

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

*We cannot fight for what we do not know:*  
**Information that Mothers of Disabled Children  
have about the Children's Act (No. 38 of 2005) And  
the Children's Amendment Act (No. 41 of 2007) in  
South Africa**

**Nonceba Meyiwa**

**Minor thesis in partial fulfilment for the degree of  
MPhil in Disability Studies  
School of Health and Rehabilitation Sciences  
University of Cape Town**

**Supervisor: Associate Prof Theresa Lorenzo**

**Co-Supervisor: Mrs Sue Philpott**

**June 2010**