical process is generally not as neat and final as other procedures,

because its stages overlap and mutual plans may become obsolete in the light of lessons from experience. It is also likely to be more fluid, open and responsive than other procedures (Denzin and Lincoln, 2000).

In this study, therefore, the participating parents were involved in the problem identification. School meetings were used to put into practice, assess and to evaluate their actions/participation in school matters. I facilitated the process for them to suggest ways in which they could alter their actions in the future. Figure 4 outlines the process followed in the Action Research design. The following chapters detail the methodology as I progress through the stages of the action research design.

#### **4.4 Data Gathering**

Documents used to obtain permission to conduct research and informed consent are appended here to as Appendix A and B.

Creswell (2007:118) describes the process of data collection as a “series of interrelated activities that aim at gathering good information to answer emerging research questions“. In qualitative research, the researcher acts as the primary instrument for data collection and data analysis (Denzin and Lincoln, 2005). The researcher’s responsibility is to collect and interpret data. Since qualitative research involves fieldwork, the researcher has to go to the people, settings, sites and institutions in order to observe peoples’ behaviour in their natural settings.

Data was mainly collected by engaging with participants during interviews, focus group sessions, observations and document analysis. Data sources in this study include the researcher’s personal journal (includes assistant researcher notes), transcriptions of focus group, individual interviews and reflective sessions, extensive notes on the participant observations of numerous meetings, observations during school meetings and learner progress reports (See Appendix C “Learner reports”).

#### 4.4.1 Interviewing

Interviewing is a two-person conversation initiated by the interviewer for the specific purpose of obtaining relevant information and a focus by the researcher on content specified by research objectives of systematic description, prediction or explanation (Cohen et al., 2000). According to Weman and, Kruger (2004) and Creswell (2005), interviewing is as popular as observation in qualitative research. There are three types of qualitative interviews, namely structured interviews, unstructured interviews, and semi-structured interviews through which an interviewer/researcher tries to elicit information from another person (Burns, 2000).

In this study, I used semi-structured and focused group interviews in order to investigate the experiences and perceptions of parents with disabled children regarding the education of their children

##### *4.4.1.1. Individual and Semi-Structured Interviews*

Before the interviews were conducted, the researcher asked for permission from the relevant school principals and educators. Participants were informed about the purpose of the research and the time that the interview would take (see Appendix I “Informed Consent Form”). They were also assured of anonymity and confidentiality. The researcher assured those participants who confirmed that they would like to be provided with the research findings, that they would be given the results (Burns, 2000; Leedy and Ormrod, 2001; Patton, 2002).

Leedy and Ormrod (2005) state that an interview should be in the form of a conversation, not in a question and answer form. In order to overcome the above problems, I advised the participants of the aim of the interview and also told them how long the interview would last. Participants were familiar with questions asked as topics focused on their experiences as parents of disabled children in public schools. The information provided was also relevant as presented through the themes in Chapter 7.

The interviewing skills I gained from my background in Social Work came in handy. Probing was carried out in a friendly and non-threatening way. Parents were

informed that although a given response was acceptable, further information might be required. This created confidence in participants that none of the responses were rejected. No value judgement was made during probing and this prevented bias. Annexure E shows examples of open-ended questions that were used. To ensure that the researcher understood what was being said by the interviewee, reflective summaries were used, sometimes reflecting feelings expressed during interviews.

Initially, interviews were conducted with parents to elicit details of their children and to arrange accessing of relevant documentation. (See Appendix D: “Interview Schedule”). There were five of these interviews in total and they were held with all parents, individually in their homes. These culminated in meetings with each parent and the class educator of the child where the teacher and the parent discussed how they saw school meetings unfolding. Expectations were also clarified in these meetings in preparation for school meetings where the progress of the child and support needed was discussed. Two of the five educators who participated in school meetings were not available for these initial meetings due to their “busy schedules”. However they did make themselves available for school meetings where children’s progress was discussed. This meant that only three of the five initial meetings were held, involving the parent and the child’s class educator.

Semi-structured interviews allow for the ordering of questions to be employed flexibly to take into account the priority accorded to each topic by the interviewee (Banks, 2007). As the process of the data gathering unfolded it became apparent that further data collection was necessary from the individuals who formed the focus of this inquiry. It was thus that individual interviews were conducted with parents and learners following up on issues that were picked up from observations during school meetings and focus group sessions where clarity was needed. These interviews allowed for further probing of the questions relating to the nature of support which learners felt was needed and where parents were also challenged to assist.

The mutual trust relationship that had developed from the researchers’ interaction with participants during the time of REHAB (See Chapter 2) made it easier to work

together and to get co-operation from parents and some of the educators whom the researcher had worked with at the time of REHAB.

#### *4.4.1.2 Focus Group Interviews*

Focus groups are a useful tool for explorative research in which collective views are sought. Emphasising the value of interaction in focus group sessions, Gibbs (1997) argues that it is this interaction that brings the participants' view of the world, their beliefs and values. It is also this interaction that makes it possible for participants to make sense of challenges encountered in their daily lives.

Focus groups were conducted with parents at a central venue that was arranged and agreed to by all parents. Although there was a schedule, questions were treated as general areas to be covered in the process of data gathering to ensure that important data was captured. As focus groups developed, the facilitator who was actively involved decided on when to ask and how to ask/phrase questions. I limited my own contribution to a minimum by introducing general themes on which information was required. Participants were also encouraged to participate spontaneously and were stimulated through probing. The researcher ensured that they were tactfully directed back to the topic when found to be sliding off the topic (Bogdam and Biklen, 2007).

#### *4.4.1.3 Participant Observations*

I, as a researcher and interviewer, carried out dual role, that of a facilitator and observer during meetings and interview or focus group sessions. Use of a tape recorder was very helpful. One of the things that added an advantage to the role of the researcher as an observer was the fact that researcher was familiar with facilitating and observing meetings with parents and educators at the time of REHAB. This advantage further assisted in the interpretation and validation of information observed during the interviews and school meetings.

I also made notes during meetings and these, together with attendance register (Appendix F) and transcripts (Appendix G) from recorded information, provided valuable reference and background material which Merriam and Associates (2002)

regard as first-hand discovery of the subject of inquiry since it occurs in the natural setting.

Observations were conducted during school meetings, individual structured interviews, semi-structured-interviews and focus group sessions.

#### *4.4.1.4 Recording Data*

According to Patton (2002), data recording is a process that involves the recording of some information using an interview guide or a focus group schedule, which is a list of questions. The researcher may rely on written notes or a tape recorder for recording interview data.

In this research, I used field notes and a tape recorder to record interview data. Informed consent was obtained from parents, learners and educators for the use of a tape recorder. Participants were assured of their right to privacy, fair treatment, anonymity, confidentiality, protection from discomfort and harm. Examples of the recorded and transcribed interviews are attached to this thesis as Appendix G.

#### *4.4.1.5 Transcription of Interviews*

Transcribing data means transforming the oral interview into a written structure for analysis purposes (Creswell, 2005). The data collected has to be transcribed verbatim. Before the researcher transcribes the interviews, they have to be tape-recorded; the tape has to be audible. This step is important, as field notes are a written account of what the researcher hears, sees, experiences and thinks in a data collection session (Groenewald, 2004). Field notes are used to back up tapes, and they are an important part of the analysis process. At this stage, it is important for the researcher to see to it that he/she does not prematurely categorise data (Groenewald, 2004). Before I transcribed the interviews, I looked at the field notes to verify the recorded information. In cases where there was a discrepancy and clarity was needed, I followed up with the participant to verify my understanding and interpretation of the issues in question. I also intentionally did not involve any other

person to assist with translations, and this helped to make sure that there were no extraneous discrepancies during transcribing and interpreting of data.

#### *4.4.1.6 Field notes*

Field notes are the researcher's or observer's detailed description of what has been observed. They are a record of the research experience, which includes observations, a reconstruction of dialogue, personal reflections, a physical description of the setting and decisions made that alter or direct the research process (Anderson and Arsenault, 2004; Creswell, 2007). These notes are written in a handy note book that the researcher carries. The notes must be written after every event because, according to Anderson and Arsenault (2004), it is appropriate to take notes in certain settings so that the researcher cannot miss out on important information in the process of data collection.

In this research, the researcher and assistant researcher took notes during interview sessions and focus group sessions. These were then reviewed. Any blanks or missing information were then filled in, any scribbled information was fixed, and missing details which one might not have had time to note was added. The records / field notes revealed what happened during the interview process. Leedy and Ormrod (2001) state that the advantages of conducting observations are that the researcher may shift focus as new data comes to light. These authors also state that the researcher should be flexible when conducting observations. This became apparent during some of the focus group sessions, like one instance when a parent expressed challenges she was going through in her marriage. As a result, I had to refocus the current discussion in order to give support to the participant. A similar situation was experienced during an interview involving one of the children. This resulted in professional counselling being recommended. However, because the parent was not comfortable about going for professional counselling, that proposal could not be pursued.

#### *4.4.1.7 Reflective Journaling*

Janesick (2004:146) describes journal writing as a process

... that allows one to reflect - to dig deeper ... it is a kind of member check of one's own thinking done on paper.

The ability to keep in tune with my inner feelings and thoughts (self-awareness), a reminder of who I am has been a learning process that this study has strongly and positively impacted on. Prior to venturing on this study, this was the area to which I struggled to allocate time. The fact that I had to keep reminding myself to allocate time after every meeting with participants, to reflect and document my experiences, feelings and perceptions in preparation for the final product of a written presentation of this study, was a learning journey for me. I have come out of this study a changed person with a different view and approach to relating to myself, others and to life in general.

My journal was used to record personal observations and feelings after the meetings, focus group sessions, support and supervision sessions as well as discussions with the assistant researcher. There were also times when I would wake up in the morning with ideas as to how to further develop this study and these thoughts went into this journal. This allowed me to explore themes and intuitions ensuring “neutrality” before presenting ideas for further reflection to participants and others in the support team.

#### **4.5 Data Analysis**

Data was analysed through content analysis (See Appendix H, theme identification and categorisation). Patton (2001) defines content analysis as the process of identifying, coding and categorising the primary patterns in the data (Patton, 2001). In this study data consists of transcriptions of interviews, researcher’s notes from research journals and reflection sessions with the assistant researcher about observations of school meetings and focus group sessions.

The researcher and assistant researcher met after every focus group session to reflect on the particular session. The purpose of these meetings was to discuss our observations of what had happened. For example, participant responses and contributions, including general emotions that might have been observed during discussions, were noted. As the assistant researcher was a disabled person with

experience in issues of disability, having worked in the disability field with parents of disabled children for eight years, the relationship that developed between us over time made it easy to openly discuss our understanding and to identify areas that needed clarity and following up with participants. Aspects that needed following up were then brought up at the beginning of the focus group session. Sometimes they were taken up at individual follow up interviews with the parent concerned. Notes from transcriptions were also discussed during support sessions with the co-supervisor and this helped identify recurring themes that informed preceding focus group discussions.

Creswell (2007) and Patton (1990) acknowledge the fact that in qualitative research; researchers often end up with volumes of data. This often poses challenges and overwhelming moments of mind blocking. I experienced this situation first-hand in the process of this research. Data in this study comprised of 29 transcripts of interviews and focus group sessions which led to about 400 pages of raw data that developed as a result of the researchers being the participant observer and facilitator in this study. In this regard, I therefore acknowledge the continuous support received through supervision and support sessions that often pointed to a number of resource materials which I found valuable. I took heed of Creswell (2007), Welman and Kruger's (2001) suggestion to reduce data by means of continuously selecting, simplifying, abstracting and transforming raw data (Welman and Kruger, 2001; Creswell, 2007).

Tape recordings were listened to and transcripts read over a few times to make sense of and to provide the context for identified meanings derived from such. Interesting patterns (that needed clarity or new information/knowledge picked up from transcripts). Topics were then given to these "chunks of meanings". These were then categorised and named according to similarities in meanings. Ultimately themes, sub-themes and categories emerged as presented in Chapters 5 and 6.

#### **4.6 Positionality**

In this section I discuss the research team, my own and the position of the respondents in this study.

#### 4.6.1 Research Team

According to Denzin and Lincoln (2000) a researcher becomes the main instrument in a qualitative research approach. A key component of my research design was that I would be directly involved in every phase of the research. In cases where an assistant researcher might be necessary (e.g. assisting during focus group meetings) a parent of a disabled child from the group that I had worked with at REHAB, but who was not participating in the study, played this role. Both my assistant researcher and participants were involved in the preparation of interview schedules, data collection and in further action planning.

This reflected a paradigm shift in research in that, parents of disabled children would be recognised as experts in their own lives (Danby and Farrell, 2004). Engaging parents of disabled children as active participants provided them an opportunity for experiential learning and enhancing their communication skills. Being a Black, South African parent, but with a non-disabled child, a disabled person as assistant researcher helped to further minimize possible social boundaries between me, as a parent with a non-disabled child, and participants who were also Black Africans with the exception of one.

Participants were based within the same District Municipality in South Africa.

#### 4.6.2 The Participants

Participants were five parents with disabled children in public schools, their disabled children together with each child's class assigned educator. For the purpose of this study, "parent" implies a biological parent of the child or the person taking care of the child and playing the role of a parent to a child. Children and their educators would only participate in school meetings as further explained below. English was not the mother tongue but second language for all participants.

As the study was directed at parents of disabled children in basic education, each of the five parents had a disabled child whose ages ranged from 6 – 12 years. There was no exclusion with regard to impairment category of the child.

#### *4.6.2.1 Understanding the Meaning Participants have constructed*

Qualitative research has an interpretive character, aimed at discovering and interpreting the meaning events have for individuals who experience them (Babbie and Mouton, 2001). According to Denzin and Lincoln (2005), qualitative research is multi-method in focus, in that it involves an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings and attempt to make sense of or interpret phenomena in terms of the meanings people bring to them. According to Patton (2002), Bogdan and Biklen (2007), qualitative research aims at creating understanding by looking closely at peoples' words, actions, beliefs, history and records within a given context. Therefore, qualitative research is conducted in the natural setting of the social actors.

Qualitative researchers try to understand the meaning people have constructed about their world and experiences; that is, how people make sense of their experiences. They are interested in understanding peoples' experience in context and see the actual settings as a direct source of rich data. In qualitative research, the participants' perspectives define what is real (Patton, 2002; Denzin and Lincoln, 2005).

In the case of this study, meetings with educators, parents and their disabled children were held in schools. This allowed for contextualisation of the research findings.

#### *4.6.2.2 The Researcher as the Primary Instrument*

In qualitative research, the researcher becomes the main instrument for data collection and data analysis (Denzin and Lincoln, 2005). My responsibility was to collect and interpret data. Since qualitative research involves fieldwork, I had to go to the parents, settings, sites and schools in order to observe parents' behaviour in their natural setting. As a participant observer, I became a member of the inner circle of the parents on whom this study was focusing. This meant that I had to play a dual role in the entire process of data collection. I also took heed of Welman and Kruger's

(2001:185) words of advice that, while playing a dual role, the researcher needs to be careful of his/her degree of participation that might endanger his/her role as an observer. I was therefore sensitive to participants' views in the way I asked questions and how my own views might influence or affect others. Because of this awareness, my questioning skills, like paraphrasing to confirm what I was hearing in my interaction with parents, were helpful.

#### *4.6.2.3 The position of the participants*

A key component of my research design is that I was directly involved in every phase of the research. Both my assistant researcher and the participants were involved in the preparation of interview schedules, data collection and in further action planning. This reflects a paradigm shift in research in that the parents of disabled children were recognised as experts in their own lives (Danby and Farrell, 2004). My engaging the parents of the disabled children as assistant researchers and active participants provided an opportunity for their experiential learning and enhanced their social skills. As a Black, South African parent but with a non-disabled child, my engaging the parent of a disabled child as assistant researcher helped to minimize possible social boundaries between myself as a parent with a non-disabled child and the participants.

Qualitative research is evaluative in nature. The researcher in qualitative research is the key instrument or tool. His/her expertise and understanding are important elements in the research process. As an active observer in the research, the researcher focuses on interests, values, strengths, characteristics, preferences and biases.

The qualitative researcher is close to the data and has an "insider" perspective. As the principal data collection instrument, the researcher defines the problems, selects research designs, develops methodologies, collects, analyses and interprets data through interviews and observations.

It therefore is a challenge for the researcher to play this role without the relevant, especially interviewing, skills. This includes the ability to give meaning to data, the

capacity to understand, and the capability to extract pertinent data. Patton (2002) believes that this theoretical sensitivity comes from a number of sources such as professional literature, professional experiences and the personal experiences of the researcher. He further states that the credibility of a qualitative research report relies on the confidence that readers have in the researcher's ability to be sensitive to data and to make appropriate decisions in the field.

It is vital that the qualitative researcher understands the phenomena and is able to interpret the social reality from two perspectives, the *emic* and the *etic*. A mnemonic used to remember these perspectives is *emic* – mine; *etic*- theirs. This simply means that the qualitative researcher tries to understand phenomena through the participants' eyes, then places that understanding within his/her theoretical framework of the phenomena and reconsiders the respondents' perspectives, in order to define, unravel, reveal or explain the world (Gough and Scott, 2000).

As a researcher I was able to expand my understanding through both non-verbal and verbal communication. I processed data immediately, clarified and summarised material, checked with participants for accuracy of interpretation and explored unusual or unpredicted responses. In order to overcome shortcomings and biases that might have had an impact on my research, I identified and monitored them.

In this research, I was the main researcher, working with an assistant. I collected processed and analysed data with the help of the assistant. I also wrote down the research findings. The assistant made some observations, recorded non-verbal responses and took some field notes, which, together with data I collected, were later analysed. My moderation of the data increased the reliability.

Before I interviewed the respondents, I created an atmosphere that encouraged them to talk openly and to respond to questions. I listened to their responses and new ideas (Leedy and Ormrod, 2001). I also asked them simple questions using Xhosa and simple English and probed to get clarity on some of the answers received (Welman and Kruger, 2001). My background in Social Work made it easier for me to relate to participants during the interviews and focus group sessions.

#### *4.6.2.4 My Own Role and Position as Researcher*

In presenting my role and position in this research, I draw on Paton's (2002:48) interpretation of a qualitative inquirer as one who "actively participates in the life of the observed where action is, getting one's hands dirty, getting personally engaged so as to use all senses and capacities, including the capacity to experience affect no less than cognition". Paton further points us to the issue of credibility of the research strategy which becomes questionable without the stance of neutrality on the side of the researcher. An interesting analogy which de Vos et al. (2002:106) invokes is that the researcher, while free to bring own self into the study, can tell the story from the point of view of the participant rather than as an expert who passes judgement on participants. In this study, the ethnographic approach used in data presentation made it easy for me to use direct quotes in data presentation and analysis to portray and to confirm that which was said.

My role in conducting this study has been that of a researcher with experience gained from my day to day work as a development practitioner with a social work background. My interest towards this study have been motivated by the desire to make a difference and to see more disabled children included and benefiting in the education in my community and in South Africa.

As a participant observer, the issue of neutrality poses tension and a dilemma as Merriam puts it, "a schizophrenic activity" in that while engaged in one part of the activity, one is reminded of the other (Merriam 1998:103). This talks more readily to the challenges apparent in my role in this study as a participant observer and also as a parent of a non-disabled child. Although I share the culture and language of the participants in this study, I was alert to the lessons learnt from the experiences of the parents who had disabled children compared with my own experiences as a parent of a non-disabled child.

Parents of disabled children are the objects of the research. Our political history and socio-cultural values have shaped their view and what they believe about their role in the education of their children. One of my roles as a researcher was to facilitate the

process of reinterpreting their past, according to their own experiences. This took into consideration the individual aspect of every parent. I strove to envision together with them an effective approach to support parents of disabled children to become catalysts of change towards an inclusive education system.

Earlier while positioning myself in this study, I quoted Paton's interpretation of a qualitative inquirer as:

one who actively participates in the life of the observed where action is, getting one's hands dirty, getting personally engaged so as to use all senses and capacities, including the capacity to experience affect no less than cognition (Patton, 2002: 48).

De Villiers (2001) points out that in qualitative research:

The researcher occupies an integral position crucial to obtaining valid data that is built on a relationship of reciprocal trust and rapport, thereby enabling participants to willingly share the knowledge of their life-world (De Villiers (2001:171).

I acknowledged the challenge posed by the issue of neutrality in my role as a participant observer, a parent of a non-disabled child with my own cultural beliefs and life experiences and a principal researcher and facilitator in this study. I come out of this study in full agreement with the term used by Merriam in portraying the role of a qualitative researcher, as that of a "schizophrenic activity" in that while engaged in one part of the activity, one is reminded of the other and one's own life experiences (Merriam 1998:103).

### **Principal Researcher**

My main role as a researcher in this study was to facilitate the process of reinterpreting the lives of parents with disabled children according to their own experiences and to envision with them a new model of empowering them to become catalysts of change towards an inclusive education system. The transformative theoretical framework which guided the study encouraged me to place myself in the data and to acknowledge the influences of my background, cultural reference points,

values and interests. It has also encouraged me to create the kind of knowledge that could enable positive changes in the lives of a group of individuals who regarded themselves and their disabled children as marginalised from the education sector and despite the fact that their inclusion was supported by the inclusive legislation and educational policies.

This study has afforded me the opportunity to both observe and become part of the educational and social transformation which is playing itself out within schools, educational departments and society at large by participating in school meetings and observing how parents, learners and educators work together in an attempt to make inclusive education reality. It has allowed me the opportunity to be part of enablers in the process of opening up the space for a marginalised group to freely and fully participate in the education of this country. I have also been allowed space to draw together pieces of past history, information from international studies, differing interpretations of recent educational policies and a particular focus upon the experiences of parents and teachers of disabled children regarding inclusion and retention of children in the education system.

As a result of the readings undertaken in the writing up of this research, I now have a better understanding of parent experiences, perceptions and needs concerning the education of their children. I am now aware that some parents who have disabled children feel vulnerable when it comes to addressing challenges experienced by their children in accessing and retaining their children in schools. The negative attitudes of the teachers and the lack of support by the Department put parents in a difficult situation with the result that they feel abused, undermined and disregarded by the education system.

The time I spent interacting with parents in the field gave me insight into new realities regarding the challenges that result from having a disabled child with the desire to have him/her experience things in the same way that every other child does. This is information that I would not have come across in the literature, since there has been little work done with specific regard to the needs for support as perceived by parents

themselves. The information I elicited from parents was authentic and believable. Again, as a parent of a non-disabled child and a community development facilitator working with parents of disabled children, the skills I acquired in working with these parents have benefitted my facilitation of interviews and participatory activities.

One other valuable insight which I believe plays a crucial role in my field of work as a community development facilitator, is the meaning put by parents in their culture. It was interesting to observe the importance and influence, albeit unconscious, parents place on their cultural practices. I come out of this research study in agreement with Tamas (cited in Stone, 1999) that for any development initiative to be sustainable, it needs to be soundly rooted in the context and the consciousness of the environment in which it operates, paying attention with full respect to local culture . During this study, we had to make sure that those family gatherings and funerals took priority over the scheduling of focus group sessions and meetings. In cases where these activities coincided accidentally, scheduled meetings had to be re-arranged. In some cases, participants ended up supporting each other during such family activities.

For me, this confirms the importance of realising and taking into consideration the context in which parents live if we expect them to participate as role players in building an inclusive education system. These are the issues that educators need to consider when arranging meetings with parents. I can say that I was able to conduct my study in a professional manner; that is, there was a spirit of harmony, co-operation and respect during interviews between myself, parents and educators who were interviewed, and during school meetings.

### **Enabling and Empowering Facilitator**

Essential to the Developmental Approach is the involvement of the community members towards a common purpose, aimed at the delivery of development services on the one hand and the upliftment of the community as a whole, on the other. Equal partnership characterised by mutual co-operation is very crucial in achieving all of the above. It is important to realise that an underdeveloped society can and should participate in an active organised way in the identification and

solution to their social needs. It is this mutual co-operation that enables the successful transfer of skills, making it possible for communities to be able to identify and solve other challenges. Experience has shown that a developmental approach to working with disadvantaged societies enables people to take full ownership of initiatives that occur in their communities. It is this passion and desire to see change that drives me to work with people in challenging situations. This has been the driving force that has made it possible for me to initiate this study, to persevere in order to see it through and to continue supporting initiatives that strive to make schools inclusive sites for learning.

#### **4.7 Research Ethics**

Research ethics places an emphasis on the humane and sensitive treatment of research participants who may be placed at different risk levels in the process of the research (Creswell, 2008:140). Consideration of ethical issues becomes imperative, particularly when working with children and marginalised groups. It is for this reason that the criteria below were adhered to in this study. This study further adhered to the ethical principles outlined in the Declaration of Helsinki (Seoul version, 2008).

##### 4.7.1 Ethical Criteria:

###### *4.7.1.1 Informed Consent*

It is essential that participants are fully informed about the nature of the research and that they consent to participate in the research with knowledge of what they are agreeing to (Clacherty and Donald, 2007). Durrheim and Wassenaar (2002) put particular emphasis on ethical considerations pertaining to the individual rights of participants. These considerations involve gaining the informed consent of all participants in the research process. The researcher saw to it that, in the gathering and dissemination of data, the anonymity of all individuals and institutions involved in the study was protected, and that all data transcripts and field notes used in this research were not in the public domain.

An informed consent form was signed by all parents who participated in this study, (See Appendix I). In addition, parents were informed of their right to refuse to participate at any time they felt uncomfortable during the research process.

Participants were informed and assured that there will not be any implications on them and their children' education, at any point should they wish to decline from the study. Care was taken to ensure that the consent form was explained in Xhosa. All of the participants who were involved in this study were literate.

#### *4.7.1.2 Confidentiality*

To protect individual confidentiality and anonymity during the research process, no participant's name was used in the write-up of the research. In identifying participants, pseudonyms were used to ensure anonymity. In addition to the consent forms signed by participants, I explained to them that it was important that the information discussed in all meetings and focus groups was not discussed with any person outside the meetings. I reiterated this discussion at several meetings with the participants to ensure that they were always certain about confidentiality.

#### *4.7.1.3 Protection from Harm*

Research questions have been prepared in a way that ensured no emotional or psychological distress to participants. As a person with some background in social work, working with parents of disabled children, the researcher maintained sensitivity in the way questions were asked. There were two cases where participants requested referral for social support. A disability organisation offered assistance in this regard.

I also took heed of the ethical principles outlined in the Declaration of Helsinki (Seoul version, 2008) to ensure protection of vulnerable groups and individuals who might present an increased likelihood of being wronged. I was cautious and open in clarifying my role to the participants as a researcher. It was important that I do not raise parents' hopes as someone that was going to intervene and solve problems they were faced with in schools. The first meeting with parents addressed expectations in working together during the study. The importance of respecting one another also came up as we discussed group rules. As a concept predisposed to abuse in the context of culture (Gouws and van Zyl in Reddy et al., 2014), I was also cautious that my actions as a researcher do not act as barrier in my relationship with parents. I believe that keeping a low profile in the course of the study contributed to

the fact that parents became open in driving and sharing valuable information that informed findings of this study. The power differences seemed a challenge during school meetings as the meetings were dominated by teachers with parents less talkative than they were in focus groups. This meant that I had to become more strategic in my neutral role facilitating the meetings.

#### *4.7.1.4 Ensuring Rigour*

As noted on data tabulation (See Appendix E) the researcher introduced a system of rigour and validity by setting time for reflective feedback during data collection and analysis, results of the study in the study and themes were presented to participants in a simple form and that was easy for them to understand (Bless et al., 2007). In addition to the use of simple terminology, translations into participant's language were done when necessary.

#### *4.7.1.5 Credibility*

Member-checking was done to ensure that the researcher's reconstruction of everything that transpired during interview sessions was the true meaning of what was said or done. Reflective periods in focus group sessions focused on clarifying and ensuring that transcriptions reflected the true meaning of what was meant and said. The researcher also used the current PhD support sessions, support and supervision sessions as a platform to continuously share the process and findings of this research with other researchers and the school support team, the Department Quality Assurance Team.

#### *4.7.1.6 Dependability*

Dependability means being able to account for changes in the design of the study and the changing conditions surrounding what was studied (Lincoln and Guba; Mouton, 2001). The traditional view of reliability is based on the assumption of replicability or repeatability. Essentially, it is concerned with how much of the findings would be replicated if the research were repeated in the same context with the same participants. In qualitative research, auditing is also a useful procedure for establishing dependability. A trail is left behind and the trail comprises the tools used

for data collection, raw data, personal notes, memo's and documented procedures for analysing the data and generating theory.

The criterion of dependability in qualitative research emphasises the need for the researcher to account for the ever-changing contexts within which the research occurs. The researcher is responsible for describing the changes that occur in the setting and how these changes affect the way he/she approaches the study. In this research, the dependability of data collected, was ensured through triangulation and through probing questions used during interviews. Probing questions ensured that the researcher had the same understanding as that of the participant in interpreting what was conveyed when clarity was needed. The data collected during interviews and observations were tape recorded and kept in the form of field notes for an audit trail. In addition, the methodology used was in line with the goals of the research.

#### *4.7.1.7 Transferability*

Transferability refers to the degree to which the results of the qualitative research can be generalised or transferred to other situations, contexts or settings (Creswell, 2007). From a qualitative perspective, transferability is primarily the responsibility of the person doing the generalising. The qualitative researcher can enhance transferability by thoroughly describing the research context and the assumptions that were central to the research.

In order to allow the reader to evaluate the transferability of the research, the researcher has to provide the readers with a thick description of the research findings. In summary, transferability is the applicability of the results of the research in one context to other similar contexts and also the extent to which the study invites readers to make connections between elements of the study and their own experiences.

To ensure the transferability of this study, I used purposive sampling. The participants I chose were all parents with disabled children in public schools. They were chosen because of their representativeness of the population about which conclusions were made. The ethnographic styles were adopted through narratives in

different styles of writing to show that which was observed in the field. This will hopefully inform further research about the degree of “fit or similarity” of this research findings (Heron and Reason, 2001).

#### 4.7.2 Ways in which the Process can Support the Empowerment of Parents

Parents are given the courage to go against prevalent community attitudes by being made aware of their rights to get an education for their children as well as by being empowered to make choices and to solve the problems surrounding this education. In so doing they become advocates and activists for the rights of disabled people in the community. While direct assistance has been provided by the project, this assistance will not always be possible and so parents do need to be directed to resources especially those that are provided by government.

REHAB has played a vital role in providing a bridge between the school and the family and in motivating struggling parents. They have also helped link them with other parents and from whom they have been able to receive correct and relevant information.

#### **4.8 Limitations of the Study**

The researcher acknowledges the small size of the sample used in this study, which may limit generalisation of the findings to other parents of disabled children. The purpose was to gain insight into the experiences of parents with disabled children in public education. In addition, it might be possible that there are other themes besides those outlined in this study that could be found to be relevant to the experiences of parents with disabled children, in other levels of the education system.

Findings from this study suggest an area for further research with the hope that organisations working with disabled parents and institutions of academic development can draw lessons and a base for further research in the field of parent empowerment and support.

#### **4.9 Conclusion**

This chapter presented the research design and the methodology. The key concepts used in the context of the study were clarified. The process followed in obtaining data has been informed by the two main research questions:

1. What experiences do parents of disabled children have with regard to the education of their children?
2. How can parents of disabled children be supported to facilitate their active participation in the inclusion and retention of their children in public schools?

Chapter 5 focuses on profiles of the parents and their disabled children. Chapter 6 concludes with the identification of themes and interpretation of findings.

## **Part 2 Findings of the study**

In this section, part two of the study, findings of the interviews conducted with five parents, school meetings, focus group and reflective sessions are presented. The aim of the interviews was to investigate their lived perceptions and experiences in order to identify appropriate support for these parents in the process of engaging in the inclusion and retention of their children in public schools.



## Chapter 5: Profiles of Participants and their Children

This chapter presents a qualitative analysis of the interviews and school meetings. The parents' perceptions of their life journey are presented. In some cases these perceptions are voiced out clearly while in other cases, these are disguised as feelings of regret, pain and pride or lessons for which to be thankful. Some of these are not even mentioned, let alone expressed, due to the character or nature of the parent. In portraying the individual parents and their children participating in this study, this chapter will follow this sequence:

- background information of parent. This will cover life from childhood and motherhood to the point when the disabled child was born

the disabled child's profile

- the child's schooling
- the family support system
- reflections from the past: Parents' views of how their past experiences have shaped who they have become

For the sake of ease of reference, table 3 below shows the names of parents and their children.

*Table 3: Names of Parents and their children*

<b>Parent</b>	<b>Child</b>
Parent 1. Thandi	Libo
Parent 2. Molly	Tito
Parent 3. Grace	Mandy
Parent 4. Natty	Steff
Parent 5. Zandi	Sindi

### 5.1 Parent 1: Thandi

#### Introduction

Thandi was the 48 year mother of Libo. Besides Libo, her disabled child, Thandi had four other children. Libo was the youngest. Three were already married while the last two i.e. Libo (the last born) and her sibling (the fourth child) lived with Thandi, her husband, who is Libo's dad, and her father in law. The five of them occupied a two-roomed shack in a small community. The community in which they lived was a

squatter camp settlement about 8km from the East London city centre. Their shack occupied an area of about 40m<sup>2</sup> with the environment around not wheel chair friendly and therefore difficult for Libo to use it when at home. It was about 100m from the local school Libo attended before she was transferred to a special school.

In the group, Thandi was the quietest of the parents who participated in this study. She was one of those parents who went out of her way to avoid 'rocking the boat' when it came to addressing issues affecting her child at school. In one instance, she quietly decided to buy the material to install ramps and she and her husband went to put up these at school after educators had complained to them that the environment at the school was not 'safe' for her child to drive around in her wheel chair. She spent her week days at school to make sure that she was there to assist her child in order to access her classroom which was situated on the second floor of the building. It was this kind of experience with the mainstream local school that Libo attended that convinced Thandi of a potential for misunderstanding, hence her decision not to challenge the school when Libo was moved from the local school. This concern on the other hand, suggests a need to inform parents about inclusive education policy, school admission policy and procedure together with their role in decision making.

### 5.1.1 Life Growing Up

Thandi spent most of her life around East London. She grew up on a farm about 30km outside East London. Her grandmother was close to her heart as she raised her from childhood when her mom and dad lived separate lives in East London. There were four other children in the family and Thandi was quiet which meant that she struggled to make friends with children of her age group.

At school I was a very quiet person other kids would even say I am mean because I was a loner and I often hanged out with kids older than me. 'Nolunya' (proud or conceited person) was a name given to me because I was quiet and this name I did not like at all. (Thandi, Interview, 2011).

Thandi mentioned that she found it easier to make friends with those older than she was and looking back, she believes that she was looking for a mother figure or

parental guidance that she thought older friends would provide. Unfortunately things did not turn out as she thought they would:

..Being friends with them did no good to me but exposed me to drugs, I got addicted to drugs in a way that it was very difficult to stop. I was even taken to social workers who also could not help. Today I live a life full of regrets. I believe that if I never wasted my time on drugs I would have completed school. (Thandi, Interview, 2011)

When she was in standard 5 and became rebellious towards parental guidance, Thandi decided to leave school and she moved to East London where she met her first husband, who is the father of her first three children. Interesting to note is the role that the political situation played in the decisions taken by Thandi and her family with regard to the place where they lived. Although Thandi does not think that policies at the time, specifically the Group Areas Act, had much influence on her life, this did come up during an interview with her:

Because of the apartheid laws at the time (Group Areas Act) police used to give us a hard time. We were restricted in terms of places where we could be and the times when we could be in such places. It was mainly because of this that we decided to go back home to the rural areas (Thandi, Interview, 2011).

**Marriage:** Love, disappointment, perseverance, hurt, anger, surrender, faith and resilience in a patriarchal culture dominated society. These are the feelings Thandi went through in both relationships – her first husband and her current relationship with Libo's dad.

A few years after Thandi had moved back to her birth place where she married her first husband with whom she had three children. She recalls the challenging years she spent in that marriage. While talking about her marriage she explains that she was not married but rather 'traditionally married'.

Interesting to note also is the fact that Thandi relates the challenges in her marriage to the 'traditional' consequences and her quiet nature which she believes made her vulnerable. As far as she could remember, her husband never once gave her in her marriage gave her money to buy groceries. He would buy everything at the end of the month. Things became worse when her husband relocated to another town and sent money to his sister (Thandi's sister in law) to get groceries for them. Despite the situation, Thandi still persisted in her marriage until the time she discovered that her

husband who had not been home for about three months at the time, was living with someone else:

...we separated when he started cheating on me. I then found out that the lady he was involved with was related to me. That was when I decided to end the marriage. (Thandi, 2011)

When the marriage ended, Thandi decided to move back to East London where she met Vuyo's father (but never married him). However, because Vuyo's dad was in a relationship when she and Thandi met, that again became a very strenuous relationship for Thandi. Unfortunately, the man died while Vuyo was still small. As a result Vuyo does not know her father. Thandi recalled how she and her husband, Libo's dad got married.

Libo was already born when we got married it was not my intention to get married to this man because he was abusive and drank a lot. The mistake I made was that, in hospital I used his surname when Libo was born. I then left him because he was abusive when drunk. In that period, I then had to apply for a disability grant for Libo which I struggled to get as Libo was using her dad's surname. That's how we got back together again and got married. (Thandi, 2011)

Despite the challenges that Thandi encountered it is amazing how she still quietly pushes on in the different roles she currently plays, making sure that there is food on the table at the end of the day for her family, accompanying her father in law (who lives with them) every second week to hospital, and attending to school meetings and fetching Libo from the school hostel to spend time with them on weekends.

kunzima ukuba u Libo afumane umntu wokumnceda esikolweni yaye kwakulula ngexesha awayehlala nathi ekhaya kuba bendinalo ixesha lokumnceda kodwa andinakukwazi ukumthatha ahlale ekhaya ngoba kufuneka ndisebenze kuba utata welakhaya akasebenzi. Xa ethe wafumana lomalana kwijob ngezinye imini uyayisela nalo mali. Enye into utatomkhulu ujongwe ndim kufuneka ndimse esibhedlele ngemini zakhe for i-check-up. *(It is difficult for Libo to get support at school. It was easy for me to help when she stayed at home with us. However, it is not possible to take her from hostel as I have to find a job because my husband is not working. When it happens that he gets a job, he uses the money to buy alcohol. I also have a responsibility to take my father in law to hospital for his routine check-up)* (Thandi, Reflection session, Feb. 2012).

Thandi acknowledges that it was easy for her to assist Libo with school work while they lived together but the situation she faced at home made it difficult to take Libo from school to stay with them. Thandi had to do some piece jobs to support her family as her husband was unemployed and using the little money he sometimes

had to buy alcohol. Thandi was also the one taking care of her father in law and had to accompany him to hospital for routine check-ups.

### 5.1.2 Profile of Libo

Libo was a 13 year old girl diagnosed with spastic diplegia at the age of seven. Her mother, Thandi, mentioned that at five months she could tell that there was something wrong with her child since she could not sit when supported while all her other children had been able to at that age. She repeatedly visited the hospital to find out what was wrong with Libo but it was only at the age of seven that the doctors only told her of the main problem. She is so close to her mother that she sometimes worries about what she would do should anything happen to her mother:

When I am here at school it feels like something is missing. I think who is going to take care of me when she's not there and that's the problem. (Libo, 2012)

### 5.1.3 Schooling

Despite being unemployed and mainly depending on Libo's disability grant, the mother organised for the building of ramps at the school. The current class is on the second floor level of the school building and the mother has to take Libo up the stairs in the mornings when school starts, take her down to the toilets at break time and down again after school. The mother spends time every day after school to help Libo with school work and to keep up with the exercises that the physiotherapist requested Libo to follow at home. (A Caring Mother, Unpublished Article dedicated to Thandi, N. Tshabalala, 2006).

The quote above highlights the challenges experienced by Libo and her mother in the quest to get Libo educated.

Libo started school at the age of 8 after some months of her mother struggling to get her admitted to her local school. It was when a disability organisation assisted her mother in negotiating with educators that she got admitted to that school. Despite all the efforts mentioned in the above quotation (A Caring Mother), and a disability organisation's continuous support of the school, Libo was transferred to a special school, mainly because the educators had to protect the school in case Libo fell from her wheel chair while at school. Her mother, who not only willingly supported educators, but willingly assisted and was actively engaged in every school activity at Libo's school, finally gave up and agreed that her child belonged in a special school as long as she was in a wheel chair.

Libo has to live in hostel at her current school because of the distance from home to school. Thandi believes that Libo's performance at school dropped when she started attending her current school. This change she attributes to the fact that she can no longer assist her with school work and teachers mainly report to her that Libo needs additional help and this has been her major concern since she cannot assist her.

Libo on the other hand was clear in stating her challenges during a school meeting:

I remember for that short period of time then I quickly forget, my mind forgets easily, I can't think properly, I just get scared when my teacher asks me about the homework (Libo, 2012)

She believed it would help her when people became patient with her:

People must become patient with me. I often ask Thenjiwe to help me but I tell her not to write for me on my book rather on paper. I think it's better I go to the teacher and ask for help rather than me asking from my classmates who are not able to help sometimes (Libo, 2012).

It was interesting to observe as each person i.e. learner, educator and parent contributed during the discussion in trying to find solutions to the problems identified. Although the parent didn't say much, one could deduce from what Thandi said that indeed parents are the ones who know their children best:

I do agree with what is already said about Libo. She forgets things very easily. When I used to help her at home with homework before she stayed in hostel, I used to teach her and stop when I see she lost interest but she needs lots of patience and she forgets easily. I am not sure whether there is something that is wrong in her head that disrupts her thinking (Thandi, 2012).

At the end of the meeting everyone had a role to play. It was not about parent, teacher or the child. It was about 'us'. The action plan below testifies to the positive outcome unanimously agreed to after the meeting:

We agreed that Rose (educator1) will assist Libo after school with homework, Nontombana (educator2) will arrange with Thenjiwe (school buddy) and Nomfuneko (child care worker at hostel) to also assist Libo with school work when in hostel. Thandi assisted by Khaya will request advice from an OT at rehab regarding kind of professional support/intervention needed to address the problem with forgetting and writing (Teacher, 2012).

Interestingly, the plan was followed through as a result Libo's school results improved dramatically that term.

#### 5.1.4 Parent Support Systems at Onset of Disability

The impact of disability can place heavy demands on parents. Therefore it becomes crucial for parents to share tasks so as to avoid burnout when one parent finds him/herself doing everything alone. Unfortunately, there are some families who still follow traditional ways of doing things which means that mothers are the ones responsible for taking care of children. Societal attitudes towards fathers' roles still encourage this tradition. These attitudes can even cause division between parents and families.

When asked about the response of her husband at the onset of the disability, Thandi stated:

This caused pain to me; I doubt it caused any pain to him because all the time he got drunk he would swear at me about Libo's disability. When Libo was still a baby, we went to see a traditional healer in (town on coast) who told us Libo had a belt around her waist that made her back bones soft since she couldn't sit up straight. She always cried from 5h00 to 5h30 every morning and I tried everything but nothing worked. This traditional healer then told us that it was a neighbour that caused all of this (Thandi, 2011)

Asked whether she believed her use of drugs had had an effect on Libo's disability earlier on, Thandi responded:

Libo was affected because I remember I was still six months pregnant when I went on labour, actually both of them even her sister (Thandi, 2011).

Observations during home visits and discussions with Thandi confirmed the challenges faced by a mother of a disabled child when both parents are unemployed with existing male domination and where there is alcohol involved. Unfortunately, children also become victims in the process. The impact of such factors seems aggravated in cases where a woman finds it difficult to challenge the situation. This might be the result of lack of knowledge exacerbated by societal/cultural beliefs and socio-economic circumstances. This seemed evident in this situation. Thandi once stated:

...he is not her father. When he is drunk he tells her that Libo is his only child and I can see she does not like this but she is a quiet child, you barely hear her talk at home. I just leave him and remind him when he is sober but he doesn't want me to talk about that when I bring it up (Thandi, 2011).

Besides challenges facing Libo at school, she seems concerned about her mother's situation at home:

My mother is looking for a job but cannot get one as she is looking after my grandfather. She has to take him to hospital and they won't ask her if she's working and with the little cents, she has to buy the essential things that are needed at home so they can eat. My mom should go work that's what I wish (Thandi, 2011).

However, it was interesting to observe Vuyo assisting Libo with her school work when I met them. This shows the importance of family and sibling support not only for the child but as a source of strength for the mother too. The practice of 'Ubuntu (Ref. 1.5.1) was also evident in the way the community related to Thandi and her family. The community seemed to be very supportive. I observed Thandi arranging with the neighbours to assist Libo when Thandi had to go to meetings somewhere else.

## **5.2 Parent 2: Molly**

### Introduction

Molly, who was 32 years of age, was the youngest in the group. She was the parent of Tito. Molly had a full-time job and also had other businesses at home. She lived with her partner and two other children besides Tito, who stayed at school and only went home during school holidays. The area in which they lived was an informal settlement

### 5.2.1 Life Growing Up

Molly grew up living with her mother in the work place where her mother worked as a domestic worker. At the age of five, she attended a crèche nearby but when she reached school going age, she was not allowed to attend a white school and had to move back to (an informal settlement/township) where she was taken care of by her grandmother, aunt and uncle as she attended school. Molly recalled that she never had a good life, not living with her mother, until the age of 12 when her mother married and they ended up living together as family again. At the age of seven, Molly

experienced the tragic death of her older sister who was found raped and murdered a few days after she went missing.

Unlike Thandi, Molly managed to finish matric and started working immediately thereafter. She currently holds a management position in a firm in East London.

**Birth of Tito and marriage:** Tito was a premature baby who weighed 1.3kg at birth. This meant that Molly had to stay in hospital for three weeks after the birth. Despite the child needing her full attention and care, on the second week, she had to go back to work as she was afraid of losing her job, where she was still working at the time of the research. Molly was already married when Tito was born.

When Molly suspected something was wrong with Tito, the doctor initially told her that there was nothing wrong. It was only when Tito was 1 year, 3 months old that the doctor agreed Tito was hypotonic.

I asked the doctor how come I was not told that earlier just after I had given birth in hospital. The doctor then said that particular type of disability does not often show early in life but as the child grows. I was alone when I went to see the doctor as Lisa's father was at work. I was young I just cried. I was 22 years and I did not know what to do. I used to cry every day. When my husband came back from work that day, I told him what the doctor had told me and he comforted me (Molly, 2012)

**Marriage:** Molly lived with her three children, two of whom were fathered by her partner that lived together with them. She and Tito' (the eldest of the three children) father were divorced. However Tito was in contact with his dad and very and was close to the younger siblings that he lived with. Molly's partner seemed very supportive and had a close relationship with Tito. Unlike Thandi, Molly had a very strong character, a go-getter, very open and she often stood up for what she believed in. Her personality worked to her advantage when it came to expressing her concerns at school, at work and within her family, unlike Thandi whose quiet character worked to her disadvantage. It also made it very easy to determine situations when Molly was not following up on school matters regarding her child as a result of her not making time to do such things. Her standard of education and character often worked to her advantage.

### 5.2.2 Profile of Tito

Tito, aged 9 years, was born two months before the expected time, weighing 1.3kg. After birth, he had to be kept in an incubator for a period of three months until his weight was 1.8kg after which he and his mother were discharged from hospital. At birth doctors could not identify anything wrong with Tito and the mother believed everything was normal as they headed home from hospital. From the sixth month, the mother suspected something was wrong as the child struggled with head control. At seven months when Tito could not roll over, crawl or sit, even when supported, the mother decided to take him to the doctor but again no problem was identified except for delayed milestones.

It was only at one year three months when Molly decided once more to revisit the doctor out of concern for Tito's delayed milestones with specific to not being able to control his neck that Tito was diagnosed as hypotonic. By that time he was 1year 3 months old.

I asked them why they didn't tell us earlier when we were in hospital (Molly, 2012)

Molly believed that something could have been done to assist or prevent Tito's condition from deteriorating had the doctors listened to her and followed up with proper examinations when she had approached them earlier. This situation affected Molly's trust in the doctors.

### 5.2.3 Schooling

A neighbour whose employer had a disabled child introduced Molly to her employer. As a result Molly joined a parent support group that she is still part of today. Through a disability organisation she managed to get Tito to a day care centre at the age of three and to a mainstream school, though with major challenges involved.

At REHAB I was encouraged to take my child to a mainstream school and I took him out of a day care centre for disabled where he had been registered for the past three years, since he was three years old then (Molly, 2012)

Although the doctor informed Molly about Tito's impairment when he was diagnosed earlier, Molly still hoped that things would work out differently for Tito. She agreed that for some time after the doctor informed them of Tito's condition, she denied that Tito would not be able to do other things by himself until teachers brought this to her attention.

In 2007 Tito was admitted at a mainstream pre-school for grade-R. The only problem they had was that he was on a nappy and he could not use his hands and then we discovered that he is handicapped he cannot use his hands and I had to take the child out of that school as the teachers and the principal were not happy. I then took Tito to another mainstream primary school in 2008. (Molly, 2012)

For Tito, writing was a challenge as his reports continuously indicated. This led to Molly's taking the decision to take Tito to Valery, a special school where he was at the time of the research. Molly hoped that things would work out better for Tito when she decided to take him to a special school. However, she still continued to face challenges:

Valery is a good school for him and they have accepted him as he is. The only problem I have is that Tito's muscles became stiff since he started school there. I am not sure whether it is the wheelchair making the muscles more stiff. The program he used to attend at REHAB was also good because children had time to exercise (Molly, 2012).

In one of the school meetings, the educator was confident about working with Tito:

In terms of oral work, I am happy with Tito I don't know with the other teachers. He has a problem with his arms getting stiff I think it is because of the muscles of another arm is not even working. I don't know if he needs to see a physiotherapist but since the schools started this year, none of the physiotherapists have been here at school. Another thing that I have noticed is that Tito is growing and as he grows his muscles seem to be getting stiffer.... Did you notice Tito's arms are still stiff, Molly? (Educator, 2012)

Interestingly, Molly seemed aware of what she wanted for her child and like any parent, she knew her child better than anyone else. She knew who to contact for advice but the challenge seemed to be managing with all other things she had to do:

He has been like that he does not want to stretch his arms, I always train him at bath time or when he gets dressed but he does not want to stretch. He is supposed to attend physiotherapy every day. It made a difference to Tito when he was seeing an OT. My wish is for him to find a kind of a device that will assist him to be able to write. (Molly, 2012)

In one of the meeting sessions I had with her two months after the school meeting, this is what she had to say about Tito's situation at school.

I am waiting for the renovations to be done if the things don't go well I will go back to school and complain and tell the Principal about the child situation here at school and at home and ask if anything that they can help me with or she can speak to the care givers. About her future I am in the process of phoning the OT that I can hear her views and get some advice on what I can do. (Molly, 2012)

It seemed that the many activities she was involved in, like running a number of businesses from home and having a full-time job, made it difficult for her to make time for everything. Reflecting back on her life growing up, it emerged that Molly was also challenged by the desire for her children to live a better life than she had. She found herself spending time away from her children;

Sometimes I feel guilty when I spend more time away from my children and memories of the times I spent alone when my mother was working keep flashing. I then remind myself that as long as my children are well looked after and as long as I am building a better future for them that is fine. (Molly (2012)

#### 5.2.4 Reflections on Own Life

When I think back, I realize I never grew up comfortably. I struggled a lot so I told myself that my children will never experience what I've gone through. I also told myself that I will never let my children live with someone else, I know what it's like and I experienced it. "...that's why I told myself I will never have my child raised by other people. (Molly, 2012)

#### 5.2.5 Parent Support system at Onset of Disability

Molly's family had been the major source of support to her in raising Tito. At the onset of disability, Tito's dad with whom Molly was living at the time was very supportive as was her partner after the marriage ended.

### 5.3 Parent 3: Grace

#### Introduction

Grace was 50 years old, a member of the school governing board, a child carer at a day care centre for disabled children and the single mother of Mandy. Born in a township in the Eastern Cape, she spent most of her childhood years in the rural

areas of the former homeland where she lived with grandparents and other family members. Grace lived with her two children, Mandy and her older brother in their family home. A few years earlier, when she went to apply for Mandy's admission at a day care centre nearby, she managed not only to get Mandy admitted in that centre but also to secure a job for her. She was still working there at the time of the study.

### 5.3.1 Her Life Growing Up

Growing up, we stayed in homeland with my grandparents and it was a very unpleasant experience but both my brother and I grew up there. My parents used to work here in [a town] hence we had to stay with grandparents. (Grace, 2012)

Grace believed that her parents' absence and reliance on others to take care of them when they were growing up had been such a challenge that she still found herself grappling with issues arising from it. She strongly believed that because of the challenges she experienced growing up; she often found encouragement to persevere when faced with challenges in raising Mandy.

That's why I told myself I will never have my child raised by other people. No matter how hard things may turn to be I asked God to give me the strength to raise my own children. (Grace, 2012)

**Marriage:** Grace had never been married. Both of her children have different fathers who are no longer in contact with them. With Mandy's father being married, Grace found it difficult for her to contact him when she needed help regarding Mandy.

He was so supportive when we were together by the time we discovered Mandy's condition. The only problem was that he is a truck driver so most of the time he is away and he is a heavy drinker. Hence I decided not to rely on him but take care of my child. (Grace, 2012)

### 5.3.2 Profile of Mandy

Mandy was born in 2000 and diagnosed with Cerebral Palsy with athetosis (hypotonic spastic quadriplegia) at five months. Grace believed that the fact that Mandy suffered neonatal jaundice affected her development; and she was born with hypotonic spastic quadriplegia. This condition affected her physical and speech development. Mandy often uses hand gestures to communicate her needs.

In an attempt to identify a suitable device for Mandy's communication needs, Mandy participated in an Augmentative and Alternative Communication program (AAC) facilitated by the University of Pretoria in 2008. Findings from that programme indicated that Mandy was an intelligent child. However educators found it difficult to understand and to communicate with her. Mandy's movements were a concern to the educators but they showed that she was trying to participate during lessons. As a result of the assessment, a computer program with a head pointer was designed with the intention of her using it at school to aid communication between educators and Mandy and everyone around her. It was interesting to note that while going through Mandy's files at home and REHAB in 2005, three years before she attended the AAC program in Pretoria, two reports from different therapists who had also seen Mandy recommended the same programme but the programme had never been implemented as educators and the mother also needed training for them to assist Mandy.

That seemed to have been the main setback in Mandy's progress as at the age of 12 she was still in grade 2.

Mandy's teachers in the years 2011 and 2012 had both admitted during school meetings that they had not been able to communicate with Mandy. However, they noticed her interest in participating when she made movements when they asked questions in class. One of the educators mentioned that she tried to accommodate Mandy by asking her questions that only required a yes/no answer and in most cases she gave the correct answers to questions posed to her. The same educator mentioned that she found it difficult to work with the mother as she often seemed so demanding:

I don't think I want to meet with Mandy's mother because she has unrealistic expectations about Mandy and she expects us to know it all..... The only thing that can help is when the teachers are trained on Lindo's program so that we can be able to teach her using that program here at school, not the way things are happening at present that the OT only works with Mandy not involving her teachers. (Teacher, Feb 2012)

Throughout the years of working with Grace, I often found her overwhelmed by Mandy's situation. Although she expressed much anger towards the Department of

Education for not intervening to assist in Mandy's situation, she somehow did not feel confident to 'speak her mind out' when an opportunity existed for her to meet with relevant officials from the Department. She also seemed confused when it came to making certain decisions around what was happening at school. In 2009, while trying to address the same school problem, she managed to secure a place for Mandy in one of the mainstream schools in East London. A national organization working for the rights of disabled children offered to support by paying an assistant educator to assist Mandy's educator in the mainstream school. However, a few days later, as Mandy was about to start in the new school, Grace changed her mind because the Department had arranged an appropriate school for Mandy to attend. Later on she found out that the school was out of town with no accommodation which meant that she had to move with the child so as to take care of her. That meant that Mandy had to remain in the school she was in as the mother could not leave her job and find accommodation for the two of them as this would mean she would not be able to work.

Despite feeling confused and desperate, Grace appeared to be able to voice her frustration during some of the school meetings. In response to the teacher's comments about Mandy's progress at school she responded:

The fact that she gets promoted to the next grade because of her age does not sit well with me. I'm not expecting miracles to be performed on Mandy but at least the effort of trying. (Grace, 2012)

### 5.3.3 Parent Support System at Onset of Disability

Grace was very close to her grandmother while growing up. Both her father and grandmother died in the same year when her child, Mandy was five years old. A year later, her mother whom Grace and her two children were living with, also died. Grace was then left with her sister who remained the main source of support to her and her children.

I was so close to my sister because there were hard times and she used to support me when I struggled raising up Mandy. I don't blame anyone for what happened because it was God's plan and my child's health does not stress me anymore. The only thing that stresses me the most is when I ask for help from someone and that person looks down on me knowing that they are my only hope, but God always helps me. (Grace, Jan 2012)

Grace also found the parent support group a place where she could share challenges and learn from other parents who also had disabled children.

The support group has helped me a lot with regards to handling a child with disability. You get views from each and every parent. Sometimes even if I am busy I cannot make it to the meeting I get worried because my heart is there.  
(Grace, Jul 2012)

#### 5.3.4 Reflections on Own Life

Despite Grace's positive outlook at the challenges she went through in life and the belief that such made her the strong person she developed to be, she was overwhelmed by challenges at school. She appeared more confident to speak out when there was someone to support her in meetings at school. She found teachers' negative attitudes very threatening and most challenging for her interacting at school.

### 5.4 Parent 4: Natty

#### Introduction

Natty, the mother of Steff, was the only one in the group who was not Xhosa speaking. Her mother tongue was Afrikaans although she had some understanding of the Xhosa language which she acquired while growing up and spending time with Xhosa speaking people. Natty knew everyone in the group as she had been part of the group since 2007.

She grew up living with both of her parents and had very good memories about life growing up. She spent a few years after school "working and just enjoying life with no children". Natty met her partner, the father of her two children, Steff and her older brother, soon after school when she started working. Since then, they had been living happily together with their two children although they were not married.

#### 5.4.1 Profile of Steff

Natty recalled memories of how the nurses and the doctor who delivered her baby, made her realize something was not "normal" with her baby as she waited eagerly for the nurses to bring back her new born baby soon after she had given birth. She did not see anything wrong with her baby when she held her in her arms after the

birth but the response she received from the doctor and the look from the nurses made her feel something was wrong. She remembers how the nurses and doctor took a long time to bring her baby to her and how the doctor felt uncomfortable talking to her about the fact that her baby had Down syndrome.

I believe that had the doctor and the nurses responded 'normal' and perhaps just told me that my baby had Down syndrome, I could not have felt so uncomfortable as I did while in hospital and really for me it felt like that doctor was inexperienced or rather acted unprofessional by the way she handled that situation. They made me feel that my baby was not 'normal'. (Natty, 2012)

#### 5.4.2 Parent Support Systems at Onset of Disability

Natty regarded her entire family, the Down syndrome organization and REHAB as the main sources of support to her.

Despite the fact that people stare at you and your child everywhere you go, my family had been so supportive. My mom has been there for us not to mention my sister whom up to now still considers Steff her own child, doing everything for her. (Natty, 2012)

She joined the two organisations when she started encountering challenges with Steff's admission to school. I also started working with Natty and Steff in 2006 when she approached REHAB for support for the retention of Natty at a mainstream school where she was doing her grade-R and in her application for primary school the year that followed.

#### 5.4.3 Current Situation with School

It had been a very challenging time for Natty with regard to Steff's schooling since the last term in 2011 when she was informed by the school and the by the Department official that Steff was not supposed to be in a mainstream school. With Natty's determination, the problems that teachers apparently had with Steff's being in a mainstream school could easily be addressed. Her main concern was the fact that the school was supposed to have contacted them as the family/parents of Steff when they identified challenges and not just take the decision that Steff was supposed to be in a special school. There seemed to be a lack of knowledge or understanding amongst teachers around the policy on inclusive education and the role that teachers

were to play. As a result, the feeling of trust and confidence of Natty towards teachers was challenged.

I do not remember a single day that teachers approached me to tell me they have challenges and how I could assist them, but they just decide that my child needs to be in a special school. They cannot even tell me what inclusive education is about and whether they are implementing that at school as they do not even know about it. (Natty, 2012)

Natty was also frustrated to be told by a Department official that *inclusive education does not work in the Eastern Cape*. There were times when a special school seemed an option in order for Natty to be relieved of the pressure she was feeling with regard to the retention of Steff in her local school

To be honest..., I sometimes think if it's worth fighting or should I just take my child out of that school. I feel drained and it is so painful. (Natty, 2012)

School meetings were characterized by tension and heaviness and a distant feel between parent and teachers. The parent appeared frustrated and very cautious of what she had to say every time she had to raise her concerns about Steff, as if avoiding responses that she wouldn't like to hear from the teachers. The first school meeting was a very uncomfortable and tense meeting. The school principal did more talking than the class teacher.

It is not easy to teach Steff because it is difficult to understand what she is saying when she speaks. (Principal, 2012)

Enquiries from Natty about how she could help seemed unwelcome and Natty kept on being referred to the Department as Steff was regarded as not suitable for mainstream school. The school remained uninterested in the support offered by Natty regarding working with Steff. Sitting there and observing how the parent and teachers were relating to each other I could sense such heaviness on the parent's side. The atmosphere was not welcoming at all

The only action plan from that meeting was that the mother had to contact the Department for Steff to be assessed. What seemed unclear to Natty was that in the previous meeting she had had with someone from the Department, she had been

told that Steff needed to be in a special school. Natty was also concerned about the lack of parent consultation when decisions were made at school about the child:

I was shocked to find this report in my child's school file when I insisted to know what was it that they have done to assist my child rather than referring her to a special school .... The report indicating that she was assessed by the psychologist was never communicated with me and that is not acceptable to me. (Natty, Oct 2011)

At the end of the meeting everyone left as if the parent and teacher did not even know each other. As we stood outside reflecting on the meeting, I could see how Natty was hurting. I could see her eyes full of tears and I was also feeling her pain. Suddenly I experienced the same feeling she had shared with me earlier that she must just take Steff out of that school but my senses returned and I reminded myself that it was all about attitude. I thought to myself:

If a poor school like Sindi's (See 5.5.1, Profile of Sindi) could accommodate parents and add up their resources in an attempt to create an inclusive environment, definitely a school like Steff's could do it too. (Researcher, Oct, 2011).

The following meeting at school was different from the first one. Steff had a different teacher who was doing her best to include her in class activities. Unlike at other meetings, the teacher and the parent talked openly about the challenges that the teacher and Steff were experiencing while the teacher took time to go through Steff's class work with the mother. Despite her positive attitude, she made it clear that Natty needed to think about what was going to happen with Steff the following year as the school could not hold her back due to the age difference between Steff and the children who would be in her class.

Although Natty was informed that Steff would be transferred to a special school the following year, she was admitted back to her school that year and although the grade was the same, the teacher was different.

Steff is settled in for speech sessions and I will see how much it works out per month. The speech therapist is willing to drop the consultation rate for Steff. I'll check her progress at school tomorrow. I said to the teacher I'm not mourning because she was not there when Steff was in grade R. The grade 2 teacher battled because she was trying to teach her grade1 work still, and she really tried. (Natty, 2012)

These are the challenges that Natty continued to face at school. As indicated, teachers and the Department went on neglecting the parent in decisions taken that affected the child at school.

#### 5.4.4 Reflections on Life

Life has been very challenging for Natty, in particular with the education of Steff. Sharing about challenges that she had been through, Natty recalled the day Steff was born when the doctor made it clear to her that something was really wrong when he took a very long time to bring the baby to her after she had been delivered. The way the doctor and nurses acted when they avoided talking to Natty while she waited eagerly to hold the baby in her arms made Natty to feel very uncomfortable. For her that experience alone made her realize the role people play in labelling others as “abnormal”. Natty believes that had the doctor acted differently, she wouldn’t have seen anything different from her baby as for her Steff looked the same as any other child when she held her in her arms for the first time. Natty’s experience with the doctor also made her lose trust and respect for that particular doctor.

Natty regarded the kind of support received from her entire family, the local disability organisations and the parent support group as the source of strength and the main reason she managed to overcome challenges at school. The fact that she was of a different colour to other parents participating in the study, who she had worked with since 2006, made her feel good and she used her situation to show other parents that it was not about colour or race - that they were going through challenges.

### 5.5 Parent 5: Zandi

#### Introduction

Zandi is the eldest sister of Sindi’s mother; however Sindi knew Zandi as her mother as she had taken care of her since she was nine months old when the mother suffered severe depression. For the sake of this study Zandi is referred to as the mother of Sindi. Zandi worked as a community rehab worker for the Down syndrome’s association. Her duties involved identifying children with Down syndrome

in her community and educating parents, schools and the community at large about disabled children specifically with Down syndrome. Zandi was very passionate about her work and believed she was born to do what she was doing at the time. She loved children and her experiences gained while raising Sindi had prepared her for challenges she faced in her job as a community worker for the disabled.

Zandi grew up in a family of 9, raised by her grandmother with all the grand children living together in one house. She recalled how the grandmother used to love her.

In the family I was the bright kid amongst everyone else. My grandmother used to like me a lot as she knew wherever she would send me; I would come back quick and bring everything as requested. (Zandi, 2012)

Just after completing her matric, Zandi fell pregnant with her first child. She considers her pregnancy the reason why she did not do well in her exams, although she managed to pass Standard 10 (Grade 12). When she realized that she was pregnant she left East London for Cape Town as she did not want her father to know that she was pregnant. The father was a very strict person and Zandi did not want him to know of her pregnancy. She then started working as a domestic worker after the birth of her first child. She then moved to Welkom where she got a job and it was while in Welkom that she fell pregnant with her second child.

In 1998 I had my last born, the fourth child, at the same year my younger sister gave birth to Sindi. I was then informed while my sister was still in hospital, after giving birth to Sindi, that she wanted to kill Sindi just because she had a light complexion. That's when I decided to take care of Sindi. (Zandi, 2012)

Sindi was nine months when Zandi started to take care of her. She was unemployed with four of her own children and had to rely on a child support grant for Sindi.

#### 5.5.1 Profile of Sindi

Sindi was born on 24 November 1998 in East London. Her mother is the youngest sister of Zandi. Zandi, the guardian of Sindi, here referred to as parent, took care of Sindi from the age of 9 months as her mother suffered from depression.

School meetings were attended by all of Sindi's grade teachers as they saw it important for them to help build a better relationship with Sindi. Despite the majority

of teachers looking forward for these meetings, one of the teachers seemed irritated and somehow negative during the meetings. It seemed as if she did not quite understand or agree with the purpose of the meetings. This is the comment she made during the meeting:

I just hope that you do not expect us to treat Sindi different to other children here at school. She must also know that she is of no difference to others here.  
(Teacher, School meeting, 2012)

It was interesting to note how during the third meeting every teacher, including the one who had been that was negative in the meeting before this one, seemed happy about Sindi's general performance, academically and socially. Sindi was above average in all of her learning areas during the first term. The teachers spoke highly of Zandi's involvement and the support she was offering Sindi. In the presence of all the class teachers (5 of them), Sindi freely participated and responded to questions where clarity was needed in terms of the support she needed.

#### 5.5.2 Parent Support Systems at Onset of Disability

Zandi did not get any social support in the community where they live with regard to Sindi. However, her children have been very supportive and accepted Sindi as their sister. Even today, most people know her to be the biological mother of Zandi. Both REHAB and Down Syndrome's Association have been the source of support. The school is now like a second home as all the teachers so supportive. Sindi also has a number of friends at school.

### 5.6 Conclusion

In this section, the data from interviews was used to compile profiles of the five parents and their disabled children including their schooling together with parent support systems at onset of disability have been presented. The intention has been to provide a picture of the lived perceptions and experiences in order to identify appropriate support needs in the process of engaging these parents in the inclusion of their children in public schools. Below is a summary of themes generated from parent interviews. These will be explored in detail together with findings from focus group and reflective sessions in the next Chapter 6.

## 5.6.1 Summary of Themes

### **Life growing up**

With the exception of one, all parents had difficult lives growing up. Their positive outlook in life encouraged them to focus on the lessons rather than the experience of pain and struggling. Similarly, they believe the lessons prepared them to withstand challenges they are often experiencing as parents having to go an extra mile to get their children accepted as who they are.

### **Their children and learning that the child is disabled**

Learning for the first time that the child was disabled evoked different emotions (denial, shock, anger towards doctors for not listening when the parent reported of suspecting something was not right. As a result the thought that the child could have helped if doctors acted earlier doesn't go away. Seek help from traditional healer and also kept trust that the child's condition will improve with time. Almost all of the fathers of the children distanced themselves including the in-laws but families support encouraged mothers. Ultimately mothers believed they had to take care of the children and be there for them. It is the reaction of others towards the child that make parents make parents to see their children as different to others for instance the reaction by doctors and nurses in delivering the news that the child is disabled.

### **Schooling**

For all parents it was a challenging getting the children admitted in local schools, as much as they were still struggling to get them retained. Three of the parents gave up and agreed to move their children to a special school mainly because children used wheel chairs.

### **Reflections on parents' lives**

Difficult times experienced at childhood made them to come out stronger and the resilience makes it possible for parents to overcome challenges in their lives. They are doing the best to be there for their children so that they cannot go through hardships as parents did.

**Parent support**

Families, local community and parents support have been the main source of support.

## Chapter 6 Creating Footpaths for Parents' Participation in the Education of their Children



## 6.1 Introduction

This chapter presents the findings of the study as a basis for creating footpaths for parent participation in the education of their children. Findings will be presented according to four themes analysed across data from eight different sources, namely: individual interviews, focus group sessions, narrative action reflections, school meetings, participant observation, field notes, learner progress reports and the researcher's reflective journal (observations and field notes). During data sorting and preliminary analysis, a larger number of themes emerged from the full the corpus of data generated during the course of the study. For the presentation of findings, I have selected only those themes that keep the focus on the aims and objectives of the study as stated in Chapter 1. Themes not included here present possible areas for future work arising from this research.

**Table 4** outlines the four themes presented in this chapter. I identified the four themes and differentiated each theme by means of various sub-themes and categories. Categories were phrases recurring across the sources of data and were thus taken as confirming prevalence of particular kinds of experiences. Categories, as presented in my findings, indicate parents' actions or responses as a result of lessons/experiences indicated as sub-themes. Findings for each theme are presented in a narrative, descriptive format, and supported by relevant verbatim quotations (mainly sub- themes) from the transcribed interviews. The findings are compared and supported by field notes. Table 4 below presents an outline of the main themes, related sub-themes and categories of parents' responses and actions.

*Table: 4 Themes Identified from interviews, meetings and focus groups with participants*

Theme	Sub Theme	Category
<b>1.Growing up</b>	Tough and unpleasant experience	Protect their children Work hard Want to be there for children
	Taught us crucial life skills	Ability to work with others Resilient Responsibility
	Teacher knows better	Self-doubt, lack confidence to challenge teachers
<b>2.Stunted involvement of parents</b>	Teacher never communicated with me Teacher avoids me	We feel undermined Taken for granted We get blamed/accused of

Theme	Sub Theme	Category
		neglecting our children Children suffer We get confused
<b>3. Inadequate awareness and information about the policy</b>	You don't know what to say to the teacher	Parents are frustrated and confused
	They had no clear idea of what it means Advise where we can get help	Teachers are frustrated
	We cannot do anything to help... we are just wasting time	Resort to special schools
<b>4. We live busy demanding lives</b>	Need income	Not supported by employers Struggle to attend school meetings during the week
	Not always with my kids	

## 6.2 Growing Up

Chapter 5 (Life Growing Up) details the stories of parents from childhood. Each story tells of how tough and unpleasant experiences influenced parents' relationships with their children, how they were protecting, working hard and striving to be there for their children so that they (children) would not experience the difficulties they had had to go through in their childhood. In this section, I draw out commonalities and differences in parents' experiences of growing up and how these experiences shaped them as parents of disabled children. I do this by using additional quotations from the full range of data sources (outlined in the Introduction of this chapter). All of the parent participants, except one, were raised by their grandparents or other members of their extended families. They grew up under very difficult circumstances that pushed them to be independent early in their lives. Memories of hardship sometimes made the parents reluctant to speak of their experiences of growing up. I remember feeling uneasy, yet eager to hear what Grace was about to tell me when I requested her to share experiences about her life growing up and she responded:

.. you are making me talk about one aspect of my life that I don't like talking about but it doesn't matter. (Grace, Interview Jan., 2012)

Grace and her siblings were raised by their grandparents in rural Transkei even although their parents were still living:

Growing up, we stayed in Transkei with my grandparents and it was a very unpleasant experience .... My parents used to work here in East London hence we had to stay with grandparents. (Grace, Interview, Jan., 2012)

For Molly, the death of her father had left her in the care of her grandparents and other relatives:

I lived with my grandparents, uncles and aunts... We were not treated well .... My father passed away in 2005, I was still very young such that I don't even remember how he looked like. On my school shoes I used to put Vaseline to get them to shine. Not that we did not have shoe polish but it was hidden so that we couldn't find and use it. (Molly, Interview, Feb., 2012)

Sindi only got to know her mother at the age of 15:

I never knew my mother hence I'm not talking about her. I never got to spend time with her while I was growing up. I only got to know her when I was 15 years. She left me while I was still very young because of work. (Sindi, interview, Dec., 2011)

Unlike others, Natty was raised by both of her parents whom she regarded as the source of support. They were still a support to her when Steff, her disabled daughter, was born (Ref. 5.4).

### 6.2.1 Tough and Unpleasant Experience

This sub-theme indicates parents' perceptions of how their experiences of growing up shaped them personally and influenced the kind of parents they became. As a result of growing up under difficult circumstances, they believed that it was important for them to see to it that their children did not experience such hardships. They also believed that their parenting styles had an effect on how they related to their disabled children and, in turn, indirectly on the way they related to teachers and Department officials. Like elephants protecting their offspring, these parents were fierce in protecting their children from being discriminated against in schools.

During one of the narrative sessions, Zandi reflected on how she believed her experiences of growing up affected the way she related to and raised her disabled child. Her determination to be 'the best Mom' also changed the way in which Zandi related to her daughter's class teacher:

The way I grew up is different from the way I raise my child because I had tough time , so I decided that I don't want my kids to experience what I went through. I open up to them about my feelings, guide them for better future. ... I want to be the best Mom they have even if I'm not with them. I built a relationship with her (daughter) by accepting that I failed to support her earlier at school because of lack of knowledge. So I ask to work in partnership with the class teacher by informing me about what they did in class so I can assist my child... Every week

I visit school to discuss where we need to focus on. (Zandi, Reflective session, June, 2012).

Although parents were certain that they were doing the best they could to be there for their children, in reality, they were often physically absent from them, as this quotation from Zandi's story suggests (*I want to be the best Mom...even when I'm not with them.*).

### 6.2.2 Taught Us Crucial Life Skills

Through difficult times parents also believed that they learnt crucial life skills that developed their resilience. Their very ability to draw the 'positives' out of the challenges they experienced while growing up was an indication of resilience. Profiles in Chapter 5 indicate how parents managed to rise above the challenges of raising their disabled children and to make sure they gained access to schools.

In one of the school meetings when we were discussing different ways of addressing Sindi's difficulties in seeing what was written on the faded chalkboard, Zandi tabled the following suggestion;

....with the paint that was left over from last year, I think I can use my skills to paint the board (smiling)... kaloku sikhule sipeyinta ngokwethu emakhaya intsha lento yokwezelwa yilonto silibaziseka these days. (*Meaning we grew up painting our own houses in any case it is new to us that we now have to wait for others to do things for us hence things delay to get done*). (Zandi, School meeting, Feb., 2011)

*Zandi's suggestion prompted me to note a similar initiative where a different school was considering moving Libo from her local school to a special school mainly because the school was not accessible for her wheel chair. Tapping into her life skills developed during childhood, Thandi (the mother) took initiative to build ramps with the assistance of her husband (Researcher notes, Feb, 2011)*

Like elephants standing up for others, parents appeared to have built a strong bond while working together throughout the period of the research. They related their ability to work together to their culture when growing up (Canney, 2010), who spent some time studying elephants in her quest to understand how they live, observed a group of about eight elephants standing around over a period of four days, apparently watching over the body of a dead elephant, which they covered with soil

and branches. On the fourth day most of the group moved on but one remained for another four days before moving on. For Canney (2010), this episode was a clear indication that elephants remain committed and loyal to one another even at the time of death.

Among the parents who participated in my study, the experience of growing up in bigger families and in the absence of their parents taught them the value of Ubuntu (humanity) especially with regard to the importance of living with others, sharing and supporting one another, especially in difficult times. Extended families took care while parents had to work in different places to where they lived and while others were not well (5.3.3; 5.5.2). Khoza (2005:266) defines Ubuntu as “a concept that views humanity in terms of collective existence and intersubjectivity, serving as the basis for supportiveness, cooperation, collaboration and solidarity”. This was evident from interviews with parents. Parents based their ability to work together on the awareness that things might be difficult for them and their children but their efforts to change the current situation would surely benefit generations to come. They also realised that just “as it takes an elephant to take another elephant out of a pit”, so their experiences would serve as lessons to those who might be in the same situation as theirs.

You know sometimes I look back and wonder how I would manage to do all that I have to do without the support group..... Though we come from different homes we understand each other and God knew I needed the skills from different people I lived with ... (Molly, Focus group. July, 2012)

I remember having to share a bowl of food as children sometimes we would be 5/6 sharing a spoon and yes by the time we finished eating everyone would be full... so ja its true what Molly said we needed such experiences to work together even dealing and working with teachers...(Grace, Focus group, July 2012).

Natty was from a different culture. Although she grew up in a small family she mentioned that growing up most of her friends came from a Xhosa culture and she learnt a lot from the way they did things and more specifically she learnt how to live and work with other people. She attributed her ability to work with others as a skill she developed at the time of growing up with friends who were from different cultural backgrounds. She also related her ability to draw strength from and to work well with other parents in the support group from such experiences:

I learnt how to speak Xhosa from my friends that I grew up with, I can now understand when you speak in your own language here and even at work I am able to assist the clients ... I am empowered just thinking about the challenges we share and seeing how others struggle ... I tell myself, if they can so can I. (Natty, Interview, Feb, 2012)

One parent believed that she learnt to be a responsible parent from the harshness of her upbringing.

From what we experienced when we grew up, we learnt how to be responsible even though they were hard on us but they helped us to be who we are today and now we are working hard for our children to have great lives. (Mandy, Reflective session, June, 2011)

The experience of growing up in the absence of her parents made Grace determined that she would personally take care of her children and make sure that she would be there for them no matter how difficult situations turned out to be (5.3.1).

### 6.2.3 Teachers Know Better

A negative aspect of growing up in the culture they did, was that parents believed that it affected their ability to confront teachers on issues. In an African culture, more specifically the Xhosa culture, a younger person is expected to show respect to anyone older than him/her. From a very young age, children are taught to act in a way that shows respects towards an older person by the way they talk and respond to such an extent that it becomes difficult to argue with an older person even when necessary. Similarly, this kind of relationship is encouraged when it comes to gender and different professional roles. Girls are expected to behave differently from boys, while people tend to show more respect to an educated person than to someone who is uneducated. Even within professions, there are those seen as better than others.

In general, a teacher would respect a nurse or a doctor when it comes to health related issues and a nurse or doctor would act the same way towards a teacher as regards education matters. One can imagine how difficult it is to challenge issues at a later stage in life having been raised within this cultural practice. This seemed to be the case with parents in this study, most of whom couldn't afford the education they needed.

Parents grew up believing that teachers know better and only they could deal with education issues. As a result they found it very difficult to challenge teachers about issues that they felt were of concern regarding their children and things that affected their children at school. This was the area where they felt their self-esteem was at stake.

I could see how uncomfortable Thandi was when I recommended that she told the teacher about what they had found helpful in addressing Libo's short memory span. She responded;

Yhu! ...andinawkwazi (Whew! I just cannot). (Thandi, Nov, 2011)

Researcher: *"Why do you think so?"*

Kaloku ngu titshala ndizobangathi ndimxelela afundise njani (Being a teacher, I will appear as telling her how to teach), I don't have a problem saying that in our school meeting. (Thandi, Interview, Nov, 2011)

Molly felt that there was no reason to argue with a teacher when s/he says a child was ready to progress to another grade despite the fact that she, the parent felt unhappy about the child's progress:

Who am I to tell a teacher about what to do...as a teacher she should know better... (Molly, Focus group, Feb., 2012)

Zandi sat quietly when a teacher sarcastically passed a comment during a school meeting. The teacher pointed out that she was struggling to understand why they had to focus on issues affecting Sindi and not doing the same for other children. In reflecting about the meeting later that day with Zandi, I enquired about how she had felt and why she had decided not to respond to the teacher when her facial expression suggested her disapproval. She responded:

I learnt that I rather keep my mouth shut at times when I see that nothing I will gain from a negative person, especially when you don't what to expect from people like that teacher (Zandi, School meeting, Jan, 2012)

Researcher: You appeared as if you wanted to say something when I looked at you while the teacher was talking, what were you thinking at the time?

To be honest I was disappointed to hear what she said as I thought that she was interested to assist when she joined the meeting..... by the way I often found that she was very unfriendly being one of Sindi's teachers last year. .. you don't know what to expect from them sometimes. (Grace, Interview, Jan., 2012).

It was evident from the stories shared by parents about their lives that they were working hard to be able to provide and to secure a better life for their children, that which for most of them was a dream that couldn't be realised during their own childhood. It was interesting to listen to, and to visualise how colourfully they were able to paint stories of their lives as they were growing up and to view their experiences of hardships as sources of encouragement to themselves and others to rise above difficult situations in their lives. It became clear that in engaging parents in the process of building an inclusive education system, we needed to understand where they had come from as their childhoods informed the kinds of parents they had become.

### **6.3 Stunted Involvement of Parents**

Parents found it difficult to engage in school activities due to the negative response they often received from teachers. Different reasons were attributed to stunted involvement of parents in schools. The general feeling amongst parents was that there was lack of communication by teachers with parents about issues affecting children when decisions were made in schools and parents were often not welcomed when they visited schools. Some of the parents attributed this to unclear role expectations and resistance of teachers to change.

#### **6.3.1 Teacher Never Communicated with Me**

Parents felt that it was important for teachers to communicate with them about issues and actions that would impact on their children, yet commented again and again on teachers' failure to communicate. During an interview, Natty commented on her shock at discovering that her daughter had been given a psychological assessment at the school:

I was shocked to find this report indicating that Steff was assessed by the psychologist which was never communicated with me ... (Natty, Interview Oct., 2011)

Another parent expressed disappointment in learning during the school meeting that the teacher would have preferred to have kept her child back in the same grade the previous year. However, that idea had never been discussed with the parent:

I am surprised to hear that you wanted to keep Lisa behind in grade1. No one has ever told me about that from the school and if I knew of your intentions, I would have definitely agreed to that as I am not happy that he is promoted every year while there is no progress with regards his learning. (Molly, School meeting, Feb., 2012)

By contrast, although Natty had expressed her concern that teachers were not informed as to what they were supposed to do to support disabled learners, during the school meeting she did not raise her concern about what the teachers were doing to support Steff. She also made no attempt to find out whether there was an area where they needed her support as a parent. When I asked her about this, she sarcastically responded:

I decided to wait and hear what they wanted me to do that I can just do what they tell me to as long as it pleases them... they believe they know better in any case (Natty, interview, Jan., 2012)

The quotation above shows how lack of communication stands as a hurdle in the process of parents and teachers working together. Parents do not know what teachers expect from them *“I decided to wait and hear what they wanted me to do...”* as a result and out of frustration, parents form their own perceptions about teachers based on teachers’ actions and attitudes towards them and their children *“...they believe they know better...”*

### 6.3.2 Teachers Avoid Me

Parents felt that in order to make it possible for them to play a role in schools, teachers needed to create space by being accommodating when they visited schools. Parents felt that this was not happening at all. One parent stated:

Teachers look away when I get to school.... They always try to avoid me... not friendly when I go to talk to them. (Grace, 2011)

Natty tried for the entire term to set up a meeting with her daughter's teacher and was made to wait for a special meeting that the teacher had already arranged to discuss the problems the teacher was encountering in teaching her child.

I did all I could to meet with the Steff's teacher but I felt she was avoiding me as she kept on telling me to wait for the special meeting that the school was apparently organising ...it is now the end of term already. (Natty, Reflection session, Sept, 2011)

My observation at the time of setting up school meetings was that it was very difficult to get teachers to set up times for these meetings even though they had agreed to make themselves available for these during my initial meetings when I informed them about the research. The general reason given for this was lack of time due to teaching. There were times when we had to wait longer on scheduled times for meetings because teachers had unexpectedly to teach a class because another teacher was not available to teach on that specific day. The same happened on two different occasions where meetings that were arranged to take place at break time and after school had to be postponed as teachers had to attend special meetings that had cropped up.

It was even more difficult to get to meet with Libo's teacher although the teacher that agreed to meet with us. The parent knew the teacher as his class teacher but the teacher later informed me that he was not the correct person to meet with as he was not Libo's class teacher (there was no teacher assigned to Libo's class at the time) and he did not feel comfortable about discussing Libo's progress. The teacher we were then referred to meet with for the following school meeting refused to meet with the parent because "the parent had high expectations from teachers about her child". As a result only one school meeting materialised for Libo (Researcher notes, Oct, 2011; Jan, Feb, 2012; Researcher diary, Oct, Nov, 2011; Jan, Feb, Mar, and May, 2012).

The situation was exceptionally different in Zandi's school where the school principal continuously communicated with Zandi's class teacher to make sure that teachers were available to meet during the school meetings. In addition, Zandi's class teacher and the school principal saw a need to engage all of the teachers that were teaching Zandi during the period of this research when school meetings were taking place. All

of the school meetings that were scheduled immediately after school took place at scheduled times.

Despite challenges experienced by parents in their attempts to participate in schools, it was evident during the meetings with teachers, parents and during focus group and reflective sessions that parents were willing to work with teachers and to do what they could for the admission and retention of their children in schools. Participating in school meetings seemed to take them out of their comfort zones as they seemed to grapple with challenging their own fears while engaging in challenging discussions about education of their children. As Natty sarcastically commented, “*what do we know about teaching in any case*”. Although parents and teachers were not very vocal during school meetings, it was easy to notice the confident and sometimes intimidating way in which some teachers presented themselves while parents appeared tense and uncomfortable. Focus groups and parent meetings appeared to be used as platforms where parents shared frustrations, some of which couldn’t be expressed during the school meetings.

You always hear the same thing, teachers on one hand blaming care givers that they don’t do their work, care givers blaming teachers on the other hand and our children suffer at the end, until when?..” (Zandi, Reflective session, June, 2012)

While the majority of parents had discouraging experiences relating to teacher attitudes in schools, there were teachers who did their best to create a welcoming atmosphere for parent interaction. Subject teachers in one school who taught one of the children were all keen to participate during school meetings and were very supportive of the parent and the child. As a result the child did well at school.

I am very happy about Sindi’s progress in Maths. She does experience some challenges here and there but what I like is that she does not keep quiet any more. When she does not understand something, she is not afraid to come and ask for clarity. (Teacher, School meeting, 2012)

I agree that Sindi is not quiet anymore. She interacts easily with others in my class and I have observed her spending time with different friends during break time and after school when they are waiting for transport to pick them. However, she doesn’t seem to like my subject as she seems to struggle a lot with Afrikaans, nhe Sindi or you don’t like me (jokingly)? (Teacher, School meeting, 2011)

Some teachers seemed to grapple with understanding their roles and what was expected from them regarding inclusive education processes and procedures. A teacher enquired in one of the school meetings:

Who is supposed to buy devices needed in teaching the disabled children, is it the State or who? (Teacher School meeting, May, 2012)

The same teacher responded to my question asking whether an Institution Level Support Team (ILST) existed at the school:

Yes we do have but the kids don't get devices and we are concerned as they are growing. (Teacher, School meeting, May, 2012)

For parents, this challenge was interpreted as resistance by teachers to change, as parents were not aware of the difficulties that teachers were experiencing in teaching disabled children. This was seen to be the main cause of discrimination amongst disabled children in local schools. Parents saw teachers as neglecting their children as examples from various scenarios below indicate. Grace told her daughter's teacher during the school meeting:

I did not see how you involved her (the daughter) in class while I was sitting there.... Tell the school principal when you find it difficult to teach her. (Grace, School meeting, May, 2012)

Similarly, Natty expressed her concern that the teacher was neglecting Steff in class:

They keep telling me that Steff must be in a special school but do not tell me what they have done to include and to help her at school. (Natty, Interview, Jan 2012)

Steff's teacher commented when I visited the school with the parent:

I cannot communicate with her as she does not understand and we are concerned that she is not with her age-group any more. (Teacher, School meeting, April, 2012)

Parents also found it difficult to interrogate some of the decisions around admissions and retention of disabled children in local schools as they felt uncertain of the roles and expectations with regard to the policy on inclusive education. In such cases, parents found it easier to resort to special schools, as the following quotes and notes from different scenarios indicate:

Natty mentioned that she would have felt more confident to challenge the school about the decision to move Steff to a special school if she had been well informed about the policy on inclusive education (Researcher notes, March, 2012). In a different meeting, Steff expressed her frustration with the school:

Sometimes I wonder if it's not better to just take Natty to a special school, it might relieve the pressure but I am not doing that.... (Natty, Interview, Nov, 2011).

When Thandi heard about the local school's decision not to accommodate Libo the following year because she was using a wheelchair, she felt it better to accept the decision by the school to take Libo to a special school although she felt disappointed initially about this decision. She felt it was better than arguing all the time with the school about the same issues as Libo had never been accepted by the teachers, despite the mother having constructed rails at the school (Researcher notes, Nov, 2011).

An interesting observation made while discussing challenges at school is that only one parent looked at matters from the teachers' point of view and so was able to work well with the teachers. All teachers in that school who taught that particular learner voluntarily offered their time to participate during the school meetings. As a result, the parent (the only one in the group) worked very well with the teachers and the child's report showed remarkable progress in the three years of the parent's involvement at school (See Appendix G: School progress reports).

In general, the learner was the one seen as having problems rather than the teacher. One teacher was asked if she thought her teaching style might be challenging to the child and in response, the teacher commented:

Having taught so many years with almost all of my children not questioning my teaching style...., what you are saying is new to me, however I am willing to discuss that if the child sees it as a problem. (Teacher, Sept., 2011)

During school meetings, I observed that parents appeared very relaxed and, as a result, participated easily in discussions. The accommodating attitude of Libo's

teacher in this meeting made it possible for Thandi to share her advice to the teacher about what she found helpful working with Libo at home;

..... helping her at home with homework....., I used to teach her and stop when I see she lost interest but she needs lots of patience and she forgets easily (Thandi, School meeting, Jan., 2012).

Reflecting on the school meeting and the interview with the parent, it became clear to me that the teacher's willingness to participate in school meetings and her positive attitude made it easy for the parent to participate during the school meeting.

Problems around parent involvement in schools revolved around misunderstandings between parents and teachers. It was clear from listening to parents during interviews and meetings with teachers that parents, on the one hand, do not understand the frustrations and issues which are problematic to teachers, while teachers, on the other hand, lack understanding about the world of parents with disabled children. Understandably, both parents and teachers relied on their own interpretation of what they were hearing from responses received in their interaction. Parents believed that teachers' positive attitudes towards children and their parents were key to developing working relationships between teachers, parents and disabled children. Teachers believed that parents were expecting much more than they were able to give to support their children in schools.

#### **6.4 Inadequate Awareness and information about the Policy**

Interviews, focus groups and observations all indicated confusion in the role expectations between parents and teachers.

##### **6.4.1 You don't know what to say to the teacher**

Though parents seemed to be clear of the supportive role they had to play, they found it contradictory that they were not welcomed when they visited schools. Grace expressed her frustration during a school meeting;

I understand that parents have a right to sit in the child's classroom .... I have been doing that since Mandy came here.... Last week I was here there was no one in her class and no one here at school was willing to talk to me. (Grace, School meeting, May, 2011)

In a different meeting one parent commented:

As a parent it often becomes difficult to just go and sit in the class because you don't know what to say to the teacher... Teachers also feel very uncomfortable and tend to look at you as someone who is intruding in their territory. It just becomes such an uncomfortable experience, what do you know about teaching in any case. (Natty, Reflective session, April, 2012)

#### 6.4.2 They had no clear idea of what Inclusive Education means

Another parent shared the same feeling of frustration and confusion regarding her role and the expectation from the school;

I really do not know what to do, or what is the right thing to do when one is a parent at school. Teachers expect that you do something like supporting your child or them. From my experiences, I do not think they mean what they say when they complain that we are not involved at school. The minute we become involved, they have a problem. They look unhappy and you can see that they don't like it when I go to school when they are teaching in class as if there is something they don't want parents to know. This makes it very uncomfortable for me to go in class when I want to. (Grace, Reflection session, May, 2012)

The school does not follow inclusive education because they had no clear idea of what it means but I will not remove my child. I will wait and be patient I want them to prove to me that it does not work then I will take her to a special school (Natty, Interview, Jan, 2012).

In one of the focus group discussions where parents were discussing possible ways of dealing with problems in schools, they concluded that the following session should focus on the inclusive education policy as they often found it difficult for them to interrogate some of the school decisions about disabled children (Researcher notes, Dec., 2011).

#### 6.4.3 Advise where we can get help

The teachers' sense of confusion was evident in their requests to me (the researcher) for advice and assistance. For example, while we were discussing challenges in one of the school meetings, a teacher expressed her need for guidance:

...I will be glad if you can advise where we can get help.... I cannot even understand when the child tries to talk to me although I can see that she wants to say something and to participate when I ask questions in class. (Teacher, School meeting, May, 2012)

In a different meeting, another teacher commented:

**It might benefit us if you can also offer your services to the school** as the situation can be overwhelming for us as teachers, how much more to these children. (Teacher, 2011)

The insert below shows that teachers do not follow correct procedures as stipulated in the policy as regards transferring learners from local to special schools. Parents are not consulted to participate in the process and this indicates a need to raise awareness amongst teachers about the policy on inclusive education with specific reference to processes and procedures on admission, assessment and support of learners. Thandi was not aware that the school had decided not to accommodate Libo the following year until she saw a letter tucked in with the school report. The letter informed her that her daughter had been transferred to a special school despite the effort she had made to build ramps at the school for her daughter's wheelchair. She shared with the group about how Libo moved from her local school to a special school:

I was told that I have to take Libo to a special school as the school was not the right school for Thandi and therefore could not accommodate her the following year.... The letter was included in an envelope with her report... (Thandi, Reflective session, Nov., 2011)

#### 6.4.4 We can do everything.... We are just wasting time

Surprisingly, some of the parents did not agree that the issue of awareness around policy was key to making schools inclusive despite their acknowledgement that teachers lacked information about the policy. The fact that teachers were not informed about the problems parents were experiencing and parents not aware of problems that teachers had with regard to implementing inclusive education, seemed to be the bone of contention. This is how parents viewed the situation;

I do not agree that by being supported teachers will deal differently with our children. There are other schools that are poor to the point of having nothing, even no chairs to sit on, but you find teachers in those schools doing all they can to make disabled learners feel that they belong (Zandi, Focus group, June, 2012)

I agree, it is just a defence mechanism to hide the fact that they are not prepared to accept disabled children in their classes. And the department is supporting them in any case by not forcing them to implement inclusive education policies in these schools. (Grace, Focus group, June, 2012)

We can do everything to help our children and support teachers in order for them to understand our children better, however with the negative attitude that the

teachers often have towards a disabled child, I believe that we are just wasting time (Natty Focus group, June, 2012).

The experiences of parents in schools regarding policy awareness proves the frustration amongst parents and teachers in making sure that schools become inclusive and that disabled children are not just admitted but retained in their local schools. For them, priority was to get their children admitted and retained in schools. Parents felt that their limited information about the policy made it impossible for them to assist their children and to confront teachers. They also believed that information about the policy would benefit them and others to confront challenging issues and those they believed to be discriminating against disabled children. Not being well informed about the policy meant that they were not able to be of assistance in schools.

During school meetings, teachers proved to be just as frustrated about the process as parents were, despite not communicating as teachers and parents about such frustrations. They also felt overwhelmed about what parents expected from them with regard to teaching their children. Their frustration when they seemed to struggle to include disabled learners was misinterpreted by parents as resistance to change.

### **6.5 We live busy demanding lives**

The ability to make time for school meetings was a problem for all parents. Three of them, who had full-time jobs, often found it impossible to honour appointments with teachers during the week; and the two who had part-time jobs mentioned that meetings scheduled during the week made it difficult for them to take extra jobs that often came up unexpectedly. For parents, work was considered very important as it was their source of income to support their families.

Employers were not accommodating when it came to requests to attend meetings as they seemed not to understand the reasons that parents could not schedule their meetings for after work. This was found to be the major challenge facing parents in the study resulting in their being seen as not being available to attend to school matters while for them, time was a major constraint as they had to leave home using

public transport in the morning and finish work late. Over weekends, the only time they were not at work, teachers were not available at school to meet them.

#### 6.5.1 We need income

Grace described how challenges at work affected her and by implication the role that she had to play at school:

We are expected to keep our cell phones off at work and that can be very frustrating knowing that something was not right at home or your child was not well. “andithethi ke nge meetings, akafuni nokuva ngazo” (not to mention meetings, she doesn’t even want to hear about them). It is difficult to get time to attend school meetings, as a result I am thinking of leaving this job but difficult not knowing when I would get another job. What can we do because we do need income. (Grace, Reflective session, April, 2012)

Sally reiterated:

I requested them to arrange meetings during my lunch hour. It can be hectic as I have to rush off at least 5 minutes before my lunch hour to make it for the meeting. Sometimes her dad cannot fetch her after school for speech lesson, so I have to take her with me after the meeting, drop her with the therapist and rush off back to work. Back in office I find my bosses work piling on my desk... hard... because **you need a source of income** and need to be there for your child. (Sally, Reflective session, April, 2012)

Thandi found herself facing a dilemma when she had to decide between giving up a job in order to make time to assist Libo whose performance at school suddenly deteriorated after she moved in to hostel. The alternative was for Thandi to leave Libo at school and rely on the support which she doubted would be offered by child care workers where Libo stayed. The quotation below illustrates some of the demands that parents of disabled children found it impossible to run away from.

Parent: I think she is doing fine where she is right now.

Researcher: Don't you think it would be better if she was at a local school or if she remained at the local school as she can get more support from home. Won't it be easier if she is closer?

Parent: The problem is that now I have a job and I will not be able to look after her and to be at school to assist her.

The same parent commented in a school meeting, indicating how her decision to move the child to hostel in order for her to generate an income impacted on the child negatively:

I do agree with what is already said about Libo. She forgets things very easily. It was better when I used to help her at home with homework before she stayed in hostel unfortunately I cannot help her now as she lives here (at school) as I have a job now and I look after his grandfather sometimes I have to take him to hospital for his routine check-up. (Thandi, School meeting, Jan., 2012)

Grace shared her frustration while we were discussing problems at school:

The work situation is also not conducive. It is difficult to get time to attend school meetings, as a result I am thinking of leaving this job but difficult not knowing when I would get another job. (Grace, Interview, June, 2012)

Molly seemed hopeless as she struggled to juggle between her different roles;

Since my son moved into hostel, I notice that he is back on nappies after all these years since he stopped using them. When I asked about this from the school, I was told that there is no one to help when they have to relieve themselves. So because he now lives in hostel there is nothing I can do as I get home late from work. (Molly, Interview, Feb., 2012).

While most of the parents in the group found it hard or impossible to prioritise their children's schooling over work, Zandi's case seemed different. For Zandi, the only answer she had to make the best of Sindi's situation at school was to put Sindi's life (school) and education first, before anything else in her life. She recalled the day she decided to take a stand to change the school's decision to move Sindi to a special school:

When I learnt that the teachers wanted to take Sindi to a special school, I refused because I believed there was much more she could do I conceived the notion to paint her classroom board black which resulted to a very positive feedback about her (Sindi) progress at school. I meet often with her class teacher to get copies of class work so as to help her at home. (Zandi, Reflective session, Nov, 2011)

Through her experience, Zandi was an inspiration to the parents of disabled children in the group who were experiencing challenges with their children's schooling. However, not every parent in the group agreed that everything that Zandi was doing in support of her child was right. Some of the parents struggled to understand why Zandi would go all the way to interfere with the teachers' responsibility to teach and to make sure that the child understood that which was being taught at school:

It involves lots of sacrifice, putting your child first to your own personal needs. You find that most of the time we are busy with our own agendas, day in day out

and we forget that years are going by and our children are growing. (Zandi, Reflective session, Nov., 2011)

Parents often found themselves spending hours in hospitals in order for their children to be seen by therapists in cases where they needed assistive devices, such as wheel chairs, for routine check-ups or for speech therapy. The fact that such services were not available in schools meant that parents had to arrange time off work and this had to be during the week as therapists only worked on week days and not over week-ends. This presented as another problem area which employers failed to understand. This in turn meant that parents had to forfeit a few (South African) rands of their income, as employers often decided to offer them unpaid leave in meeting their requests for time off. Grace was not aware that her employer was going to deduct money from her monthly salary until she noticed something strange with the amount deposited in to her bank account at the end of the month.

.... I decided to check with her (employer) in case there might have been a mistake on their side when they paid my salary only to discover that she added all the hours when I had to assist with the wheelchair as the bus driver had no assistant picking up children to school. In addition ... being the same month that I had to take Mandy for her assessment in hospital that in all costed the whole day's income. (Grace, Reflection session, March, 2012)

For Thandi, it was better for her daughter to stay in hostel as the problem of unreliable school transport made it difficult for the employment agency she joined to rely on her when a job opportunity cropped up:

I found that I had to turn down more of the job opportunities when Libo travelled from home to school on a daily basis.... I had to be there as most often no one was available to assist getting her in and off the bus as a result the agency stopped calling me about the jobs ..... people see consider you unreliable but at the same time you need that income..... it is much better now. (Thandi, Reflection session, March, 2012)

Molly's situation was different as she had a more secure job:

If I have to take Tito for physio, I will just take a day's leave then do other things as well on that day. (Molly, Interview, Feb., 2012)

In addition to hours spent in hospitals, consultation with therapists meant additional costs in parents' monthly budgets. Although consultation was free in public hospitals where children were often seen by therapists for nothing, some of the parents had to

pay double their travelling fee as they were often expected to first report at work a few hours before heading off to take their children from school to hospital and again back to work if they were fortunate enough to leave hospital early enough. In that way they didn't have as much of their salaries deducted:

Sometimes I don't even have the money to first travel to work and then go to fetch child from school and again if it happens that we finish early, I am expected to go back to work otherwise I have to forfeit that day's income (Grace, Interview, Jan., 2012).

Natty decided to discuss a plan with the speech therapist that would allow Steff to go for speech lessons at a discounted fee. Natty saw that as an alternative to save her the hassle of spending hours in hospital waiting to see the therapist. The plan also meant that Steff was no longer going to miss out on lessons at school which she had to do when she saw the therapist in a public hospital:

The speech therapist agreed to see Steff twice a week. Knowing that she used to work with Steff before when I had a medical aid, she easily agreed to offer a discounted fee. Her dad will take her after school and I will help where possible. (Natty, Interview, Jan., 2012)

Observing and listening to parents' stories confirmed how the conflict of interests they were experiencing between work and wanting to be there for their children. Molly shared that her life was so busy that she hardly managed to find time to focus on her personal needs. Her weekends were as busy as her weekdays. This was evident when we had to reschedule meeting times in order to accommodate Molly's busy week-end schedule. We had to continue with the focus group an hour late when Molly came rushing in:

I do apologise for being late, as I mentioned that this week I had to travel home (out of town) every day after work as we had a cow slaughtered, we worked yesterday (Saturday) and I had to attend a funeral this morning, hence arriving only now. I decided to come straight here from the funeral before taking Tito back to school. (Molly, Focus Group, May, 2012)

The quotation above exemplifies the general pattern of parents' schedules over weekends. Saturdays and Sundays appeared to be the days on which they had to fit in everything that they couldn't do while they were at work during the week.

It was also clear that they were somehow aware of the fact that they were often not available to spend time with their children due to various things they were doing in order to earn a living. This was evident in the words of this parent:

I know I am not always with my kids, however as long as I know that I am securing their future so that they don't experience what I went through... that is ok" (Molly, Interview, Feb, 2012)

Sindi proved she would do anything to protect and support her disabled child. This is what she shared when we reflected after a meeting where a teacher had passed a negative comment at the end of the meeting:

I was also glad that Sindi was not present in that meeting, because she would have been hurt to hear her teacher say that... fortunately I have lots of support from other teachers and I'll keep working with those who want to work with me. (Zandi, Interview, Jan, 2012)

Libo's mother saw it necessary for her to work in order to secure a brighter future for Libo so that her life might be better than the one she had lived while she was growing up than the one

There is no way I can turn down a job when an opportunity exists.... If Libo stays at school, I am able to work and provide for her. Besides...it pains me to see my children going through the same struggles because my family couldn't afford to do things for us. (Thandi, Focus group, Nov, 2011).

Grace also shared her commitment to being available for her disabled child in order to avoid the pain she went through having grown up in the absence of her parents (Ref. 5.3.1).

Listening to the stories of parents and spending time observing them rushing to our meetings on Sunday afternoons after church, sometimes calling me to vouch for them so that employers would release them to attend school meetings or general check-ups in hospitals in the course of the study, it was evident how busy parents' lives were. Their meeting times seemed to be the platform where they got to vent their frustrations as parents in general. In interviews and focus groups, a general tone of frustration was apparent in the relationships between parents and their employers. The relationships seemed to be characterised by mistrust as employers

struggled to understand why parents had to attend to matters during work hours instead of after work or over weekends.

While the relationship between parents and teachers also seemed challenged as they all struggled to find convenient times that would suit both their work schedules, there were some parents who ended up stuck in their very busy schedules as they “secured better futures” for their children. As a result, the end of each term came with the realisation that they had not yet managed to deal with problems at school. Though children seemed to be at the receiving end of these challenged relationships, it was interesting to see how parents shared lessons and encouraged one another about ways of handling their challenges.

## **6.6 Conclusion**

Chapter 6 has helped to “clear the bush” for easy visibility of foot prints for those seeking to understand parents of disabled children while working with them. The first theme, “Growing Up”, helped in understanding the context from which the parents came. It helped us to answer the question, “Who are these parents that we want to work with?” in order that we may understand why they do things the way they do and why they respond the way they do. Themes 2 and 3 (Stunted Involvement of Parents and Inadequate Awareness about Policy) focused on the situation in schools where parents strive to get involved. Finally, theme 4 (Busy Demanding Lives) looked at the context in which parents live. One critical barrier is the failure of employers to recognise the rights of parents of disabled children to take time to attend to their family responsibilities. While employment should be seen as a means to empower employees, for parents of disabled children employment causes more pressure, especially when the employer is unsupportive of employees.

South Africa’s Constitution and Bill of Rights have made it possible to challenge and overcome such barriers. The Mercury (13 June 2012), described the case of a single mother of a young autistic son who took her employer to court because she was denied her right to take care of her disabled child (3.1). This case made history and brought hope to parents of disabled children who often find themselves challenged when they have to attend to pressing issues affecting the health of their children during work hours. The court ruling in favour of the parent set a legal precedent

...that employers must reasonably accommodate the family responsibility of their staff. For parents of children with disabilities, this case will hopefully signal an acceptance that their child-care responsibilities are important and not automatically out-weighed by employers' needs (Holness, 2012 cited in the Mercury, 2012:1)

Even though the Promotion of Equality and Prevention of Unfair Discrimination (PEPUDA) and the Bill of Rights protect employees against unfair treatment at work, parents of disabled children still continue to fall prey to their employers when it comes to attending to the needs of their children (6.5.1). This policy includes ensuring that physical and attitudinal barriers do not keep disabled people (including carers of disabled children) out of work opportunities (Swartz and Schneider, 2006).

Therefore, with this information in mind the next chapter focuses on analysing findings. In addition, possible approaches and solutions towards working with and supporting parents of disabled children are discussed.

### **Part 3 Thesis building**

In this Part, I focus on the interpretation of the findings, argument and thesis building (Chapter 7). In Chapter 8, I then share my experiences in the process of engaging in this study and the impact thereof in my life.



*Focus Group Session*

## Chapter 7: Answering the research questions: building a thesis

“Ezosiweyo azibhabheli mlonjeni” directly translated as “You do not shoot a bird and then sit back and expect a meal to be ready, but you have to continue to work in order to have a meal at the end of the day”

The citation above is a Xhosa idiom meaning that when one starts a job it is important to see it through to the finish. Unless you do something towards finishing a job, it will remain incomplete. Relating the citation to inclusive education, the questions becomes why it seems slow or difficult to get things happening in schools. Is there something we might have done wrong in our policy planning or perhaps something that we ought to be doing but are not? Perhaps, as the idiom referred implies, it is time for us to realize that as good as our policy looks, it remains our duty to see it implemented so that our goal to have disabled children included and retained in schools can be realized.

This study sets out to answer two broad research questions:

- i. What experiences do parents of disabled children have with regard to the education of their children?
- ii. How can parents of disabled children be supported to facilitate their active participation in the inclusion and retention of their children in public schools?

At a descriptive level, the first research question and its related objectives have been addressed by the profiles and findings presented in Chapters 5 and 6. In this chapter I reflect on these findings in a more analytical way by making and substantiating eight claims. Then extrapolating from the analysis, I build a thesis that answers the second research question. The claims draw out the significance of the findings by focusing on socio-cultural, personal and structural features of parents in relation to teachers, the Department of Basic Education and the parents' employers.

## 7.1 The Approach to Thesis Building

The profiles and experiences depicted in the previous two chapters, together with the literature review in Chapter 3, help us draw lessons for building mutually beneficial relationships between parents of disabled children, teachers, the Department of Education and the employer in the process of making inclusive education happen. Findings suggest that genuine relationships between schools, parents and employers can be formed based on communication and understanding of the policy on inclusive education.

At the heart of these relationships is what Mkhabela (2005, cited in Owusu-Ansah and Mji, 2013:2) calls a “collective ethic in which the survival of the group derives from harmony through interdependence and interconnectedness.” It was clear from the parents’ experiences that one of the valuable skills they learnt during childhood was the ability to work cooperatively. This skill helped them find the strength to persevere and deal with difficult situations they faced in their efforts to engage with teachers. While the parents in this study did not themselves use the term ‘collective ethic’, the findings reveal how much value they placed on working together and supporting one another as parents of disabled children and on working with teachers. The value of a collective ethic thus underpins this chapter and motivates the recommended approach to supporting parents of disabled children.

The first broad research question for this study had two related objectives, namely:

- To investigate the experiences and needs of parents with regard to their disabled children with a specific focus on the challenges they face.
- To explore ways in which parents of disabled children can be supported to facilitate their active participation in the inclusion and retention of their children in public schools.

At a descriptive level, these objectives have been accomplished through the presentation of findings in Chapters 5 and 6.

In this chapter, I build a thesis by analysing and discussing the findings according to four aspects that characterise experiences of parents with disabled children. These are what I call ‘the four Cs’, namely: Constraints, Complexities (and contradictions),

Capabilities and Compassion. For each of the four Cs, I make and substantiate a number of claims that together build the central thesis of this study. The four Cs focus on the following key issues:

- **Constraints** – Although the policy on inclusive education stipulates that parent participation is key to the implementation process and that no decision can be made about a disabled learner without parental input and involvement in the decision making process, this is contradicted in practice where parents experienced a completely different world from that portrayed in policy documents. Constraints are what parents experience as barriers to their participation in schools.
- **Complexities (and contradictions)** – Active participation of parents in the education of their children involves more than just making time to attend school meetings or being there for their children. Internal and external issues in the lives of parents also affect decisions regarding the nature of support needed at a particular time. These issues appear to be simple and easy to deal with yet parents found that there were underlying and subtle issues that needed to be addressed in order to facilitate their participation in schools. Nussbaum (2011:76) puts it simply referring to complexities as “multiple elements whose relationship to one another needs close study.” In some cases actions by teachers and the Department of Basic Education officials seemed contradictory to parents’ general understanding of what the policy required of them. In other cases “life happened” when specific plans in the process of engaging with school matters by parents and teachers has already been set in action. An example relating to parents in this study is the situation where a parents is denied by the employer to break off from work for a school meeting or when the parent who is the bread winner in the family, feels s/he cannot afford to take an unpaid leave to attend school meeting. These are the multiple elements in parent’s lives that teachers working with parents need to understand (Nussbaum, 2011).
- **Capabilities** – Nussbaum (2011) in her Capabilities Approach refers to capabilities as a set of related opportunities to choose and act, opportunities

enabling a person to do and to be (See 3.6). In this context, I refer to capabilities as innate abilities, attributes or gifts possessed by parents (See Opening section; Chapters, 3 and 5). These are the qualities that I have observed from my interaction with parents, in particular, with the way these have benefited parents resulting in their overcoming difficulties in the process of engaging with schools. I am specifically referring to the aspect of resilience. For parents, their resilient attribute enables and assures them that their constant involvement at school despite unwelcoming attitudes by teachers is necessary in order to bring change. In the agentic role as parents, they are driven naturally to persevere participating in schools. However, external factors being lack of support by department officials and resistant attitude of teachers which is lack, would make their involvement impactful in the course of making schools inclusive sites for learning (Nussbaum, 2011).

- **Compassion** –the term compassion is often associated with humanity which makes it a generally acceptable ethical manner in which human beings are expected to relate to one another and to other animals. In other words, the meaning implies showing and giving love unconditionally. I have purposely singled out this attribute from parent capabilities because it does not only relate to ‘mothers’ as parents in this study, but rather to the universal attribute of “Ubuntu” (humanity), which enabled parents to persevere in ensuring the inclusion and retention of their disabled children in schools.

### *Summary of thesis building*

My summary on findings is that negative attitudes of teachers towards parents and disabled children constrain parent participation in schools. While the policy on inclusive education calls for parents to actively participate in the process of making schools inclusive, the department of education lacks support and intervention by the in facilitating parent involvement in schools. In addition, teachers indicate that they struggle to understand disabled learners, meaning that disabled children cannot be included where communication does not exist between teachers, children and parents. I refer to this situation contradiction to the policy because teachers need parent in order to understand children but do not welcome them in schools. The

department promotes inclusion and parent participation but not facilitate the process through which it can be possible.

The two innate skills or abilities I discovered that parents in their agentive role have shown are: the ability to focus on the positive things in life; to persevere and to pull through the challenges they experience in schools and their own lives; and, the ability to support one another in selfless ways. These qualities I refer to as Capability and Compassion. I deal with the analysis of these findings in the section that follows in the process to answer the questions posed by this.

## **7.2 Analysis**

A synthesis of the main findings is given and based on these findings and recommendations are made to facilitate support of parents as they ensure inclusion and retention of disabled children in schools.

### **7.2.1 Constraints**

What are the barriers to parents' participation in the education of their disabled children? To answer this question, I draw not only on the data presented in the two previous chapters but also on similar studies locally and internationally as outlined in chapters 2 and 3. Due to the Afrocentric nature of this study as chapter 4 (4.2) specifies, I also draw on the aspect of culture in looking at the role culture plays in parents' participation in schools. As a cross reference and main theme in this study, I continuously refer to organisations such as Institution Level Support Team (ILST) and the District Based Support Team (DBST) as the support structures in place for the implementation of the policy on Inclusive Education that stipulates the need for parent participation in schools. I make and substantiate three claims about the nature of the constraints and how they can be overcome or at least managed or minimised:

#### **Claim1: Socio-cultural values and practices constrain parents in the process of engaging with schools.**

Bruner (1996) referred to parents as social agents whose parenting skills are already shaped and influenced by their own "self-generated intentions" and cultures (3.5).

Owusu-Ansah and Mji (2013) noted that almost all knowledge is informed by culture and therefore the culture must be examined for its particular influence. Mkhabela (2005) argued this point further by stating that in seeking knowledge within an African culture, we need to recognise the African voice and reaffirm the centrality of the cultural experience. Listening to parent life stories, it was evident that socio-cultural values had an impact on how parents viewed their role with regard to the education of their children. In section 6.2.3, “Teachers know better”, I relate to the Xhosa term ‘intlonipho’ which implies that a younger person needs to show respect to an older person at the same time looking up to the educated ones by showing respect towards them (1.6.1) I further discuss how this cultural practice is evident within different status groups and how this practice disadvantages some people because of abuse by others for their own benefit (see 6.2.3). This was evident in parent teacher relationship during school meetings where parents found it difficult opposing views of teachers where parents in their agentive role had different views about their children. On one side, teachers felt that parents were expecting “miracles” about their children’s education while parents saw potential in their children. Parents believed that their children had the ability to do better at school when teachers support them, however they could not tell this directly to teachers during school meetings (6.3.2) this shows the power relational challenges that culture has promoted resulting to parents not feeling comfortable to confront the teacher as people culture has taught them to look up to- with respect (Gouws and van Zyl in Reddy et al., 2014).

### **Summary Claim 1**

The following section indicates that differences in parent professional relationships can be complex and cut across culture.

### **Claim 2: Professional domination in parent-professional relationships deters parental engagement**

Cooperation, mutual respect and trust are key elements that will determine success or failure in the process of implementing inclusive education (Henley, Ramsey, and Algozzine, 2002). In a European context a similar study to this one conducted by Lundebj and Tossebro (2008) found that in cases where parents were in disagreement with professional view points, they were regarded as problematic.

Parents in Dembinski and Mauser (1997) also expressed the same need that professionals be more patient and open to them about their reports on the child's diagnosis.

I made a similar observation during the school meetings, noting that teachers appeared to be dominating during discussions with parents and that in such meetings parents appeared intimidated and withdrawn (Ref.6.3). This suggests that even in situations where teachers are simply talkative by nature, parents with a "teachers know better mentality" can be too intimidated to participate and to engage in confrontational conversations with teachers. Contrary to the rest of the parents, Natty's sarcastic remark that teachers regarded themselves as knowing better (Ref 6.3) suggests that she was concerned and frustrated that teachers were denying them the opportunity to support and work together because they wanted to appear better informed than the parents. Parents in the UK who participated in Lundeby and Tossebro (2008) study shared the same concern. They noted concern that in the process of working with professionals, they were regarded as objects, being told when it was time for them to attend to their own feelings, even when they didn't see a need to do so.

The study by Lundeby and Tossebro (2008) indicated that professionals working with parents believed that they understood parents better than parents understood themselves to such an extent that they found it difficult to continue with sessions when they believed there was a need for parents to attend to their feelings, such as grieving even when parents didn't believe they needed to. While Lundeby and Tossebro (2008) attributed this to the teachers' striving to be professional in the way professionals work, I tend to concur with the parents that this suggests professionals wanting to appear as knowing better, perhaps because of the desire to keep parents confident about the advice and support offered to them and their disabled children.

This finding again suggests some correlation with the themes of "growing up" and "stunted involvement" as a result of teacher attitudes. Parents mentioned that the undesirable attitudes of teachers made them feel unwelcome in schools. Lemmer and Van Wyk (2004) noted that parent participation in school activities often depends on the extent to which schools communicate with parents. Their study confirmed that

it was the same when participants who were school managers reported that they found it easier for parents to engage in school matters in situations where teachers and frontline personnel created a welcoming environment (Lemmer and Van Wyk, 2004), reiterating what I believe is a prerequisite for successful parent- professional relationships: joint ownership. When the school environment seemed inviting to parents, they in turn felt part of the system.

This experience proved true in Zandi's case where the school principal and the teachers were more involved and appeared to work more closely with the parent compared with the other parents in the study (Ref. 6.4). However, having observed how parents and teachers related to one another during school meetings, I tend to resonate with Lundebly and Tossebro (2008) and Engelbrecht (2008)'s view that parent- professional relationships tend to be professionally dominated. Zandi also confirmed the same attitude regarding her interaction with the school where she attributed the support she was receiving to her decision to ignore everything else but do what teachers wanted (Ref 6.2). This discussion confirms the need for parents and teachers to understand each other's point of view in order to develop mutually beneficial relationships that are based on trust, mutual respect, and cooperation (Henley Ramsey and Algozzine, 2006).

### **Claim 3: Unclear role expectations and inadequate policy awareness hinders parents' participation in inclusive education**

Unclear role expectations, inadequate awareness about the policy and unsupportive management are interrelating constraints as one seems to lead to another. Although the latter statement indicates complexity of these concepts, I opted to include them in my discussion as constraints to parent participation in schools because, in the midst of the confusion as a result of the complexity of these concepts, parents found it difficult to identify their expected role in order to participate in schools.

White Paper 6 on Inclusive Education (Department of Education, 2001) is about recognizing the vital role community plays in the education system of the country. It encourages the establishment of inclusive sites for learning whereby parents, teachers, learners and other professional role players are recognised as key role players in the process (Ref. 3.3). It was for the purpose of supporting schools that

the Institution Level-Support Teams (ILST) and the District Based Support Teams (DBST) were established (Department of Education, 2008). It is important to note that, while the policy allows for the establishment of the support systems in schools, nothing has been mentioned about community and parent support. Educators still grapple to understand the concept of inclusive education (McKenzie et al., 2008). This is the area where REHAB (McKenzie et al., 2008) saw a gap which they aimed to address through their inclusive education project (Ref1.6). In a study of vulnerable children in schools, Mallmann (2003) suggested that the educator's attitude largely determines the acceptance or rejection of a disabled child in a classroom and at school. This suggests a need for education institutions to integrate training into pre- and in-service education in order to ensure that learning sites become inclusive (UNESCO, 2007). Therefore, countering discrimination and enforcing policy implementation needs to be a core part of inclusive education policies and programmes in schools.

Parents who participated in this study felt unwelcome at school and uncomfortable sitting in classes while teaching was in progress despite their acknowledging that they were aware that the policy allowed for them to visit schools and sit in classes whenever they found time to do so (Ref. 6.2). Teachers, on the other hand, appeared to battle to make time for school meetings with parents. Parents interpreted the unavailability of teachers and the fact that they felt neglected by teachers when they visited schools as indications that they were not welcome in schools.

Teachers acknowledged the fact that they found it difficult to allow times for the school meetings even though they had initially agreed to participate in the study (Ref 6.2) This suggests three things: lack of awareness of the policy, as support was requested by some of the teachers (Ref 6.3), lack of support by management (as teachers were expected to attend special meetings despite planned meetings with parents) and lack of commitment to inclusive education. It is evident from the observations, perceptions and experiences of the participants that there is need to empower not just teachers but all role players about issues of inclusion.

### *Summary of Constraints*

In analysing the constraints in the context of parent involvement in schools, the previous section argued that culture has played a disempowering role towards the participation of parents in schools and in the way parents relate with teacher. An element of inequality in teacher parent relationship was evident. Parents on one side were more submissive in their response during school meetings and teachers on the others side appeared more dominating in school meetings. Parents felt unease to oppose teacher and were also quiet in meetings than when they were on their own as parents. It has been argued through different international studies that the element of inequality in parent professional relationships cuts across culture. Inadequate information about the policy with specific to role clarification also deters parent participation in schools.

The following section examines the complex nature of parent teacher relationships.

#### 7.2.2 Complexities (and contradictions)

My discussion in this section focuses on the intricacies and contradictions that hindered parent involvement in schools. Now I present my argument to support two main claims arguing on one hand that the natural desire by parents to gain control over their children's lives with hope that they would have the best future becomes challenged in the presence of "authoritative" nature of, and resistance by teachers to allow parent involvement in schools while at the same time parents are considered key participants in the process of implementing inclusive education (Department of Education, 2006) On the other hand, the agentive role as family provider critically challenges parents in situations where employers are not supportive to parents..

#### **Claim 4: Parents are torn between the needs of provision and the needs of care**

The stories shared by parents served as evidence of the busy, demanding lives they lived. They confirmed the commitment of parents to do anything to support their families (Ref. 6.4). Working parents' flexibility made it possible to plan meeting times around parents' schedules, although it sometimes seemed difficult to get all the

parents together at the agreed times, everyone showed commitment to the study until the end. The purpose of action reflections and focus groups was to allow time for parents to share experiences and to learn from one another. They were able to vent their frustrations and as a result discussions about starting an inclusive home school and a community-based organisation with the aim of raising awareness of inclusive education were initiated.

Participation in discussions during school meetings seemed difficult with parents appearing more reserved when compared with their participation in focus groups and action reflections - with the exception of Thandi who is quiet by nature. All parents except Grace felt uneasy about attending school meetings without support from the researcher. This can be attributed to the short period of the study. While I expected parents to continue with school meetings after the period of the study, it seemed impossible for three of the parents who still felt uncomfortable about initiating these meetings with the school.

It was of concern to me that parents often spent time away from their children. However, the agentive role of parents compelled them to work hard investing so that their children would not have to struggle as they had (Ref.6.1; 6.4). It was evident from their busy schedules that parents ended up spending time away from their children just as their parents hadn't been able to be with them, as they indicated in their stories of growing up. However, being aware of the parents' cultural, historical and economic value systems, I was sensitive and cautious in facilitating discussion around this matter (Mertens, 2003). As a result, I allowed Grace to lead the discussion around this issue as it happened that by chance that, while reflecting on the previous section, the discussion lead to that issue. Rix and Paige-Smith (2008) found that by virtue of being a parent, the possible self sees a future with the child that is based upon the childhood the parent experienced and subsequent agentive encounters.(3.5). What came up from the discussion was that it was considered more important by parents to bring income that would support the family and ensure better financial security for the children than to be physically present at home for the children. It was also important for parents to know that they spent evenings with their children even if they were away most of the time during the day. This was the main difference between the relationships that parents in this study had with their children

from the kind of parent relationship they had had with their parents with whom they had never spent time.

It was unexpected to discover from reflecting sessions with parents the impact of employer attitudes on parent participation in matters affecting the disabled child. As the theme of this study argues that disability remains “an elephant in the room”, an important finding reveals that employers preferred to offer their employees unpaid leave when they requested time off to attend to school matters rather than engaging in discussion with the parent about matters affecting their children. Lack of support by employers resulted in tension and conflict between parents and teachers. Teachers regarded parents as irresponsible and neglectful of their children when critical /special matters had to be attended to during work hours (Ref. 6.4). Although such cases were not regular occurrences, the results impacted on the parents as they received less income when they were already struggling to live on the regular monthly income.

One critical barrier is the failure of employers to recognise the rights of parents of disabled children to take time to attend to their family responsibilities. While employment should be seen as a means to empower employees, for parents of disabled children employment causes more pressure, especially when the employer is unsupportive of employees.

South Africa’s Constitution and Bill of Rights have made it possible to challenge and overcome such barriers. The Mercury (13 June 2012), described the case of a single mother of a young autistic son who took her employer to court because she was denied her right to take care of her disabled child (3.1). This case made history and brought hope to parents of disabled children who often find themselves challenged when they have to attend to pressing issues affecting the health of their children during work hours. The court ruling in favour of the parent set a legal precedent

...that employers must reasonably accommodate the family responsibility of their staff. For parents of children with disabilities, this case will hopefully signal an acceptance that their child-care responsibilities are important and not automatically out-weighed by employers’ needs (Holness, 2012 cited in the Mercury, 2012:1)

Even though the Promotion of Equality and Prevention of Unfair Discrimination (PEPUDA) and the Bill of Rights protect employees against unfair treatment at work, parents of disabled children still continue to fall prey to their employers when it comes to attending to the needs of their children (6.5.1). This policy includes ensuring that physical and attitudinal barriers do not keep disabled people (including carers of disabled children) out of work opportunities (Swartz and Schneider, 2006).

It was evident during the reflection sessions how frustrating this issue was for parents. Thandi's case bears testimony to the extent that experiences of unsupportive employers were negatively affecting different aspects in her life as a parent (Ref 6.4). To assist in addressing this problem, a human rights perspective was considered an option. A need to empower parents on employment and labour matters with specific reference to their rights as employees was identified. However, engaging the employer in a meeting was not considered an ideal option as parents believed involving a third person would make matters worse. It was preferable for parents to find ways of coping with unfavourable situations at work as at least they were able to put bread on the table at the end of the day. This suggests a need for employer awareness about disability, parents of disabled children and inclusive education as the final section of this chapter expands.

There is something we can learn from Uganda, an advanced country when it comes to implementation of inclusive education. Their adopting a community-based rehabilitation approach to implementing inclusive education proved a successful working model from which much can be learnt. As a result, Uganda's education system is characterised by strong unity and co-operation between families, government, and private and non-government sectors towards supporting families of disabled children to ensure that they participate and benefit in the education system. (Milward et al, 2005). South Africa could consider using lessons from Uganda who engaged communities and supported them through their Alternative Basic Education for Karamoja (ABEK) project and the Oriang Inclusive Education Project in Kenya (Coleridge, 2006) in its efforts to achieve a successful, parent and community integrated inclusive education system.

### **Claim 5: A contradiction between professional attitudes and Inclusive Education Policy complicates parent-professional relationships**

Despite the move towards parent involvement in the inclusion of disabled children in schools, parents' views are still neglected in decision making processes (Soodak, 2004). This seemed true in the case of parents in this study. In the process of engaging with teachers, parents identified some actions which from their own interpretations, they found contradictory to what they believed was the correct way of doing things and what was expected from them. Parents felt undermined and taken for granted when teachers failed to consult and involve them in decision-making concerning their children. They found it contradictory that teachers did not engage them as they expected them to participate in education matters concerning their children. This is indeed provocation of policy as it clearly stipulates that no decision has to be made without parent involvement as (Department of Education, 2008). In addition, parents form part of the multidisciplinary team tasked with the role for evaluation and placement decisions (IDEIA), (IPAS Commission, 2004).

A Department official whom the parent trusted to mediate in a problem the parent and the school were trying to resolve was cited as saying that “inclusive education does not work in the Eastern Cape” (5.4.2)

Other studies looking at parent-professional relationships confirmed the findings that parent-professional relationships tended to be dominated by professionals and that professionals often undermined parents' point of view in problem solving and decision making around their disabled children (Andreassen, 2004; Engelbrecht et al., 2005; Prezant and Marshak 2006; McKenzie et al., 2008; Lundeby and Tossebro, 2008). While I agree with the parent's view, another interpretation would be that inadequate information about expectations according to the policy and resistance to change results in teachers keeping to their own ways of doing things, mainly because they believed it had worked before. Some teachers acknowledged they needed help (Ref.6.3).

Another contradiction was around parent-teacher interaction in schools. The fact that parents felt avoided by teachers (Ref 6.3) and that teachers struggled to make time for school meetings with parents did not help with parent participation in schools but rather contrasted with what the policy says (Ref 3.2). There seems to be correlation

between the two points presented here, avoidance of parents by teachers and teachers struggling to make time for school meetings, suggesting an excuse not to meet with parents as one teacher noted (Ref 6.3.2) on one hand, while on the other, the demands by management also impede teacher commitment to meeting with parents. This also indicates a fault at management level, suggesting lack of commitment to policy implementation as teachers found it difficult to make time due to special meetings they were expected to attend (Ref 6.2). This absence of support by management and the difficulty to make time for meetings by teachers was difficult for parents to understand and to make sense of, as they expected support from schools and the Department of Education who expected them to engage in school matters. While the issue of culture has been discussed earlier as a “constraint to parent participation” (7.2.1), it also comes out strong as a complex matter in that parents believe in the value of Ubuntu and therefore relate in ways that show for instance that they are respectful in relating to others, thereby being torn between desire to please others and suppressing their own frustrations in the process. This proved a tormenting and vulnerable situation for parents to be encountered with (6.3.1).

**Claim 6: Inadequate communication between parents, teachers and Department officials hinder parents’ participation in schools.**

Parents found their own strategies of responding to teachers by avoiding them as a result their decision to “leave it all to the teachers” (Ref 6.2) did not help as their children were the ones negatively affected. Teachers did not communicate to management or the Department of Education their need for support which was lacking (Ref 6.3) and parents struggled to understand why teachers did not ask for help in areas where they needed support. In the absence of communication, parents and teachers made their own interpretations of how the others were feeling or what they were thinking and then based their decisions for actions on their own judgements and perceptions which widened the gap between the two parties. The elephant was also present in the room regarding the issue of communication between parents and teachers. This calls for an urgent need to build equal and respectful parent- professional relationships as without communication, the child suffers the most (McKenzie et al, 2008; Lundeby and Tossebro, 2008).

Research in America on engagement of parents in the education of their children dates back to as early as the late 70's with support initiatives by the government put in place to empower parents and teachers around inclusion (Ref 3.2, pg42). As a result of such supportive initiatives by the state, all stakeholders were able to overcome challenges around inclusion of disabled learners.

The REHAB project assisted by empowering parents and teachers to work together and, as a result, a few disabled children were admitted to mainstream local schools by teachers who had benefited from the REHAB project (Ref 2.4). McKenzie et al., (2008) further noted that both parents and teachers were aware that they were not communicating issues of concern about each other. However, none of them was prepared to break the ice to get the communication flowing. This lack of communication also suggested a need for parents and teachers to get to know about each other in order to work together.

Mbigi and Maree (1995), writing about change management, mentioned the need for self-awareness as well as an awareness of the current situation in order to understand all the dynamics of the situation. This suggests a need for teachers and parents to get to know who they are in order for them to understand each other as they work together making inclusive education reality. Given time, it is possible to address the problem around lack of communication between parents and teachers. The challenge is who will take the lead in the process of making this change happen. I expand on this question in the following section.

### *Summary of Complexities*

The main complex issues hindering active parent participation in schools revolve around the parental agentive role, teacher attitude and lack of engagement by department officials.

Parents found themselves torn between the need to provide for their families and to offer support in time of need. Employers were unsupportive and therefore impatient when parents request time off to attend to school meetings and professional appointments. The negative attitude of teachers contradicted policy expectation of parents as their unwelcoming attitude expelled parents rather than encouraging their

involvement in schools. The department officials also failed to facilitate a conducive environment for parent-teacher engagement, the expected role for them to play as bearer of the policy on inclusive education. In the presence of these issues, parents became confused and less encouraged in their willingness to work with teachers.

Now we look deeper in the qualities presented by parents and how these sustained and encouraged them in dealing with challenges identified in the process of engaging in schools.

### 7.2.3 Capabilities (Competences)

In Nussbaum's (2011) Capabilities Approach, the term "capability" refers to a combination of personal (internal) abilities and external opportunities, namely the political, social and economic environment that enables individuals to live a basic, dignified life. In this study, I share a similar view with Nussbaum in that I specifically refer to what I call the innate ability of parents to withstand difficult situations in their efforts to participate in the process of including and retaining their disabled children in schools. Below I present my claim and discussion to substantiate my point of view.

#### **Claim 7: Resilience is a key innate ability that helps parents withstand difficulties at work and in schools**

According to Fergus and Zimmerman (2005), Cameron et al (2007), and Ungar (2008), being proud of one's culture and adherence to cultural norms and practices makes an individual feel grounded. This grounded-ness in turn helps to enhance an individual's resilience or fosters a sense of belonging and resilience. Resilience is a result of the interaction between an individual and ecology that provides health resources and opportunities to access these resources in a culturally accepted way. Listening to and observing parents throughout this study has taught me much about the meaning assigned by parents to culture and their innate ability to bounce back more strongly every time they experienced a difficult situation. The outstanding lesson gained from engaging with participants in this study is the ability of women to exert a strong and fearless outlook in trying to protect themselves and their families while feelings of hurt, insecurity, fear and doubt would be killing them inside emotionally. I like the way Hoohlo (2012), talks about resilience: "we all come with a reservoir of strength that can withstand severe psycho-emotional, physical and

mental storm, however, this reservoir is something not innate, for if it was, we all would not flounder at the site of adversity” (Hoohlo, 2012:136). Masoga (2012) believes that resilience is a combination of skill and attitude. We learn through hardships to draw out resilience when situations call for it and by so doing our skills become sharpened.

For parents in this study, culture holds value because it provides them with meaning and a sense of belonging while living through adversity. Therefore, in order for an individual to be resilient, he /she has to be culturally grounded in knowing where he/she comes from and that he/she is part of a cultural community tradition that is expressed through daily activities. McCubbin and McCubbin (2005) state that cultural practices and beliefs guide individuals and families as to how to cope when faced with tragedy. As elephants protect their babies and those around them in time of trouble and death, this determination and ability to persevere is noticeable in the way parents stand in support of one another and protect their children. Dass-Brailsford (2005) further affirms that spiritual and religious practices help to build resilience. It is this spiritual connection that helps to build commitment to serving others, something that was evident in my interaction with parents.

The participating parents had a definite ethnic identity, which contributed to their social and psychological meaning and sense of belonging. For the parents, this bond encouraged a sense of cohesion in working together and guided them to access resources, which enhanced the development of resilience (Cameron et al., 2007). I have also learnt much about team work and how finding one positive thing and realising that there is a purpose for every challenging situation, makes you a person better able to teach others to overcome similar situations in life. Parents constantly reflected on difficult situations they had experienced in a positive way noting that such challenges made them resilient. It was also evident how their difficult situations influenced their agentive role as parents. They emphasised that they would do anything to make sure their children do not go through challenges they experience.

Character plays a major role in the way we do things and therefore can be a tool or a barrier to the way we tackle challenges in life. I have found the willingness and ability of the parents to support one another to be very crucial here. Having worked

together for some time, they seem to understand one another's strengths and weaknesses and this facilitates their supporting one another. This understanding of one another, cooperation and support amongst parents confirms the spirit of Ubuntu which Letseka (2012) locates within the African context as the base on which the African "moral" norms of kindness, generosity, compassion, care and courtesy rest. This spirit of solidarity was considered important by parents and in dealing with difficult situations at school and in within their families and communities while raising their children (5.1.1; 5.3.3; 5.4.3; 5.5.2; 6.2.1).

### *Summary of Capabilities*

I have learnt much about the value of Ubuntu and the strength, resilience and the bond shared by these women. Mabovula (2011) notes what she terms the core attributes of Ubuntu while Mbigi (1995: 2) refers to these as key values of Ubuntu. These are "compassion, respect, human dignity, collective unity and group solidarity". In her definition of Ubuntu Mabovula (2011: 41-42) further adds that these core attributes encourage conciliation rather than confrontation. In the process of engaging with schools and teachers about addressing problems experienced in schools, parents were aware their efforts might not benefit them directly but generations to come (parents in this study). I often find it difficult to separate resilience to the concept of Ubuntu. For the practice of Ubuntu requires one to be tolerant of people and circumstances while resilience is the ability to tolerate difficult circumstances while encouraged to face even more difficult situations and still smile to those around you.

Defining the concept of resilience, Dyer (1996) notes "protective factors" that tend to influence the process of resilience. She describes these factors as "healthy skills and abilities or competencies" that the individual can access within, interpersonally or through family support. Dyer's view of resilience is affirmed by Nussbaum's idea around capability implicating that resilience thrives in situations where there is some source of support available and in a culture that promotes values of Ubuntu, such support becomes available. I have observed this in action in the way parents managed to support each other while dealing with challenges in schools. During information sharing and focus group sessions, parents shared about specific

problems they happened to experience, be it at school or at home, but relating to their children. One of the slogans that is commonly used by South Africans in times of political struggles which relates to the attitude expressed by parents in solidarity against challenges in schools is the one that says “an injury to one is an injury to all”, meaning your pain is my pain. I have also learnt much about team work and how finding one positive thing and realising that there is a purpose for every challenging situation, makes you a person better able to teach others to overcome similar situations in life.

#### 7.2.4 Compassion

In the previous discussion I argued that parents possess an innate quality of resilience which gives them the ability to withstand difficult situations in the education of their children. My point of discussion around the claim I make here focuses on the quality of Compassion as a natural gift or strength against all odds, has made it possible for parents to realise that even in hostile situations, they can still relate to others and respond with love. Compassion is one of the innate agentive skills parents possess, a bond that guides parent child relationship, an aspect that teachers would benefit in terms of gaining more understanding about children the teach in working together with parents. Like elephants listening through their limbs, parents find that by listening to their instincts they are often able to pick up when a child or another parent in a support group is going through difficult time. This way, they are able to discern when a disabled child (and not necessarily their own child) is being bothered by something at school. Here the fitting idiom is the one that reminds us that: “It takes an elephant to take another elephant out of a pit”. Parents of disabled children have found it easy to help each other, drawing lessons from similar life experiences.

As a result, parents hold onto the hope that with time and understanding between themselves and teachers, future generations will benefit from the inclusive schools that they together with teachers are able to create. It is the compassionate nature of parents that encouraged them to be resilient and acting selflessly in forging their way through the schools despite difficulties noted and to still understand that

teachers might be going through their own challenges despite being victims of teachers negative attitudes in schools.

**Claim 8: Childhood and motherhood experiences instilled a sense of Ubuntu that was evident in the way parents related to teachers and professionals**

Parents in this study worked together seeking ways to understand beyond the disappointments when they felt let down in their attempts to engage with schools (*The Symbol of an Elephant*, Pg. 16). This attribute of loyalty can be seen in the way parents in this study managed to work together, supporting one another in dealing with challenges in different schools where their children were enrolled. Parents relied on loyalty and unity amongst themselves to pull through the challenges in relation to their children's education. Sedibe (2013) defined Ubuntu as the social currency of Africans and further describes the concept as the Reconstruction Development Program (RDP) of the soul. This definition talks directly to the driving force and the spirit that kept parents committed in their interaction with schools, despite the disappointments outlined in Chapters 5 and 6. It is interesting to note in this study, how parents valued the support received within their communities just by knowing that their disabled children were accepted despite other situations they found to be discriminating against their children (Ref 6.3). For them, a community is like family. The support group also became a community where they called on each other and could open up about the frustrations and challenges they faced with regard to their children.

The key values of Ubuntu that put emphasis on compassion, solidarity, conformity, respect and human dignity (Ref. 1.5) were evident in the way parents conducted themselves throughout this study. For parents, it was important that they worked together in unity in order for inclusive education to succeed. They were aware that people are not all the same. Amongst them there were those who were strong and able to stand up and be vocal for what they believed was right, while they were also sensitive to those amongst them who were quiet by nature and the need for them to work together supporting one another. They were also aware that they could not deny one another the support they could offer even when a parent was not co-operating with the group, as the child would suffer. They were also aware that it might take longer than they anticipated for change in the education system to take

place but their efforts to do what they were capable of, would benefit generations to come (Ref 6.2). Although they were disappointed by the actions of the teachers, they still respected them and chose to respond in ways that would afford them the dignity they deserved as humans. In so doing they ended up withdrawing because fighting back was an option which they opted not to consider.

Despite their children suffering the consequences of their decision to “leave it all to teachers” (Ref.6.2), they were open to the possibility that there might be social circumstances driving teachers to act the way they did although it was frustrating for them to be at the receiving end of such unfavourable responses from teachers and Department officials. The spirit of solidarity amongst parents became the main reason for them to see it through to the end. In other words, by working together, parents believed that they could make inclusive education happen despite the difficulties outlined in this study.

While my discussion here has concentrated on the positive aspects of Ubuntu, there is also the problem that those committed to the values of Ubuntu may be abused in the process of working with those in power (Gouws and van Zyl, 2014). Commenting on the abuse of Ubuntu practice, Giannan, 2011 argued that other cultures have attestations to the fact that every human person is to be treated as a value or as an end, not as a means to an end. She further mentioned that this view, which essentially reflects a Kantian perspective, is claimed to be “universal and universalisable”, an appraisal that should be learned and understood by all those who make use of other people literally as means to achieve their selfish goals/ends (Giannan, 2011:64). This relates more to the role parents are expected to play in implementing inclusive education (Department of Education, 2001).

It is apparent, from the way parents and teachers related to each other in this study, that parents were not receiving the respect which they were giving in the way they were relating to teachers. Their experiences growing up also acted as barriers to the parents’ being assertive and being vocal on issues they were not in agreement with teachers about. For that reason, the fact that they were upholding the values of Ubuntu made them more vulnerable to those who were authoritarian and focusing on power in working with others.

As challenging as it may have been in the light of the parent experiences in working with teachers, the fact that parents were aware that they had a role to play in order for change to happen for the inclusion of disabled children in schools pointed us to the role that parents were to play in being leaders for change to happen in the context of inclusive education. Development is a process and everyone in it will always have something to give for it to succeed. The question is what are you willing to give?

For if we are honest with ourselves, we know that we all face challenges that are big or small... to overcome fear and doubt, to keep working when the outcome of our struggle is uncertain and to forgive others and to challenge ourselves (Obama cited in Mandela, 2010:xiii).

As parents of disabled children continue to work together in addressing the challenges facing their disabled children, they are encouraged by the knowledge that even if their children might not be able to enjoy the fruits of their efforts, generations to come will. As one of the parents commented,

...the situation might not change at school, but I will make it a point that no other disabled child will go through what my child has experienced in that school (Parent 5: 2011).

### *Summary of Compassion*

The values of Ubuntu were evident in the way parents related to teachers and amongst in their own relationships as parents of disabled children. They were encouraged to work in solidarity supporting one another where it was necessary. The selfless attitude they presented in working with teachers encouraged them to focus on the positive things by focusing more on the future with the hope that through their involvement in schools, the situation will change for the benefit of all disabled children.

The innate abilities possessed by parents is considered an important key quality and the driving force for parents as social agents in the inclusion of disabled children in schools.

### *Summary of findings*

My summary of findings is that negative attitudes of teachers towards parents and disabled children constrain parent participation in schools. While the policy on inclusive education calls for parents to actively participate in the process of making schools inclusive, the Department of Education lacks support and intervention in facilitating parent involvement in schools. In addition, teachers indicate that they struggle to understand disabled learners, meaning that they cannot be included where communication does not exist between teachers, children and parents. I believe this is in contradiction to the policy as it encourages parent participation in schools. While teachers need parents in order to understand children, their attitudes make them feel unwelcome in schools. The department promotes inclusion and parent participation but does not facilitate the process to make it possible.

## **7.3 “Eating an Elephant, one bite at a time”**

### 7.3.1 Introduction

The eight claims defended in the previous section are eight “bites” towards “Eating an Elephant”. Having answered the first question in the preceding section, this section addresses answers to the second question of this study: How can parents of disabled children be supported to facilitate their active participation in the inclusion and retention of their children in public schools?

In addressing this question, I draw conclusions from the analysis above in order to build a thesis and develop guidelines for supporting parents to participate actively in addressing challenges pertaining to the admission and retention of their disabled children in schools. I argue that “professional” and teachers in particular, working with disabled children can benefit more about understanding children they work with when they see parents as **social agents and best informants** about their children. In inclusive education, disabled children can also play an agentive role regarding issues of diversity and inclusion in schools and society at large. The innate abilities of parents (7.2) qualify parents to play major role in the process of implementing inclusive education. Successful integration therefore requires teachers to display reasonable positive and accepting attitudes towards disabled children and their parents. As parents and their children come from diverse backgrounds that play a

role in the way they do things, gaining more understanding about them requires the context in which they live considered when working with them. In this light, I propose relevant approach to working with parents and further argue why it is crucial to contextualised teacher parent relationships in the community and local culture and why relationships between parents, teachers and employers need strengthening.

This study is positioned at a time when the Eastern Cape Department of Basic Education continues to make headlines out of concern that the general standard of education is deteriorating with frustrated parents, community and political organisations calling for accountability and action towards an improved education system. Interesting to note in this process, is how the issue of disability and inclusion remains an “Elephant in the room” while ironically other countries continue referring to South Africa as a champion when it comes to policy on Inclusive Education. Even at international level, specialists believe our policy is unbeatable and no other country can match it. Perhaps the current situation presents an opportunity to reflect and draw lessons from the past to inform our action moving forward.

In summary, the claims presented in the preceding section of this chapter indicate that socio-cultural practices, professional dominance and unclear role expectations between parents and teachers constrained parents’ participation in schools. In addition, the complexities associated with the multiple roles parents played in their families resulted in their living hectic lives and this in turn had a negative effect on their engagement in schools. However, because of their innate resilience and the compassion with which they were able to relate to others and one another, they remained confident that with time and perseverance, inclusive education can be realised. It is against this background that I present my recommendations for the nature of support needed to facilitate active participation of parents in schools.

Based on the findings of this study, I recommend:

- An Afrocentric and Capabilities Approach using the CBR Guidelines on Education and Empowerment components specifically. A Community-Based Rehabilitation approach will counteract the overpowering of parents’ voices by those of practitioners and allow parents as social agents which through

engagement, we constitute and out of which we are constituted (3.5.3), to play a meaningful role in the process in including a disabled child in learning.

- Empowerment of parents and teachers and awareness around Inclusive Education Policy, disability and employee rights with focus on employers, communities, teachers and all role players in inclusive education
- Transformational leadership aimed at empowering parents as facilitators and drivers of inclusive education
- Policy evaluation focusing on the implementation of White Paper 6 on Inclusive Education, with specific progress made and challenges experienced.

### 7.3.2 An Afrocentric and Capabilities Approach powered by the CBR Guidelines towards an Inclusive Education system

Findings from this study confirm that, unless our development approaches can encompass the values of Ubuntu in a transformative way, it is impossible to achieve a sustainable development (Mbigi and Maree, 1995). The two approaches, Afrocentric and Capabilities approach informed my approach to this study. Owusu-Ansah and Mji (2013) claim that an Afrocentric approach acknowledges the African voice and reaffirms the centrality of cultural experience. An Afrocentric approach assisted in opening up the world of parents so that at the end I could understand why meetings had to happen on specific days and not on others, why it was important for parents to prioritise work to spending time at home with their children.

It is imperative that in developing strategies for effective transformation, reference should be made to the African religious and cultural experiences as these are encompassed in all aspects of their lives (Mbigi and Maree, 1995). Dass-Brailsford (2005) affirm that spiritual and religious practices help to build resilience and that it is this spiritual connection that helps to build commitment to serving others, something that was evident in my interaction with parents. The attitude of selflessness, the interconnection and solidarity exhibited by parents in working together was very evident and made it possible for them to support one another at the time of need and in turn parents. I observed with fascination when parents requested feedback from specific parents on areas reported as challenges in previous meetings during focus

group and reflective sessions. In cases when a parent would not make it for planned meetings, those present would be concerned worrying if anything bad would have happened to the person to an extent that parents would call and enquire at the end of the meeting. Throughout the period of the study parents showed attitude that they believed it was not about them but about the children's future at the end of it all. I was able to gain more understanding as to why it was important to begin and to end every meeting with a prayer and even to pray together at times when one of the parents shared an overwhelming problem in her life or why it was important to cancel meetings when one of the parents had a funeral or a traditional occasion so that others in the group could also be there to show support.

It is the Capabilities Approach that made it possible to discover the resilient nature of and the humanity in parents. Parents acknowledged that they were able to work in unity and to support one another in addressing difficult situations in schools even when they were not directly affected. They were always there for support if one of them got overwhelmed by a problem at school. For parents in this study, culture holds value because it provides meaning to them and a sense of belonging while living through adversity. Therefore, in order for an individual to be resilient, he/she has to be culturally grounded in knowing where he/she comes from and that he/she is part of a cultural community tradition that is expressed through daily activities.

McCubbin and McCubbin (2005) state that cultural practices and beliefs guide individuals and families as to how to cope when faced with tragedy. Parents believed that it was for a purpose that they had been through difficult times growing up. They drew strength from lessons they had learnt during times of hardship. They were encouraged to persevere in life and to work harder so as to secure the best future for their children. The value of Ubuntu, which was evident through the respectful manner "intlonipho" in which parents related to teachers and employers, though not reciprocated, resulted from lessons learnt about socialisation during childhood. I noted earlier in the previous section the crucial values of Ubuntu possessed by parents. Parents realised that, united, they were able to overcome difficult situations in schools and at work. It was important for employers, teachers and the Department of Education officials to treat parents with the dignity that human beings

need, realising that they had needs, some of which were demanding because of the nature of support that was required for their disabled children.

It is evident from the observations, perceptions and experiences of participants that there is a need to empower not just teachers but all role players around issues of inclusion. For a long time in the past, parents had not been excluded from participating in the education system and in particular to participate in the education of their children. In general, teachers and parents operated in two different worlds and parents who were non-educated regarding matters that have to do with schooling as concerns for teachers (McKenzie et al., 2008; Lundeby and Tossebro, 2008)

In order to address such imbalances of the past within the education system, specifically parent participation and the inclusion of disabled children in the education system, we need to focus our emphasis and effort on the empowerment of parents and the community at large as the two were not recognised as role players in the past. The CBR Guidelines (Ref 3.5.3) is a relevant tool that can be used in the process of empowering role players around issues of inclusion with specifically, inclusive education (Okune, 2008) as it acknowledges the following Indigenous Knowledge Systems:

1. An inclusive and human rights approach towards developing the lives of disabled people. The “training in the community for disabled people manual” was developed as a guide and skills development tool for professionals working with disabled people at grass-roots level
2. The importance of empowering disabled people, their families and communities as a means to achieve equal rights and opportunities for disabled people in their communities
3. That communities and their needs differ (thereby reinforcing the centrality of the African culture) and therefore implementation needs to take cognisance of the various aspects under review. For example, the education component, focuses on early childhood development, non-formal, formal (primary), secondary (including higher) and life-long learning. Based on the community situation and its needs, an education development project needs to be appropriate and relevant to the needs of each community.

Because of its emphasis on community empowerment, active participation and rights based and holistic approach to community upliftment, the CBR can be used as an appropriate vehicle to develop a transformation leadership program for parents of disabled children, ensuring active participation in the inclusion and retention of disabled children in schools.

As a platform for sharing experiences within the African continent, the Community Rehabilitation Africa Network (CAN) (Ref 3.5.3) is an appropriate vehicle while CBM International focusing is the right platform to share information and to lobby for relevant support internationally. The international platform can benefit both African and Western countries in terms of cultural exchanges, empowerment and awareness specifically for Inclusive Education Development.

For parents, teachers and employers, the presence of CBM in South Africa presents an opportunity to grow a collaborative problem-solving culture (Miles, 2009). The platform can benefit education, work and community sectors, in building effective relationships, to reflect upon and to interrogate education practices that will ensure inclusion and retention of disabled children in schools. In addition, CBR information sessions present a platform where parents who are well-informed about policy matters can support the less informed with specific reference to rights and responsibilities as in the case of the parent who took legal steps against her employer when she was deprived time to attend to her disabled child (Ref 3.1)

### 7.3.3 Awareness around Inclusive Education Policy and disability with focus on employers, communities, teachers and all role players in inclusive education

Combined with Capabilities and Afrocentric approaches, a critical approach in exploring the world of parents made it possible to identify and talk about parents' frustrations relating to issues of culture and how they felt powerless to challenge teachers where it was necessary (Ref 6.1). At the same time parent capabilities were identified as a point of departure in overcoming challenges. The findings revealed inadequate awareness around the policy. However, I noted that inadequate communication between parents and teachers made it impossible to identify specific

reasons why teachers were regarded as portraying a “negative attitude” towards children. In this case, I cautiously argue that teachers might have been frustrated as a result of underlying unresolved issues affecting them in school. For example, the lack of support from the Department of Basic Education in the light of the existing critical conditions in the Eastern Cape Province.

A previous similar study by REHAB concurred with the findings of this study. The high number of learners in classrooms seemed to be one of the concerns that affected teachers’ ability and willingness to accommodate disabled children in their classes (McKenzie et al., 2008). This emerged in my previous work with teachers during the REHAB project and again from the school meeting in this study. Teachers mentioned that they found it difficult to include learners who had speech defects during class lessons.

One of the teachers admitted that he did not know how to accommodate / teach the child during lessons and therefore the child felt isolated or neglected during the lessons. Wood and Goba (2009) reported that it could result in a “lose-lose” situation when learners become deprived of the teacher’s attention. Teachers complained about their professional workload - that with no teacher aid/assistance in class, they had to fill those gaps and sometimes they found themselves playing counsellor/ social worker roles, which is not an easy task, especially since teachers have not received any kind of training in these areas (Coombe, 2003; Bhana et al., 2006; Theron, 2007). With many children in a class, teachers become challenged and their frustration affects their relating to others.

Coombe (2003) noted that teachers were not coping with the multiple roles that they had to play in situations where they have to include vulnerable children in their classes. For example, with a lack of resources in schools, teachers had to play a number of different roles such as caregiver, social worker, counsellor, and educator. This was a challenge for them, according to Theron (2007). Some teachers felt stressed and responded inappropriately to marginalised children.

Children need to be loved, to be cared for, to feel accepted and valued by individuals and to have a sense of belonging. They also need psycho-social support, which is

support that goes beyond catering for the physical or material needs of an individual, to his/her emotional and social wellbeing, which has a bearing on psychosocial health (Killian, 2003; Subbarao and Coury, 2004). By taking these into consideration, teachers will be playing a major role in supporting parents. This might have been a reason that teachers became frustrated and ended up reacting “negatively” towards disabled children and their parents. However Yssel et al. (2007) warns that teachers need to be aware that a school is a microcosm of the world. Therefore in order to understand the realities of parents of disabled children, teachers need to guard against any possible attitudinal barriers (Yssel et al.,2007).

One of the strategies I adopted during the focus group and the information sharing sessions with parents was to summarise and translate the policy document on Inclusive Education as parents indicated a need to be informed about the policy. This strategy worked so well that parents organised copies of the document in the form of small brochures which they handed out to other members of the parent support group. The fact that the document was written in their own language, and in a summarised version, made it easy for them to understand it and to teach others in their communities. This suggests a need to empower stake holders around Inclusive Education Policy using Indigenous Knowledge Systems as used in this study. In practice, significant ideas and practices need to be translated so that they are locally relevant (Mbigi and Maree, 1995). An example would be to simplify and translate policies relating to Inclusive Education so that different sectors in communities could relate to them.

Having noted that parents do possess leadership qualities that need to be enhanced, it would be a futile exercise to rely solely on parents to drive the change process in the education of the disabled children as leadership is a two way process (Maynard (2011) In other words, the roles of the teachers and employers are also crucial. Parents seemed to be more frustrated that time was being wasted and their children were getting older and no intervention from the department was taking place. In a study on vulnerable children in schools, Mallman (2003) pointed out that the educators’ attitudes largely determine the acceptance and/ rejection of a disabled child in a classroom and at school. Therefore, countering discrimination must be a

core part of inclusive education policies and programmes in schools. Training in addressing issues of disability and discrimination needs to be integrated into pre- and in-service education in order to make learning sites inclusive (UNESCO, 2007). This is the area where academic institutions can play a role towards empowering teachers by integrating inclusive education as part of teacher training and development.

#### 7.3.4 Transformational leadership aimed at empowering parents as facilitators and drivers of inclusive education

The overall discussion in substantiating the claims I made earlier in this chapter points to two specific realities. One of these is the fact that parents are expected to play an active role in the process on implementing the Inclusive Education Policy (Department of Basic Education, 2006). However the socio-cultural, economic and political environment in which they were raised and currently live hinders their engagement in the process of inclusive education. Secondly, I have argued that in my interaction with parents and in my work environments (including the period of undertaking this study), I have identified two innate abilities (gifts / strengths) parents possess: resilience and the ability to lead.

Nussbaum's Capabilities Approach (2006; 2011) maintains that capabilities are not merely innate abilities but involve the social, economic and political "opportunities" in one's environment. Note the term "opportunity" which she interchangeable uses with the term "freedoms", depicting that humans are created (born) with a quality' of dignity in them and therefore need to be respected in order for them to flourish in life. Nussbaum (2006; 2011) stresses that environmental factors play a major role in enabling or disabling a person. Environmental factors are key determinants of what the person is able to do and to be. Simply put, it is pointless to rely on one's innate abilities when there are no opportunities or freedom to nurture and to express those gifts in order to become what you were created to be. Concurring with Nussbaum' point of view, I acknowledge the fact that parents are capable of taking on the leadership role as drivers in the process of making inclusive education reality in their communities. I argue that stakeholders for inclusive education (including employers) (Ref. WP 6 on Inclusive Education) can work together by supporting parents in their leadership role thereby enhancing the ability of parents to lead. The

leadership role I refer to is that of parents being facilitators for the inclusion and retention of disabled children in schools focusing on their local communities.

Having presented my view on the issue of the interconnectedness between internal abilities and external environment “combined capabilities”, I acknowledge that it is practically impossible to base my argument solely on stakeholders’ supportive attitudes in order for parents to take on the leadership role. Mbigi and Maree (1995) argue that in the context of the South African history, and I include the cultural and socio-economic diversity, for change and sustainable development to happen, citizens need to embrace the inward journey of discovering who they are in order to realise who they can become.

We need an inclusive structure that will incorporate the African, Eastern and Western concepts and practices supported by African intellectuals and powered by parents and community based organisations (Mbigi and Maree, 1995). Success of an initiative, where a diverse group of people find themselves working together, calls for some form of mutual respect, compassion, conformity and solidarity amongst participants. The latter statement talks to the values of Ubuntu as key consideration (Mbigi and Maree, 1995; Mda, 2000 and Sedibe, 2013), Which could be considered an RDP of the soul and a universal tool for successful development projects, Considering that a robust relevant strategy is necessary if we are to expect parents to confidently perform their new role, I advocate a transformational leadership program informed by an Afrocentric and Capabilities Approach, which acknowledges both Indigenous Knowledge Systems and the values of Ubuntu in community development. I further believe that Community Based Rehabilitation Guidelines (WHO, 2010) is an appropriate vehicle to drive this program.

Nussbaum (2006) holds that in political participation, the capability to engage women is vital and considers this as an “appropriate social goal”. This relates to transformational leadership for parents of disabled children, a strategy I advocate in this study. Despite the history of marginalisation in leadership roles and in the field of education, findings in this study confirm that parents are capable of being leaders. The acknowledgement by parents that they could not sit back while their children suffered in schools confirms the ability of parents to lead. A number of writers on

leadership agree that the most crucial and key quality of a leader is that he/she is a doer (Bass and Riggo, 2006; Maxwell, 2007 Leigh and Maynard, 2011). Parents made it a priority to attend to matters that required their presence in schools despite teachers and employers presenting as barriers in that process. They were prepared to do what they could to make sure that their children did not experience the same difficult situations in life growing up as they had. This was evident in the busy lives they lived working hard in their attempts to secure better lives for their children.

The concept of leadership includes more than just interaction between leader and follower but rather the ability to inspire others to see the wood for the trees. Without knowledge and confidence in what you believe, it is impossible to inspire others. Transformational leaders therefore, are seen as doers who inspire those around them by providing meaning, hope and challenge to their work. (Bass and Riggo, 2006; Leigh and Maynard, 2011). This leadership talks more to the expected role of the District Support Team entrusted with the task to support schools on inclusion matters. It was worrying that teachers felt despondent about getting support from the Department while the policy stipulates that the District Based Support Team (DBST) is the main body entrusted with the role of supporting schools. This suggests lack of capacity which might be a result of lack of policy understanding at management level. The comment by an official at management level that “inclusive education does not work” (Ref 5.3) also proved lack of commitment to inclusive education and therefore there is an urgent need for not just empowering managers but for a skills assessment of officials employed by the Department of Education and the evaluation of the Inclusive Education program by the Department of Basic Education if we are to impact change at school level.

It is evident from the observations, perceptions and experiences of participants that there is need to empower, not just teachers but all role players, about issues of inclusion. In order to address the imbalances of the past within the education system, specifically parent participation and the inclusion of disabled, we need to focus our emphasis and effort on the empowerment of parents and the community at large as the two were not recognised as role players in the past. CBR as a strategy for community development (Ref 3.5) empowers role players around issues of inclusive education (Okune, 2008) empowering disabled people, their families and

communities at large promotes the equal rights and opportunities for disabled children as learners (Ref. 3.5.3). More importantly, to effect the change needed in the process of making schools inclusive is the fact that it calls for a bottom-up approach to community upliftment (talking more to parent, employer and teacher relationships) that is fostered through CBR programmes. In addition, the context in which parents and their children live, learn, work and play would be the focus of attention. The holistic view in developing parent skills is also key to the successful policy implementation regarding inclusive education.

The transformational leader is an effective listener who recognizes and is accepting of other members' individual differences (Leigh and Maynard, 2011). This leadership approach talks to the approach presented by parents in their relation with teachers. Mbigi and Maree (1995) argue that it is impossible for managers to create change unless they themselves are changed. The challenge becomes the issue of ensuring that parents irrespective of education and location (rural/urban) take on this role. Research conducted and experience in the field of inclusive education and parent participation confirms that parent professional relationships are often dominated by professionals as parents were not part of such forums in the past (McKenzie et al., 2008; Lundeby and Tossebro, 2008; Polat, 2010). Hartley, Murira, Mwangoma and Carter (2005) added their observations in working with rural women, noting that in many cultures, community leadership tends to be male-dominated while women mainly focus on family nurturing.

It is crucial that parents are supported in their attempts to play their role in the inclusive education platform. As mentioned in this section earlier, the Afrocentric approach to parent empowerment can play a significant role here as conventional western teaching may not always be adequate or relevant. Mbigi and Maree (1995) note that transformation is not only an academic journey but a collective social, spiritual and psychological journey that involves the creation of new rituals. This is an area where parents might find dances, songs and story-telling, poetry and proverbs relevant. While it focuses on change, transformational leadership is said to inspire followers to commit to shared visions and goals challenging them to be innovative problem- solvers while sharpening leadership skills in the process of challenge and support (Bass and Riggo, 2006). This makes the transformational leadership

paradigm an ideal choice for consideration in supporting parents of disabled children towards inclusion.

## **7.4 Conclusion**

A number of “combined capabilities” afforded me the opportunity to build the thesis of this study. Amongst these are the passion I have for the community development work I do, the resilience and the patient manner in which I have been able to engage with different people and overcome difficult situations in the process. The choice I made to use critical theory, and a selection of research approaches that continued to challenge me to think about relevant strategies for addressing my research questions all have been instrumental towards building of this thesis. The Afrocentric and Capability approaches combined with the indigenous forms of my data collection such as stories told by parents about their lives and the role played by culture in shaping their lives, their interaction with teachers and discovering the impact their relationship with employers had on their participation in schools were all vital.

Finally, all these opportunities combined made it possible for me to present this thesis which in summary calls for a program that will empower parents of disabled children to facilitate the process of inclusion and retention of disabled children in schools. This transformational leadership program needs to be informed by the Capabilities and Afrocentric Approaches as these acknowledge the value of Ubuntu, vital in parent professional relationship that Inclusive Education is about. The logic behind this transformational leadership program for parents is that when parents become empowered, they can then become assertive in negotiating their ways with employers and teachers and other professionals such as therapists working with their disabled children. The awareness programs focusing on Inclusive Education Policy that I advocate will help build partnerships based on understanding, solidarity, respect and compassion amongst stakeholders in the process of ensuring inclusion and retention of disabled children in schools. As Mbigi (1997:34) advised:

The starting point to finding one another is for us to celebrate our cultural diversity. We need to accept our differences, cherish our similarities and forge a common collective agenda that will lead to a high sense of collective shared destiny.

Truly, without this, it will be very difficult for us to succeed!

## **Chapter 8: A Research Journey: Significance, Limitations and the Role of the Researcher**

### **8.1 Introduction**

The decision to separate this chapter from the main thesis is to keep focus to key participants in the previous section. This section mainly focuses on lessons and experiences of the researcher.

Initiating and participating in this study has been an interesting and challenging experience for me. The most challenging ‘assignment’ was to get to the point of deciding to take on the role of the principal researcher. In reality, I am a community development facilitator who is passionate about issues of empowerment and social justice. For this reason, the developmental paradigm had a strong influence on this study.

Participants came from a community where my stance on issues of social justice and civil society was known and I had to engage with people who saw me as a “whistle blower” having exposed issues of corruption in my local community. This meant that I had, first of all, to position myself strategically and stay focused in my role as a researcher. This in turn helped me to clarify my new role, that of a researcher, to parents and educators who knew me as a REHAB facilitator, a civil society “whistle blower” and a disability inclusion “activist”.

Taylor et al. (2008) points out that tradition and culture play a significant role in our lives and an aspect of our lives that need consideration in our developmental engagements with others. The qualitative aspect of this study made it possible for me to engage with and observe participants in their settings, an Afrocentric approach helped me analyse their actions according to their own culture and the context in which they live while a Capabilities approach guided my analysis of how teachers, the Department of Basic Education, employers and participants’ own circumstances affected their participation in schools.

The purpose of this study and the approach it took has been a very informative personal journey for me with moments of self-discovery in the process of engaging

with parents of disabled children. As the principal researcher, I had to take off my own lens and see the world through the lens of others. The decision to take on this study and specifically, my role as a principal researcher in the field I have been involved (for more than ten years) as a development facilitator and civil society activist, was like stepping out of myself into a 'new self' so that I could achieve my research goals without being biased by my own view of life. Although it was challenging to stay focused, having to keep reminding participants and educators of my role in this research also helped me to remain focused. I took heed of Creswell (2008) advice that one cannot deny the fact that in qualitative research the researcher comes with his/her own experiences and beliefs that do affect how one analyses data. However the ability to temporarily suspend one's own beliefs, maintaining some balance between objectivity and empathy, becomes vital.

The session that now follows focuses on the significance and implications of this study, its limitations, my position in relation to the dual role I played; and I also share thoughts from my personal diary in an attempt to show how my role as a researcher has affected/influenced me holistically.

## **8.2 Significance**

I begin this session by drawing lessons from my interaction with parents during this study and suggest possible lessons in the field of development and training. I also suggest ways in which further research could expand on findings from this study.

**Development Field:** Findings of this study confirm that culture plays a major role in what people do and become in their lives (Nussbaum, 2011). Development practitioners need an understanding of culture in order to work facilitatively and to get a better understanding of and co-operation from parents and other stakeholders they work with. The Afrocentric and Capabilities Approach which has informed this study acknowledges the values of Ubuntu. As a result, I gained respect from parents and also I managed to respect them and their actions and the decisions they had to take. With solidarity, trust and openness, parents managed to support each and to overcome challenges they came across in their participation in schools (Mbigi, 1995). This is vital if we are to strengthen relations between parents, teachers and employers. Leadership programs aimed at empowering parents to be "assertive" in

relating to teachers and other professionals, at the same time showing that they can be assertive in negotiating their ways with their employers. For parents, employers and teachers, the presence of CBM in South Africa presents an opportunity to grow a collaborative problem-solving culture (Miles, 2009). As an established Community Based Movement with international networks already established, the platform can benefit schools and communities in their attempts to build effective relationships, share experiences and lessons with others in the field of inclusive education, reflect upon and interrogate education practices.

**Policy:** We need to ask the question about how the policy helps facilitate parent participation and at how the National Development Plan (NDP) and Integrated Development Plans talk to inclusive Education Policy. Through the IDP and NDP, community based organisations can be able to build effective partnership with local and national government. Another crucial aspect towards enabling policy implementation is that when systems are in place stakeholder participation should be supported; government can then put in place enforcement laws to hold citizens accountable for the success of inclusive education programs.

**Academic institutions and graduates:** Empowerment is about building capacity. My recommendation for Nussbaum's Capabilities approach in empowering stakeholders to engage in the implementation of Inclusive Education policy is it should acknowledge innate abilities and external factors in empowering individuals. In selecting potential educators, academic institutions need to start with what qualities students (potential students) have by making selection criteria talk to qualities or personal attributes and selecting those with a passion to work with people and build on these. Placements for student practice need to take into consideration Indigenous Knowledge Systems in order to make training relevant to those it intends to focus on.

By so doing teachers will become accountable and committed to the process of inclusion with an understanding of the families they have to work with. Academic Institutions can also see to the accessibility of information at the level of understanding by the end user (develop manuals for NGOs). The tertiary institutions have a role to play in building the capacity of educators around the policy on

inclusive education. Undergraduate and postgraduate courses would benefit students and educators in advancing their knowledge specifically of the White Paper 6 on Inclusive Education.

### **8.3 Limitations of the Study**

I am aware that there are some easily discernible weaknesses in this research study. For example, I noted the following limitations:

- The study covers only a small fraction of the number of potential participants for such a study. This limits the claim of representativeness. However, it was not the intention of this research to assemble representative data but to assemble data which would shed light on what parents of disabled children in basic education view as relevant support for them in the process of actively engaging in the education of their children. The study only involved rural parents of disabled learners in public schools and all participants were mothers, not a single father was involved. Although only two of the participants lived with their partners, the decision that only the mother of the child should participate was jointly and voluntarily made by those parents.
- In addition, related to the limitation concerning the quality of the interviews and, by implication, data emerging from these, is the fact that the interviews were, to a large extent, carried out in isiXhosa and translated into English during transcription. Some meaning and nuances may have been lost in the translation. As the type of data collected was qualitative, it was possible to get more insight into the perceptions of participants and meanings given to events. However, as pointed out earlier, these perceptions and meanings were interpreted keeping in mind the nature of data gathering process and my double role. This might possibly have placed restrictions on the type of meanings expressed (vocally). On the other hand, this created opportunities for open discussions within the group.
- Within limitations such as different context, limited time and changes in repeated measures in which a research study is conducted, I acknowledge these variables might have an impact in influencing findings from another study of the same nature as this one. This study took place over a period of 18 months with gaps of about 1 and 3 months in between the school meetings, interviews, focus and

reflective sessions. For this reason, I also acknowledge that findings from this study might have been influenced by the limited time period and different contexts (school, home and other places) in which interviews, focus groups and reflective sessions have been conducted. However, I believe that the schools, policy makers, disability organisations and researchers interested in developing parent teacher relationships can benefit from the findings of this study.

### 8.3.1 Potential Contribution of this Study

To the theory, the study adds to the literature already existing on experiences and views of parents with disabled children, and, more importantly in my view, do so in a way that is specifically contextualised to the circumstances peculiar to rural parents with children in public schools. In my readings, while reviewing literature on previous research conducted, I did not come across literature pertaining to the experiences of parents with regard to what they viewed as relevant support for them in the process of engaging in their children's education. The study contributes to the existing literature and offer new insights into the problems from another perspective, which provides material for future research.

The finding that teacher attitudes and Department interventions have a strong impact on parent involvement in schools makes an important contribution to the design of future research into developing co-operation amongst parents, educators and the role that the Department can play in making the policy on inclusive education reality. Findings of this study can also contribute to changing peoples' mind sets around disability in schools.

As regards the development field, as a development facilitator working with professionals in different fields, this study has helped me gain skills and knowledge that I can pass on to relevant professionals who work with parents and disabled children that I come across in projects I engage in. I can make recommendations to academic institutions and other learning support institutions for the development of courses aimed at supporting parent interventions and making schools inclusive sites for learning. This could result in future graduates in the education field being well informed about the policy on inclusive education and with better understanding of

issues affecting parents of disabled children, thereby contributing to development of professional expertise. Educators will also be conscious of how they relate to and affect disabled children and parents.

The study has contributed to knowledge about research methodology for working with groups for whom English is not their home/first language and who experience difficulty in orally explaining their thoughts and feelings. For example, I found the combined use of narratives from the interviews, reflections and collective learning very effective for collecting the kind of data I needed to collect. Future researchers in this field could replicate the methods I used in this study for working with similar groups.

#### **8.4 My Personal Journey**

I have been referred to as someone who is diplomatic in my approach in addressing socio-political issues on the ground. This might be the reason that I seem to be cautious in relating to some of the politicians and business-minded people in my circle. For me, community development and politics are completely different things and, therefore, need to be addressed separately. I have experienced situations where people at grass roots level who are desperately in need of social services suffer as funders withdraw the support which was initially aimed at improving their lives because of disagreements amongst politicians with regard to the credit given to one political party or another. I have experienced situations where children had to suffer and have their destinies compromised while those regarded as their carers enriched themselves and others in the community keeping quiet mainly because you don't talk about such issues! Yet we continue asking questions that we cannot answer when the current younger generation behaves in ways we don't understand.

I have observed disabled children moved out of their local schools to different schools with negative implications for the family in terms of support for the child, because it was just the easiest thing to do in addressing challenges at school. Parents continue to send their children to school for the sake of attending school despite concerns about what will happen to their children when they reach time to be out of school. With little or no knowledge about the policy on inclusive education and despite, the challenging socio-economic and cultural situations in which parents

were raised, they still persevere with the hope that things will change one day. In my interaction with these parents, I have learnt the true meaning of what it means to persevere in patience. Despite the noise made by parents in this regard, they seem to be listened to only in times when it is politically convenient to get them talking. While these parents continue to find support in working together, I believe amongst others, disability NGOs and community activists can play major role in supporting parents with disabled children. Nussbaum (2011) warns those in power to be cautious that their actions do not deprive others of basic human rights. They deserve to live a dignified life.

Mbigi (1995) and Ramphela (2006) advise that morality needs to inform the actions of leaders if they are to retain their credibility and to empower people to be the best they can be. An important suggestion by Mamphela (2006) is that we need to find effective ways of addressing our own challenges from our past. In an African culture, a true leader is one who willingly serves others. The connotation is that you do to others what you would like to be done to you. Through the ability to serve and withstand difficult situations, parents can play a major role when supported as leaders in making schools inclusive. Through their stories about their childhood experiences, they proved that they are able to face their own challenges, an indication that they are capable of leading by example. As leaders, parents can hold others accountable for their roles in the process of implementing inclusive education.

Issues pertaining to civil society empowerment and development are very crucial to me and close to my heart. I mentioned earlier that this is what I believe I was born to do. I strongly believe that a developmental approach rather than the conventional approach is key to unlocking the gifts and potential that exists in most people in disadvantaged and underdeveloped society. I concur with Taylor's (2008) view that a conventional paradigm for development often leads to dependency and disruption of existing viable paths of development, while a developmental paradigm, on the other hand, involves working facilitatively alongside people so that they may develop their capacity to exert authority over their own lives and futures, to make their own choices. This supports my argument that academic institutions, community organisations and local municipalities have a major role to play in ensuring that

stakeholders are empowered to play an effective role in the process of making inclusive education reality.

For five years I have been supporting parents with the aim of addressing the gap between the rights of children and their access to education. My personal and cultural beliefs are constantly challenged in my attempts to establish how these parents manage to support their children in making sure that they are included and as well as retained in schools. As a person who believes that one does not just do something for the sake of getting it done or because everyone else does it, I often find myself in trouble and in many cases, I find myself stuck in assignments without realising it when I start advising or tackling such issues. The challenge here is that although I seem to attract such issues in my life, issues that often start as small/minor things like giving advice they end up taking a bigger portion of my time. I end up being absorbed in a number of projects as a result. Being a single parent I continue to draw lessons through the challenges of trying to find balance between motherhood and being a support to others.

At one point in my life, when my son was still at pre-school, I had to fetch him from school after work, spend some time with him during bath and supper time and then I had to take him with me to the community meetings as there was no one to help at home. I remember the comment he made when I had to ask a friend to stay with him in the car while I attended one of the meetings. He watched through the window while I was talking, facilitating the meeting and commented, “Sis Yandi, I did not know my mom is a preacher... and when is that church coming out...” Although I was parenting a very young child at that time, I had to make sure I attended evening meetings as that was the time when everyone was available in the communities I was committed to support.

Reflecting on one of the sessions with parents, I was reminded of my son’s comment when he referred to me as “a preacher”. This made me to interrogate my communication and listening skills in my community engagements, working with parents in particular. I realised that my desire to see things work out the way I “foresaw” them posed a challenge in the way I facilitated discussions with parents. By spending more time talking than listening (unconsciously because I wanted to get

things done), I ended up doing things for, rather than empowering others to do things themselves. For this reason parents kept coming back to me in trying to address their challenges. This became evident when parents became panicky when they realised that I was not going to accompany them when they had to present their challenges during the parliamentary hearings (Parents and Researcher, UNCRPD, August, 2012). Although this particular study does not report on it, this incident has impacted positively on the confidence of parents in addressing their challenges.

Culturally, I continue to experience challenges, especially in rural communities where older men find it challenging to appear to be “taking orders” from a young girl / woman whom they see as their daughter, in the same way that parents feel uncomfortable giving orders to the teachers. There were times when I was new in the field of work that community meetings would drag as we tried to reach consensus in discussing differing views of the younger and older generation on how project issues needed to be dealt with. There were situations where older men would openly comment “*sekutheni ngoku siphathwa ngabantwana? Ngathi izigqibo zale lali zithathwa ngabo nje ngoku*” (what happens now that decisions in this community are taken by children) (IDT, 2000). Women barely spoke in those meetings, although the situation seem gradually to be changing as more women are now taking leadership positions in their communities, but you still find many of them keeping low profiles especially in rural communities and especially less educated and older women. Such situations taught me to be firm yet respectful in order to successfully achieve specific goals in different communities. These are the some of the experiences that have helped me to understand the challenges facing parents with disabled children.

School meetings were the most challenging for me as the facilitator and researcher. During and after the school meetings I went through different emotions. There were times when I felt energised as I looked forward to getting parents, learners, educators and employers to freely share their thoughts and feelings about issues at school and at home regarding the learner. I often ended up frustrated, observing the frustration, panic and fear that were visible as parents participated, while educators were very relaxed, so much so that their stature (the boldness in expressing themselves) appeared to be intimidating and dominating. This also made me angry

at times especially when the teacher appeared as the one who knew everything and failed to acknowledge the parent's wealth of knowledge about the child.

I cried a few times, reflecting on some of the meetings because I knew how it felt to be in an intimidating situation where you had to participate or express yourself in the presence of other people. That difficulty, which is normal in the beginning, but is so much worse in an intimidating situation. I worried, wondering whether parents would follow up at times when they were not available; we rejoiced together when they shared encouraging stories about their children's progress and when they managed to share their frustrations without my presence to a number of people in parliament. I personally felt the encouragement as I facilitated school meetings and this had a positive influence on my relationship with my child. It became something strange to go to bed without chatting about life at school. Generally, this had tremendous effect on the way we dealt with school matters at home.

## **8.5 Conclusion**

Discovering myself in the process of working with parents has been a challenging, yet exciting and enriching journey. The combination of indigenous knowledge systems and focus groups and reflective sessions has made it easier for parents to share their experiences and participate freely in the study as story telling related to their way of life. This chapter has expanded on how development workers and academic institutions can learn from this study in order to strengthen and ensure successful partnerships with parents. Findings have confirmed that parents possess the ability to take on the leadership role and to drive the process of inclusive education in their local communities when supported and empowered to be assertive. Hence my recommendation for a transformational leadership program that will allow ghosts from their past to be laid to rest (Ramphele, 2008) so that they can in turn help others lay to rest ghosts hindering the process of making schools inclusive sites for learning, thereby "awakening the elephant in the room".

The findings can be used as a guideline for the development of programs for working with and supporting parents of disabled children in the field of inclusive education.

## **Part 4: Conclusion and Recommendations**

This final section gives a summary of the entire study and based on the findings of this research, puts forth recommendations suggesting areas for further possible research.



*Reflective Session: Researcher*

## **Chapter 9: Reflective Summary of the Study**

### **9.1 Introduction**

The symbol of an elephant was used as an opening to this study. The idiom of ‘an elephant in the room’ has been used to show how uncomfortable people generally feel when it comes to addressing matters relating to disabled people and specifically disabled children in schools. The *leit motif* of an elephant that threads through this study also relates to the strong character of women, the resilient nature, compassion and the collective unity observed through childhood stories of parents (Chapter 5); the way they worked together during focus groups and reflective sessions as well as their participation in school meetings. (Chapters 6 and 7). The need for this kind of study is related to literature reviewed in Chapters 2 and 3 specifically to similar studies conducted in the field of inclusive education and parent participation, the REHAB project is an example of recent work conducted in the Eastern Cape Province and the area where this study was conducted. These chapters again put in perspective the challenges and earlier recommendations relating to inclusive education in South Africa and the Eastern Cape in particular. The methods used to obtain data and the approaches adopted in conducting this study (Chapter 4) which were Critical, Developmental, Transformative and Afrocentric helped me gain deeper understanding of the world of parents with disabled children and how external factors both limit and enable them to engage actively in the education of their children. These approaches helped me to be creative and to engage with parents and teachers in a way that succeeded in digging deeper into the challenges relating to parent participation in schools and ultimately informed my recommendations of what would facilitate parent participation in the inclusion of disabled children in schools (Chapters 7, 8 and 9).

The section that follows presents an overall summary of this study and concludes with recommendations based on the findings.

### **9.2 Methodology**

The qualitative nature of this study allowed me flexibility to interact with parents in places that were convenient for them and most importantly, places and times that would cause as little disruption as possible to their daily activities and roles. This

made it easy to observe parents in their own settings. For instance, some of the interviews were conducted at home while a parent was assisting the child with school work and, in one instance I had to sit with the parent while she had to relieve someone who was helping with running a spaza shop at home. We then fitted the interview into a time when the shop was not busy.

I found using the Critical Theory and a Developmental approach fitted well together, allowing me to be critical in analysing data. The questions I asked about why parents and even teachers were doing things in certain ways helped me in to think of other ways of doing things in order to plan for transformative action. In addition, an Afrocentric approach brought clarity in cases where I found myself challenged to understand some of the parents' actions.

Data was gathered through individual interviews, school meetings, observations, document analysis, focus groups and reflective sessions and the researcher's personal journal. The Transformative and Developmental frameworks that have guided this study made it possible for me to engage with participants, learn more about them and to become part of the group, while consciously aware of my own cultural background, values and interests in the process. This framework further presented a platform where parents found themselves planning, sharing and venting their frustrations amongst themselves. They also managed to put into action lessons they shared during focus groups and reflective sessions when they attended school meetings.

In this section I present a synthesis of the 4 themes in the findings presented in Chapter 6.

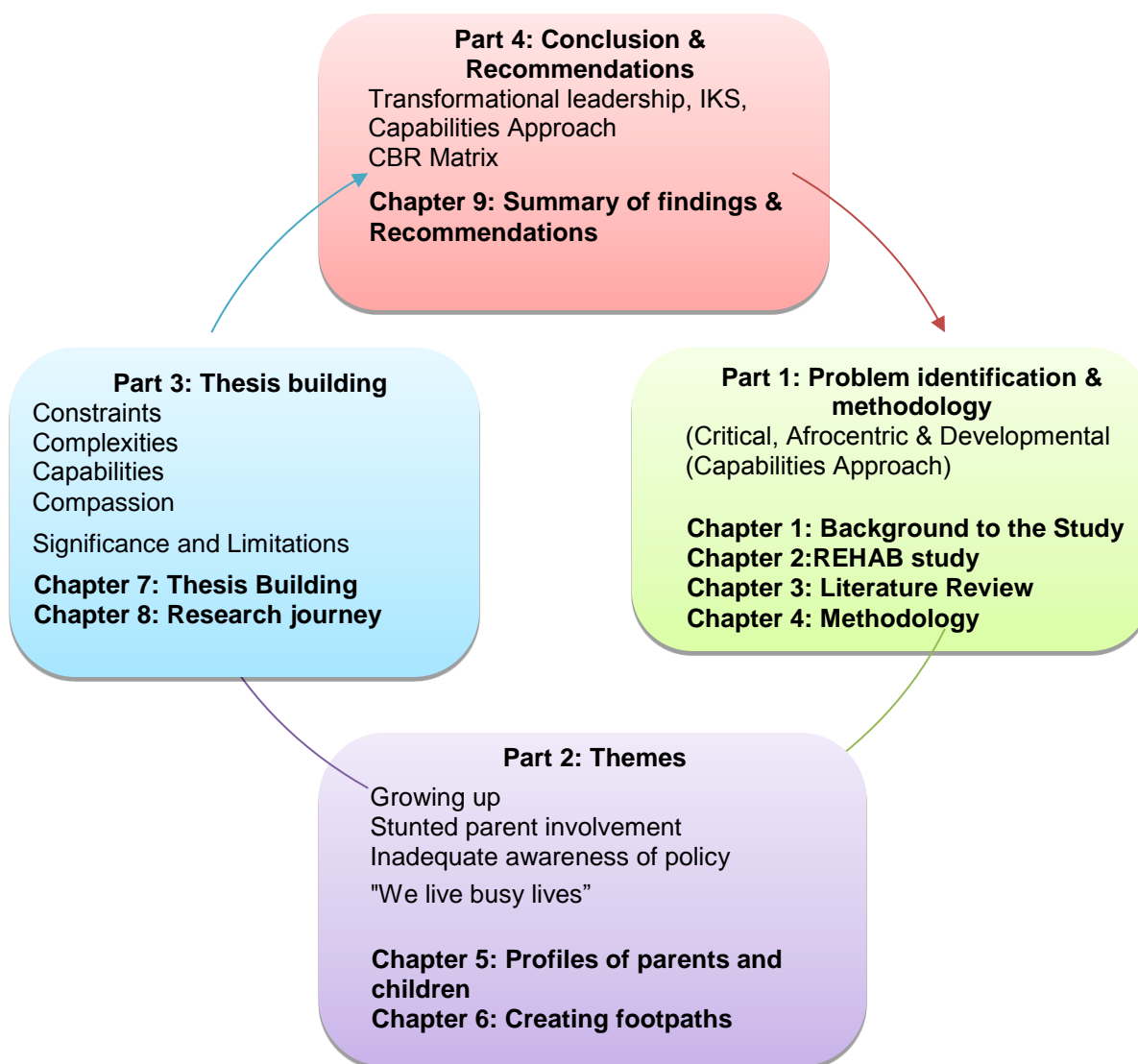


Figure 5: Overview of the Research Process

### 9.3 Background and context of research

My realisation of the need to undertake this research developed at the time of my involvement with REHAB, a disability rights organisation in the Eastern Cape Province of South Africa. The REHAB programme aimed at addressing the gap between the rights of children and their access to education. While the current policy on inclusive education acknowledges the need for parents to play a more active role in the learning and teaching of their own children, despite limitations due to impairments or chronic illnesses (Department of Education, 2001:50), parents still find it difficult to take on this role. During the time of my involvement as a project facilitator at REHAB, I became acutely aware of the anecdotal evidence as revealed through parents of disabled children of the challenges and barriers faced by these

parents. Findings from the REHAB program confirmed that parents of disabled children still experienced difficulties gaining access for their children to schools and those who managed to get their children admitted in mainstream schools, still struggled for them to be retained in those schools. This experience correlates with McKenzie and Loebenstein (2006) earlier research findings that the ability of parents to understand or to gain access to their rights is still influenced by socio-economic status and ability to exercise individual and collective power.

It was in this light that I saw a need to explore parents' experiences in order to identify their needs for possible support and suggest strategies to policy implementation. My interest in particular, was to explore the experiences of parents with disabled children to determine the nature of support they needed to ensure the admission and retention of their children in the public education system.

As a South African citizen, a country with only 20% of disabled children accommodated in Special Schools and about 250,000 disabled children excluded from education (Department of Education, 2007) and having worked as a community development facilitator in Eastern Cape with parents who have disabled children, I saw a need to focus my research in this field. According to the Census information, the highest prevalence of disability is amongst Black Africans who make up the majority of the Eastern Cape population (Stats, 2008). The population of the province is largely rural and the language used by the majority is isiXhosa. It was for these reasons that participants in this study were chosen, as the focus was mainly on rural parents with disabled children in public schools.

The main questions explored in this study were as follows:

- What experiences do parents of disabled children have with regard to the education of their children?
- How can parents of disabled children be supported to facilitate their active participation in the inclusion and retention of their children in public schools? (Ref 1.2.3)

By asking these questions, I wanted to analyse experiences of parents with disabled children and their perceptions and needs concerning the education of their children,

their involvement and how they could be supported in the process of engaging to ensure admission and retention of their children in inclusive schools. I make recommendations that parents with disabled children might find informative, encouraging and also relevant when they experienced similar situations in their lives.

#### **9.4 Synthesis of Findings**

The culture of our society, with specific regard to African culture, has for a very long time painted a picture that the role of educating a child lies entirely with the school. The fact that the education policy fails to recognise indigenous knowledge further created an understanding amongst the African community that the family system has no role to play in educating children. This misconception has to some extent created a boundary between the role played by the school and that of the family with recognition mainly given to the school. For this reason, parents continue to entrust their children's education solely to the teacher.

Despite the current changes, indicated in White Paper 6 on Inclusive Education, acknowledging public participation and developing partnerships between the school and family (Department of Education, 2001, rural parents, the majority of whom have low levels of education, grapple with fitting into this scenario. Kalyanpur et al. (2000) view this move as an attempt to oust the lack of parental involvement and the balance of power between professionals and parents that has historically been skewed in favour of professionals.

This study therefore argues that for parents who have historically been distanced by the schools from participating in the education of their children, there needs to be an understanding from the parents' point of view of how they can be supported in order to fit into a new participative role. The study further argued that parents and teachers are not informed about the current policy, what it expects from them as role players in the process of implementing inclusive education. I have further argued that employers make it difficult for parents to attend to matters relating to school and their children during the week, as parents spend most of their time at work. Thus, this research aimed to address the problem regarding appropriate support in the process of empowering parents of disabled children, so that they can actively participate in the inclusion of their children in schools.

## **9.5 Summary of Research Process**

The main purpose of this research was to identify appropriate support for parents in the inclusion of their children. In order to achieve this purpose, a participatory action research (PAR) design was adopted, as outlined in Figure 5 above.

### **9.5.1 Part One: Problem Identification and Methodology**

Chapters 1, 2, 3 and 4 form the first part of this study where data was collected in order to identify the problems and challenges that parents of disabled children face with regard to the education of their children. . In these chapters, I cover the research process and methodology of the empirical qualitative study in depth. In reviewing literature focus was on the existing literature relating to policies and previous research studies around inclusive education, parent involvement and admission and retention of disabled children in schools. A detailed report on the REHAB project (McKenzie et al., 2008), in which parents in this study participated, has been outlined.

It became evident from the literature that parents experienced many challenges in the inclusion and retention of disabled children in schools. From the literature study, I concluded that the nature of support parents needed to actively engage in the education of their children needed to be investigated. The focus group sessions with parents and school meetings allowed me time to spend with parents, educators and disabled learners and also provided an opportunity for parents and educators to reflect on ways in which they could work together to support learners and thereby assisting towards the retention of disabled learners in schools.

### **9.5.2 Part Two: Findings**

Chapters 5 and 6 which formed the second part of this study explained the empirical study undertaken to supplement the literature study with knowledge of how parents of disabled children viewed the process of inclusion with specific regard to their participation, admission and retention of disabled children in schools. This study filled a gap in the existing literature, since none of the previous research studies

focused on the views of parents regarding appropriate support for them in order to actively participate in the inclusion and retention of disabled children in schools

The findings indicated external factors that had negative and positive impacts on the ability of parents to engage in schools. These are: childhood experiences, perceived negative attitudes of teachers, inadequate information and awareness about Inclusive Education Policy and the multiple roles of parents within their families. I deal with the discussion of findings in Part 3 with the intention of building my thesis.

### 9.5.3 Part Three: Discussion: Thesis Building

In Part 3, Chapters 7 and 8 of this study, I discuss the findings that emerged from the data analysis.

I concluded that:

- Socio-cultural factors, professional domination and unclear role expectations *constrain* parents from participating in schools.
- *Complexities and contradictions* relating to the fundamental role of parents in their families, inconsistency between professional attitudes and the policy and poor communication between parents, teachers and Department officials deter parent involvement in the education of their children.
- Despite the negative encounters in schools, parents possess innate abilities such as *resilience* and *compassion* that enable them to withstand difficult situations and to find hope even when the situation seems hopeless.

The **study revealed that parents of disabled children find it challenging to work with teachers on school** or education matters affecting their children and this in turn makes it difficult for disabled children to receive the support that they need. **Participants in this study reported that teachers have negative attitudes towards disabled children and their parents.** Parents had personally experienced this in situations where they visited schools to sit in class during teaching and also when they had approached teachers regarding concerns about their children. In such cases parents received negative responses and found teachers responses focused more on the impairment of the child than on the strengths. **As a result, parents feel**

**unwelcome in schools. They felt undermined and abused of their rights to participate in the education of their children.** Parents also felt that the Department fails them as it does not intervene in support of disabled learners by enforcing the schools to implement processes for the inclusion and retention of these learners in schools. They mentioned that they felt helpless in the face of the problems brought about by lack of intervention by the Department and that they needed and expected the Department to make educators accountable for not adhering to procedures and processes that would allow schools to be inclusive areas for learning.

Participants in my research study mentioned that for them it was still something new that parents were given space to engage in school matters with specific regard to their children's education as that specific area had been for a very long time in the past the educator's domain. For them as parents with disabled children, they often did their best to support their children for them to succeed at school so that they too can live independent lives. Some of the participants who were quiet by nature found it threatening to engage with educators whom they found to be unapproachable. In addition, uncertainty amongst parents around inclusive education policy and what is expected from role players was another challenging area for parents. **Participants felt that there was a need not only for them to get information around the inclusive education policy, but in addition, they saw a need for educators to be empowered on inclusive education matters.** According to my research findings, the educators' responses to disabled learners and their parents aggravated the situation.

Findings from this study show **that parents of disabled children are often called to attend to issues at school during work hours** when educators are available at school. This timing puts further strain on the parent as they have to request time off work resulting in conflict between employer and parent. While the parents view the education of their children as vital and therefore top priority in their list of responsibilities, they often find themselves in a dilemma when teachers fail to understand why they cannot attend meetings requesting them to see teachers at school. As a result, parents are often accused of being irresponsible and not co-

operating with teachers' requests. This suggests that teachers do not focus on the child holistically when addressing challenges at school.

On the other hand, parents' relationships with their employers are ruined as the employers find it difficult to release parents during work hours to attend such meetings. While it is seen as vital to attend school matters by parents, they see it as equally important to keep relationships good with their employers who are also found to be unsupportive by parents. Both of these challenges put more strain on the parent of a disabled child.

According to my research findings, the participating parents found it very challenging to actively engage in the education of their children. **The negative attitudes of educators formed a stumbling block for their involvement in school despite their attempts to engage in the education of their children.** Inadequate support by the Department and their employers also tend to aggravate the situation. Parents did not know what the teachers expected from them. In the same way, they felt teachers themselves were not aware of what was expected from them when it came to implementing inclusive education policy. They saw this as an indication that they, together with educators, needed help for the successful implementation of inclusive education.

### **A summary of Findings**

Findings of this study have thus confirmed that parents possess the ability to take on leadership role to drive the process of inclusive education in their local communities when supported and empowered to be assertive.

#### 9.5.4 Part Four: Conclusion and Recommendations

Based on the findings presented in the preceding section I deduced a number of critically relevant facts.

Life experiences, culture, personal attributes, absence of information and inadequate support from the Department and employers seriously limit parents' ability to actively participate and support their children in the process of making schools inclusive sites

for learning. Parents need income to support their children and families, acceptance of their children by educators, support and a welcoming attitude from teachers when visiting schools and when approaching schools for help and in support of their children.

Therefore, a transformational leadership program aimed at supporting and empowering parents to be drivers of inclusive education processes that would see to the inclusion and retention of disabled children in schools is key to making inclusive education reality. An approach to implementing this leadership program needs to be informed by Indigenous Knowledge Systems in order to ensure sustainability of outcomes and a Capabilities approach will ensure affirmation of parent abilities and an enabling environment that will encourage them to take on their role. Based on Ubuntu values that inform the CBR guidelines Education component (WHO, 2010), I conclude that this qualifies the CBR guidelines as a vehicle by which parents can be supported as leaders in implementing inclusive education and empower them to be assertive in negotiating their needs with employers and educators.

## **9.6 Recommendations Arising from Conclusions**

In Chapter 8 I summed up recommendations, emphasizing the CBR guidelines' education component for parent and community empowerment awareness around Inclusive Education Policy, disability and employee rights with focus on employers, communities and teachers and transformational leadership for parents as facilitators of inclusive education and policy evaluation.

The policy on inclusive education acknowledges the vital role that parents play in the education of their children and calls for active participation of parents in the process of ensuring that schools become inclusive sites for learning (Department of Education, 2008). While focusing on experiences of parents with disabled children in public schools, findings from this study have challenged me to think of different ways in which parents of disabled children can be supported in their attempts to engage and to actively participate in the education of their children.

The feedback session that aimed at member checking made it possible to engage parents in the process of identifying ways in which schools, families and

communities can possibly support parents in their attempts to actively participate in the education of their children. In addition, academic institutions, disability organisations, policy makers and employers can also use the recommendations to inform their future action plans regarding disability and inclusion. Overall recommendations based on the findings of this study are highlighted below:

- **Change of teacher attitude:** One of the two main recommendations put forth by participants in this study is the need for teachers to change the unsupportive attitude which they might be unconsciously portraying when relating to disabled children and their parents. The call for an attitude change can be as complex an issue as any change in one's personal life. This issue came up often during the focus group sessions with some parents arguing that there is no training that can help address this problem other than the Department intervening by working closely with, monitoring and evaluating progress and supporting schools to ensure accountability of school managers when it comes to implementing inclusive education measures.
- **Departmental support to parents and schools:** The second main recommendation of this study is that the Department needs to be seen to be working with and supporting parents in order for parents to play their role of being active role players in the process of making schools inclusive sites for learning as the policy for inclusive education outlines (Department of Education, 2008). Participants in this study experienced negative responses from Department officials who discouraged them in their attempts to get their disabled children admitted to and retained in their local mainstream schools. In one meeting where a parent was trying to work with the school in identifying challenges noted by the educator relating to the child's performance at school, the Department official was cited as saying that inclusive education does not work in the Eastern Cape (5.4.1). It was for this reason that a recommendation was put forward for the Department to ensure that officials employed work in support of rather than against policies that the Department intends to implement.
- **Training of Trainers Program** aimed at supporting educators and parents. The Department could identify and train unemployed graduates and parents of disabled

children who could work with the District Based Support Teams (DBSTs) in order to make sure that systems are in place in schools for the implementation of the policy on inclusive education. This strategy could be co-ordinated through community based organisations (CBOs) that would work with local schools and also could raise awareness on inclusive education in local communities, including programmes focusing on employers. While focusing on installing systems in schools, this programme has the potential to create a platform for different role players to work together thereby strengthening co-operation between parents, their employers, learners and educators.

- **Training courses on Inclusive Education for Educators.** The higher education institutions have a role to play in building the capacity of educators around the policy on inclusive education. Undergraduate and postgraduate courses could benefit students and educators in advancing their knowledge with specific regard to the White Paper 6 on Inclusive Education. As a cross cutting issue, an awareness on inclusive education policy needs to be an integrated (inter-departmental) course focusing on social, education, health and development issues that would allow different professionals to participate while broadening their own knowledge in addressing disability inclusion. In-service training at special schools, irrespective of whether the student or educator intends to work at a special or mainstream school could help broaden the students' knowledge. Educators could also benefit from this kind of training by developing their communication and listening skills in order to relate in a positive manner with learners and parents, specifically those from poor socio-economic backgrounds. This training could also help sensitise role players of others' specific needs, challenges and strengths.
- **Accessibility of information at the level of understanding by end user.** Currently, the information on the inclusive education policy is not easily accessible and available. Copies are still only available in English despite claims by the Department that different language versions are available. Findings of this study suggest that access to simple and understandable information can help parents to understand what is expected of them as active role players in the process of implementing inclusive education.

- **Building sustainable relationships between the parent, educator and learner.** Institutional Level Support Teams (ILSTs) can offer support to parents, learners and educators by facilitating joint meetings that aim at monitoring and supporting learners, educators and parents in order to ensure learner progress, retention and continuous support and co-operation between the parent, learner and educator.

#### 9.6.1 Recommendations for Further Research

Two main recommendations put forth by parents from the findings of this study were that:

1. There needs to be a paradigm shift in the way educators relate to disabled children and their parents so that parents might find it easier to get disabled children admitted and retained in local schools. In addition, there needs to be a paradigm shift in what parents believe about themselves. They need to see themselves not as victims but as agents of change.
2. The Department of Education needs to support parents and their children to make sure that schools become inclusive sites for learning.
3. Findings of this study have confirmed that parents possess the ability to take on leadership role to drive the process of inclusive education in their local communities when supported and empowered to be assertive. In the light of the strong indication for parent support and empowerment, I therefore recommend a need to follow up on this study with the main focus on “Parent Empowerment” (See point one on recommendations - 7.3.1, p. 186).

Based on these two recommendations by the parents who participated in this study, I suggest the following areas for possible research:

1. This study did not engage the Department and educators or other stakeholders in the area of inclusive education during focus group discussions. For this reason, further research should engage parents, educators, therapists, doctors, nurses, heads of schools and the Department of Education, relevant policy makers and employers of parents of disabled children. This could allow space to discuss possible ways of addressing issues identified by parents as challenges

in order to allow access, productive learning and retention of disabled learners in schools.

As the issue of disability remains "an elephant in the room", I believe that as we continue to engage more people in different sectors of society, people will start easing up and feeling more comfortable to talk about and to address challenges relating to disability. When we become comfortable talking about disability, we will in turn become aware of how our actions can be disabling to those around us. This kind of study would therefore enable people that parents relate to in their work places, at school and policy makers, to start engaging with parents in ways that would be supportive to them, thereby making it easier for parents of disabled children to participate and to address challenges as soon as they surface. In this way parents would be able to confront challenges that might hinder their active engagement in the education of their children. I acknowledge that it can be intimidating for parents of disabled children to engage in discussions regarding current challenges identified in the education sector. Therefore parents that would participate in the proposed study would be purposively selected to allow representation of issues affecting parents at grassroots.

2. An exploratory study, looking at the supportive role of parents and educators to learners in a school where inclusive education has been successfully implemented. Lessons from such a study could then guide future strategies that aim at building and strengthening parent-educator relationships.

The two key objectives were to:

- Investigate the experiences and needs of parents with regard to their disabled children with a specific focus on the challenges they face,
- Explore ways in which parents of disabled children can be supported to facilitate their active participation in the inclusion and retention of their children in public schools.

**Table 5: Summary of findings**

<b>Experiences and needs of parents</b>
Socio-cultural factors, <i>professional domination and unclear role expectations</i> constrain parents from participating in schools
Complexities and contradictions relating to the fundamental role of parents in their families, inconsistency between professional attitudes and the policy and <i>poor communication between parents, teachers and Department officials</i> deter parent involvement in the education of their children
<i>Support from employers</i> vital for parents but currently lacking
Despite the negative encounters in schools, parents <i>possess innate abilities</i> such as resilience and compassion that enable them to withstand difficult situations and to find hope even when the situation seems hopeless
<b>Ways to facilitate parents support</b>
Include inclusive education policy in teacher training courses Simplification of policy to be end user friendly Building sustainable parent, educator and learner relationships
Change of teacher attitude  Departmental support to parents and teachers around issues of inclusion (understanding and implementing inclusive education policy  Train of trainer programs aimed at community and employer awareness around inclusive education policy
Community Based Rehabilitation programs supporting and empowering parents as leaders/drivers in implementing inclusive education policy

## 9.7 Conclusion

In this chapter, I have summarised the study, presented the conclusions reached in terms of the research questions, and made recommendations as to how parents of disabled children could be supported to participate actively in the education of their children. I have also outlined how my study has made a contribution to knowledge and the field of education and development. Willingness of parents to work with teachers and their resilient and compassionate natures indicate the potential of parents to drive the process on inclusion. However, the socio-cultural circumstances in which parents were raised requires a transformational leadership program informed by Indigenous Knowledge Systems and Capabilities Approach aimed at supporting and empowering parents to lead the process of including and retaining disabled learners in schools. The CBR Education and Empowerment components are the main vehicles that could best drive this kind of programme.

I have experienced significant personal development during this journey, which will certainly benefit my future work with parents of disabled children.

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## Appendices

### Appendix A Permission Request for education department consent

The Director: Planning and Research  
Eastern Cape Education Department  
Private Bag  
Bisho  
5608

Dear Sir/Madam

#### **Introduction**

My name is Ntombekhaya Tshabalala from the University of Cape Town, Department of Health and rehabilitation. I am currently registered for a PhD in disability studies. This self-initiated study is a requirement for me in order to complete my studies. I am particularly interested to explore experiences of rural parents with disabled children regarding the education of their disabled children in the context of inclusive education. The title of this study reads:

**An exploration of the experiences of rural parents about the inclusion and retention of their disabled children in public education.**

#### **Purpose of the study**

The purpose of this study is to explore experiences of parents with disabled children. The aim is to identify appropriate support in the process of engaging parents in the inclusion of their children in public schools. Through this study, I am hoping that needs of parents will be identified for possible support. Ultimately the findings that will emerge from this research study will inform and support inclusive initiatives and strategies in the development of inclusive sites for learning.

School meeting sessions involving the parent, the child and the child's educator will form an important aspect of this study. These meetings will focus on areas posing as challenges for children with specific to their school work. The educator and parent will then identify possible ways that they can be of support to the child. These

meetings will be held once a term between June and December 2011, at the beginning of the school term at convenient times that will not disrupt classroom activities. Convenient times for these meetings will be arranged with educators that will be participating in this study. Each meeting will take about 45min-1hour.

The researcher and research assistant will participate as facilitators during these meeting sessions. An attendance register will be completed for the meeting sessions as proof of attendance for final write up of the research study. The information that will be shared in our meetings will be treated as confidential. Only pseudonyms (false names) will be used on reporting research findings. There is no financial reward for participating in this study.

The inclusion of specific learners and educators that will participate in this study will depend on informed consent from school principals, parents, educators as well learners themselves, who are able to participate in a voluntary capacity. No pressure will be placed on learners to participate in the study, and there will be no repercussions regarding their decision not to partake in the research process. The researcher and research assistant will comply with all of the ethical guidelines outlined in the proposal.

I will be available to discuss any issue of concern that might arise in the process of this study. Findings of this study will be made available for your department.

Please note that Ethics approval of this study has been obtained from the Faculty of Health Sciences Human Research Ethics Committee, University of Cape Town.

We therefore request permission to conduct this study

Thank you for considering this request.



Province of the  
**EASTERN CAPE**

**DEPARTMENT OF EDUCATION  
EAST LONDON DISTRICT**

Dr. WB Rubusana Building \* NU 1 Mdantsane\* Private Bag X9007 \* East London \* 5200 \* REPUBLIC OF SOUTH AFRICA \* Tel: +27 (0)43 708 6208 Fax: +27 (0)43 760 0545 \*Website: ecprov.gov.za

Date: 03 October 2011

ENQUIRIES: MRS A C ESBEN

Ms N Tshabalala  
School of Health and Rehabilitation Sciences  
University of Cape Town  
**RONDEBOSCH  
5201**

Dear Ms Tshabalala

**PERMISSION TO CONDUCT RESEARCH STUDY: PHD IN DISABILITY STUDIES:  
AN EXPLORATION OF THE EXPERIENCES OF RURAL PARENTS ABOUT THE  
INCLUSION AND RETENTION OF THEIR DISABLED CHILDREN IN BASIC  
EDUCATION**

Your letter on the abovementioned matter has reference.

Permission is hereby granted for you to conduct the abovementioned research study in schools of your choice in the East London District.

This permission is granted on condition that tuition time is not disrupted and that you obtain the necessary permission from the school principals as well.

We wish you well in your endeavours.

Yours faithfully

  
**W M NGWANYA  
DISTRICT DIRECTOR**

# Appendix C

# Learner reports

Admission No: 6300  
 Birth Date: 19990709  
 School Closes: 2011/09/30

Grade: 5D  
 Class: 5D  
 Date: 2011/11/14

School Reopens: 2011/10/10

Subject	Term 1			Term 2			Term 3			Term 4		
	Final %	Level	Grade Ave %	Final %	Level	Grade Ave %	Final %	Level	Grade Ave %	Final %	Level	Grade Ave %
Language 1	60	3	47	56	3	54	56	3	53			
Language 2	41	2	45	61	3	52	45	2	46			
Mathematics	40	2	32	54	3	42	58	3	49			
Life Orientation	52	3	65	53	3	55	44	2	47			
Arts and Culture	66	3	65	54	3	55	59	3	58			
Economic and Management Sciences	65	3	53	70	4	48	78	4	51			
Natural Sciences	49	2	52	68	3	54	77	4	61			
Social Sciences	48	2	53	52	3	36	56	3	38			
Technology	64	3	57	61	3	51	77	4	62			
<b>Learner Total / Average:</b>			485	54		529	59		550	61		
<b>Result:</b>												
<b>Days Absent To Date:</b>												1

General Remarks:

Signatures:

Class Educator:  
 Principal:

Admission No: 6300  
 Birth Date: 19990709  
 School Closes: 2011/09/30

Grade: Grade 5  
 Class: 5D  
 Date: 2011/11/14

School Reopens: 2011/10/10

Subject	Term 1			Term 2			Term 3			Term 4		
	Final %	Level	Grade Ave %	Final %	Level	Grade Ave %	Final %	Level	Grade Ave %	Final %	Level	Grade Ave %
Language 1	60	3	47	56	3	54	56	3	53			
Language 2	41	2	45	61	3	52	45	2	46			
Mathematics	40	2	32	54	3	42	58	3	49			
Life Orientation	52	3	65	53	3	55	44	2	47			
Arts and Culture	66	3	65	54	3	55	59	3	58			
Economic and Management Sciences	65	3	53	70	4	48	78	4	51			
Natural Sciences	49	2	52	68	3	54	77	4	61			
Social Sciences	48	2	53	52	3	36	56	3	38			
Technology	64	3	57	61	3	51	77	4	62			
<b>Learner Total / Average:</b>	<b>485</b>		<b>54</b>	<b>529</b>		<b>59</b>	<b>550</b>		<b>61</b>			
<b>Result:</b>												
<b>Days Absent To Date:</b>					1							

General Remarks:

Signatures:

Class Educator:  
 Principal:

Grade R to 6: 1=1-34% Not Achieved; 2=35-49% Partial Achievement; 3=50-69% Satisfactory Achievement; 4=70-100% Excellent Achievement

ASSESSMENT-KEY

- 1. Not Achieved
- 2. Partial Achievement
- 3. Satisfactory Achievement
- 4. Outstanding / Excellent Achievement

LEARNING AREA	TERMA
Isixhosa	R
English	R
Mathematics	R
Life Skill	R

Comments: Educator:

*PARTIAL ACHIEVEMENT*

Comments: Parent:

School stamp

Educator

Principal

Date

Days Absent

Parent

School Re-open:

*N-10 L*

*09/12/2011*

*7*

*11 01 2012*

## Appendix D Interview schedules

### Focus group and reflective sessions

1. Who are you – yourself, family and community and school of your (disabled) child? Getting to know each other, 2 people introducing each other one thing you'd like others to know about yourself, your family, the community you come from and about the school of your child.
2. Why are you part of this group? Imagine that you had an opportunity 2/3 years back to be part of a group like this, where two or three women/parents had an opportunity to meet and talk about issues that affect them with regards education and their children. In which way do you think this could have impacted on you as a parent with a disabled child?
3. What would you like others in the group to know about you as you will be working together during focus group sessions?
4. What would you like to get from the focus group sessions?
5. What will you give to the group? Follow up from Q2, having thought about yourself and your experiences as a parent, what are the things that another parent can learn from your situation and your experiences by now?
6. What is your understanding of inclusive education?
7. Is it a privilege for a disabled child to be educated or a right – why say so?
8. Are you aware of the policy supporting education of the disabled children?
9. As a parent, what do you understand to be your role in the education of your child? As a parent, do you think parents have a role to play in the education of their children? ....Why do you say so?
10. How does your role differ to that of an educator? Does a parent play a different to that of an educator or not? Please explain more...
11. In which way would you say your own understanding of your role as a parent differ to that which the current policy on inclusive education, stipulates regarding the education of your disabled child?
12. What is your understanding of roles and responsibilities that the policy on inclusive education stipulates? What do you think of the roles and responsibilities as stipulated in WP6?
13. Does your role as a parent of a disabled child differ to that of a parent of a non-disabled child regarding the education of your children?

14. In which way do you participate in the education of your child?
15. What do you find as challenging in participating /engaging in the education of your child – within your family, community and the school.
16. How do you deal with these challenges?
17. What do you find to be helpful?
18. If support would be offered to help you deal with the challenges you are faced with, in the education of your child, what would you ask for?

### **Meetings with educator, parent and learner**

1. Challenges faced by learner at school
2. Educator' views
3. Parent's views
4. Support needed and recommendations by the learner, educator and parent to deal with challenges
5. Plan of action
6. Reflect on action
7. Identify progress

**Appendix E      Data tabulation**

**Sources of Data and Purpose there of**

<b>Phase</b>	<b>Instrument</b>	<b>Purpose</b>	<b>Scheduled time</b>	<b>Hours</b>
<b>1</b>	<b>Meeting with REHAB Director</b> <b>Meeting with parents</b>  <b>Training of research assistants</b> <b>Attendance register</b>	<b>To identify participants</b> <b>To discuss suitable times for meetings</b> <b>To be able to assist with data gathering</b> <b>To keep record of participants</b>	<b>February 2011</b>	<b>1hr</b>  <b>1hr</b>  <b>4hrs</b>
	<b>Reports on REHAB project- Inclusive education and parent support 2006-2008</b>	<b>To be used as background information to this study (first chapter of my thesis) as parents/ participants were participants in REHAB study. Relevant participant information will also be retrieved from this previous research that the researcher has done with parents.</b>	<b>March – April 2011</b>	<b>40hrs</b>
<b>2</b>	<b>Individual interviews with parents and observations of contexts</b>  <b>Interview schedules</b>	<b>To break ice and to get to know each other and to introduce research</b> <b>To be used as guide for interviews with different parents (details of parent and child)</b>	<b>June – 2011</b>	<b>10hrs</b> <b>(5parentsx2hrs)</b>

<b>3</b>	<b>Focus groups with parents</b>	<b>To explore experiences of parents regarding their perceptions as to their role, the school and community in the education of their children.</b>	<b>June – October 2011</b>	<b>3 x 4hrs</b>
	<b>Meetings with class educators of disabled children</b>	<b>To inform about the study and obtain commitment to co-operate with parent in supporting the learner and to discuss possibility of learner progress monitoring sessions with educator learner, parent and researcher, once a term.</b>	<b>June 2011</b>	<b>5x1hr</b>
	<b>Progress monitoring sessions with parents, educator and learner</b>	<b>To discuss challenges and progress of the learner, identify areas of support by the parent and educator. This will trek any possible changes to the performance of the learner in the period of parent involvement throughout the study, parent participation, experiences and</b>	<b>July – November 2011</b>	<b>5 x 1hr x3sessions</b>
	<b>Participants</b>		<b>Sept 2011</b>	<b>1 x 4hrs</b>

	<p><b>feedback (parents with educators)</b></p> <p><b>Learner feedback (individual sessions)</b></p>	<p><b>perceptions of the process in the period.</b></p> <p><b>To reflect on the process from beginning of research and to generate overall feedback and views on findings from data analysis</b></p> <p><b>Disabled learners reflecting on their experiences (evaluation-benefits &amp; challenges to learners)</b></p>	<b>Sept 2011</b>	<b>5 x 1hr</b>
<b>4 (continuous)</b>	<p><b>Reflective sessions</b></p> <p><b>Journals and diaries</b></p> <p><b>Minutes of meetings</b></p>	<p><b>To discuss and obtain critical analysis of findings by researcher and research assistants from each session with participants</b></p> <p><b>To document field notes</b></p>	<b>July – Jan 2012</b>	<b>19 x 1hrs</b>

**Appendix F      Attendance Register**

**Meeting / Workshop Theme:** \_\_\_\_\_

**Date and Time:** \_\_\_\_\_

**Place:** \_\_\_\_\_

<b>No.</b>	<b>Name and Surname Igama ne fani</b>	<b>Address and contact no. Idilesi ne nombolo yomnxeba</b>	<b>Signature / Sayina</b>

2 I would like to gain as much knowledge from other parents about my child's condition to be able to assist him and make life as easy as possible to cope with

3 I'm a compassionate and caring mother. I care about my child's future and I want only the best for him. I would like to supply him with all the necessary tools to succeed in his education.

4 To gain all possible knowledge on how to deal with a child who has disabilities

② I should be strong enough to stand on my own and fight for my right. I think I know. Be able to empower others.

④

Realised that there is a lot of women in the same position I'm in - hope to get a answer to the way forward

Focus group 5

Think of the story you told me about life growing up (from childhood up to now) and share:

1. How your experiences growing up are affecting the way you relate to and raise your child

The way I grew up is different from the way I raise my child because I had tough time, so I decided that I don't want kids to experience what I came through. I open up my feeling, sharing with them, guide them for better future. I don't have secrets I call a space building trust and bond with them. I want to be the best mom they have even if I'm not with them.

2. About what you have said, where do you think you need to change

I think I need to add more on what I'm doing by digging for more information for them.

I think what I'm doing made my home warm and full of love because they send me message telling that we love you mom, they never forget mothers day and one another's birthday wishing good luck for each other.

3. What do you find has helped you in your experiences regarding how you relate to your child

Working with Rehab social workers, courses I attend and Kaya for inclusive education has helped me because I did not know that I also have to participate in my child's future. I used to blame teachers that they don't do their work but now I know I have to have input. I wish all parent could understand how important it is to assist them because we learn also from them.

4. What is helping you in relating to the school where your child is at (i.e. teachers and other parents at school) and

I built relationship by accepting that I can see I failed to support my child due to lack of knowledge. So I ask to work in partnership with the class teacher by informing me about everything, class work be given, to make copies of daily work so I can assist my child according to the way she teaches her at school. Every week I visit school to discuss her achievement and where we need to focus.

5. Where do you think you need help to improve on- to make it easy for you to relate to the school?

I think my child school is accessible to me because whenever I feel visiting I'm welcomed only few that does not understand by child's difficulty. Otherwise I'm happy with every teacher.



## Playing with the clay -

- a. • At the time:  
Make something that I can use / something that can be used as decor
- b. • Wish I stood up more for her - her rights! Her place in ~~society~~ <sup>society</sup>. Make people more aware of LB and how to treat them.
- c. • My family has been very supportive from day one. I find most of the time - not all the time - the community very supportive. The school and department has been of NO use. Request - Support - blonde standing.
- d. • With meeting at the group meetings I find out that there is a lot of parents (mothers) that is struggling with the same thing. our children like are a small group but there must be thousands of children and parents out there.
- e. • Feel that we have touched a lot - can not think of anything that we missed.
- f. • Know that I have the support of everyone and will always have - we will always be there for each other. Each parent will do anything to give their child a better education and place in society. Knowing your rights just make it a little bit easier. But there is a barrier when it goes to the schools and education department.

**Table: Themes identified from narratives of participants**

Theme	Sub-theme	Categories
Teacher attitudes and department interventions have a strong impact on parent involvement in schools	<p>1.1 It is a challenge to participate at school and to engage with teachers on challenging matters affecting disabled children.</p> <p>1.2 Teachers' negative responses aggravate the situation for disabled children.</p> <p>It is a challenge to participate at school and to engage with teachers on challenging matters affecting disabled children.</p> <p>Teachers' negative responses aggravate the situation for disabled children.</p>	<p>Parents feel undermined.</p> <p>1.1.2 Parents feel taken for granted.</p> <p>1.1.3 Parents feel abused.</p> <p>Parents receive negative responses and attitudes from teachers</p> <p>Teachers tend to focus on the impairment rather than potential and strength in assessing disabled learners at school.</p> <p>1.2.3. Teachers have a negative attitude to disabled children and their parents.</p>
Cultural beliefs, personality traits and lack of information impact negatively on the confidence of parents to engage in education matters of their children	Parents find it challenging to voice their views on matters that they do not agree with teachers affecting their children in schools.	<p>Parents fear rejection as a result of similar past experiences</p> <p>2.1.2. Self-doubt. Parents lack confidence in arguing with "trained" teachers on education matters even when they know they are right</p> <p>2.2.3 Parents and teachers lack information</p>

		about details on the inclusive education policy with specific to role players and what is expected from parents and teachers.
Basic needs vital in the demanding lives of parents with disabled children	Parents with disabled children have basic needs to be met in dealing with pressure they are facing in the context of inclusive education (Parents need income) (understanding) (support)	As the term implies in an “inclusive” education system the teacher looks at the child holistically.

**Introduction**

My name is Ntombekhaya Tshabalala from the University of Cape Town, Department of Health and Rehabilitation. I am currently registered for a PhD in disability studies. This self-initiated study is a requirement for me in order to complete my studies. I am particularly interested to explore experiences of rural parents with disabled children regarding the education of their disabled children in the context of inclusive education. The title of this study reads:

**An exploration of the experiences of rural parents about the inclusion and retention of their disabled children in public education.**

**Purpose of the study**

I am particularly interested in hearing about your different experiences as parents with disabled children in relation to the education of your children. In so doing, I am hoping that we will be able to identify the kind of support you need in supporting your children to succeed at school.. Through this study, I am hoping that your needs will be identified for possible support. Ultimately the findings that will come out of this research study will inform and support programs of support to ensure that children, parents and teachers work together and that all children (disabled and non-disabled) are treated equally and given the kind of support they need to succeed at school.

**Why have you been invited to participate?**

Since our previous involvement in the REHAB project on inclusive education, I have identified you as potential participants to this study. The relationship that developed amongst the parents and me as the facilitator during the implementation of the REHAB project is the reason why I am interested in working with you in this research study. In addition, as parents with disabled children, I believe that your experiences in the education of your children are specifically relevant for this kind of the study. I have identified other parents from the Rehab support group whose children are in public schools.

**Information about the research**

Your commitment to the study will involve participation in individual meetings, school meetings and focus group sessions. Individual meetings will involve the parent, the researcher and co-researcher (who will be assisting in the process of writing minutes during the meetings). The focus of these meetings will be on discussing arrangements and planning and establishing convenient times for our meetings, getting information about you and your child and following up on specific information that might need clarification from other meetings. School meetings will involve parent, the child and the child's educator. These meetings will focus on challenges facing parents with assisting child specifically with school work. During the focus group sessions, parents will find time to share experiences, discuss challenges and hopefully learn from each other's experiences in the process. One focus group session will be conducted towards the end of this study whereby educators, parents, and researcher will share their experiences during their involvement in this study.

### **What will be required of you?**

Your responsibility as a participant in this study will be to avail yourself for the meetings and to participate by sharing your experiences with other parents of disabled children who will be participating in this study. There are 3 (1-2hr) individual meetings that have been planned; however, there might be times when a follow up meeting might be requested depending on the outcome of each meeting. The total number of school meetings will be 3 and these will take about 1 hour each session. There will be four focus group sessions and these will require that you set aside about 4 hours of your time per focus group session. This study will be conducted from the month of June to November 2011. Our first meeting will discuss preferred times and convenient days for these meetings and focus group sessions. The researcher will visit the parent at home or will agree on a convenient place together with the participant for individual meetings. A convenient venue in the community will be arranged where the focus groups will take place. An attendance register will be completed for the meetings and focus group sessions as proof of attendance for final write up of the research study.

Your permission is requested for the use of video tape and camera during focus group sessions to ensure that the researcher captures as much data as possible. This will help the researcher in writing up of findings. You will be allowed to request

for the camera not to be used and that the video recorder be switched off where you feel uncomfortable. You will also be given permission to decide on the photos to be used for the write up of findings.

**Are there risks involved in your taking part in this research?**

There are no risks involved in your taking part to this study. Should there be a need for further counseling during these sessions, the researcher will refer the individual to REHAB or any relevant support system for further intervention sessions.

**Will you benefit from taking part in this study?**

There is no monetary reward for participating in this study, however, the researcher will arrange a light meal and drinks during the focus group sessions.

Your participation is **entirely voluntary** and you are free to decline to participate. Your unwillingness to participate in this study will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. The information that will be shared in our meetings and focus group sessions will be treated as confidential. The researcher will keep the research information in a locked cupboard in her office. Only pseudonyms (false names) will be used on reporting research findings.

Should you feel that you have been treated unfairly by the researcher in the process of your participation in this research and for any further information, you can contact Prof. Marc Blockman (Chairperson of the Human Research Ethics Committee) at 021-406 6534. You will receive a copy of this information and consent form for your records.

Please note that Ethics approval of this study has been obtained from the Faculty of Health Sciences Human Research Ethics Committee.

Thank you for considering this request.

## **Informed Consent Form**

The researcher has thoroughly explained to me the information sheet and the content of this consent form and provided clarity where necessary. I clearly understand the nature of this research study and all that is required of me. I have had all my questions answered. I do not feel that I am forced in any way to take part in this study and I am doing so out of my own free will. I am aware that I can withdraw at any time and will not be prejudiced in any way.

Signed:

Participant: \_\_\_\_\_ Date and Place: \_\_\_\_\_

Researcher: \_\_\_\_\_ Date and Place: \_\_\_\_\_

Witness: \_\_\_\_\_ Date and Place: \_\_\_\_\_

## **Learner information Letter and consent form**

16 June 2011

Dear (Learner) \_\_\_\_\_

### **Information about research study: Invitation and Consent to participate**

This study is about understanding ways of getting your parent to be able to support you with your school work. In order for this to happen, we need to understand challenges that affect your performance at school so as to get both your parent and your teacher to help you. We also need to discuss ways of getting your teacher and your parent to be able to help you and we believe that it is important to get your views on how they can be of help to you.

In order to get this information, I will organize meetings that will involve yourself, your parent and your class teacher where we will talk about challenges you experience regarding your school work and how your parent and teacher can help. During these meetings you can speak in a language that is easy to speak in. Your parent will also talk about the areas where s/he need to be supported in order to help you at home as well as how your teacher can help you at school. There will be a total of three meetings, one in July, the next one in September and the last one in November. These will be arranged at convenient times that will not disrupt your classroom activities. The meetings will take about 45min-1hour of your time.

I will explain what is needed at each point so that you understand what is being done. You can decide if you want to take part or not and if you participate you can decide to leave if you want to. I will also be sending a letter to your parent/caregiver who must agree for you to take part in this study. I will also explain the study in detail to you. We will use the information we get to assist other learners, teachers and parents to find better ways of working together in helping other learners. Your name will not be mentioned in any of the reports of this study.

Thank you for considering this request.

**Response Form Section 1: Learner**

I have read the invitation and understand what the research study is about. I hereby agree / do not agree to participate in this study.

**Learner (Name in block letters):** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_ **Contact number:**

\_\_\_\_\_

**Response Form Section 2**

This section is only to be completed by “participant sister/brother” if the learner is unable to read and understand the request independently.

I, \_\_\_\_\_ have read the letter to  
\_\_\_\_\_ (participant’s name).

I have explained what the letter says and have made it clear as possible.

\_\_\_\_\_ (participant’ name) has understood what the letter says and has provided me with a verbal response indicating that s/he will / will not participate in the study.

**Name of “participant sister/brother”**

\_\_\_\_\_

**Signature:**

\_\_\_\_\_

**Date:** \_\_\_\_\_ **Contact number:**

\_\_\_\_\_

## **Permission letter for educator consent**

### **TITLE OF THE RESEARCH PROJECT**

An exploration of the experiences of rural parents about the inclusion and retention of their disabled children in public education.

Dear Educator \_\_\_\_\_

### **Introduction**

My name is Ntombekhaya Tshabalala from the University of Cape Town, Department of Health and rehabilitation. I am currently registered for a PhD in disability studies. This self-initiated study is a requirement for me in order to complete my studies. I am particularly interested to explore experiences of rural parents with disabled children regarding the education of their disabled children in the context of inclusive education. The title of this study reads:

**An exploration of the experiences of rural parents about the inclusion and retention of their disabled children in public education.**

### **Purpose of the study**

The purpose of this study is to explore experiences of parents with disabled children. The aim is to identify appropriate support in the process of engaging parents in the inclusion of their children in public schools. Through this study, I am hoping that needs of parents will be identified for possible support. Ultimately the findings that will emerge from this research study will inform and support inclusive initiatives and strategies in the development of inclusive sites for learning.

School meeting sessions involving the parent, the child and the child's educator will form an important aspect of this study. These meetings will focus on areas posing as challenges for children with specific to their school work. The educator and parent will then identify possible ways that they can be of support to the child. These meetings will be held once a term between June and December 2011, at the beginning of the school term at convenient times that will not disrupt classroom

activities. I will then arrange with you to identify convenient times for these meetings. Each meeting will take about 45min-1hour of your time.

The researcher and research assistant will participate as facilitators during these meeting sessions. An attendance register will be completed for the meeting sessions as proof of attendance for final write up of the research study. The information that will be shared in our meetings will be treated as confidential. The researcher will not reveal your names to anyone during this process. If there is information that is confidential that you do not want the researcher to share, your wishes will be respected. The researcher will keep the research information in a locked cupboard in her office. Only pseudonyms (false names) will be used on reporting research findings. You are free to withdraw from the study at any point and should you withdraw there will be no penalty. There is no financial reward for participating in this study.

I will be available to discuss any issue of concern that might arise in the process of this study. Findings of this study will be made available for your department. Should you feel that you have been treated unfairly by the researcher in the process of your participation in this research and for any further information, you can contact Prof. Marc Blockman (Chairperson of the Human Research Ethics Committee) at 021-406 6534. You will receive a copy of this information and consent form for your records.

Please note that Ethics approval of this study has been obtained from the Faculty of Health Sciences Human Research Ethics Committee.

You are therefore requested to participate in this study.

Thank you for considering this request.

## **Informed Consent Form**

The researcher has thoroughly explained to me the information sheet and the content of this consent form and provided clarity where necessary. I clearly understand the nature of this research study and all that is required of me. I have had all my questions answered. I do not feel that I am forced in any way to take part in this study and I am doing so out of my own free will. I am aware that I can withdraw at any time and will not be prejudiced in any way.

Signed:

Educator: \_\_\_\_\_

Date and Place:

\_\_\_\_\_

Researcher: \_\_\_\_\_ Date and Place: \_\_\_\_\_

Witness: \_\_\_\_\_ Date and Place: \_\_\_\_\_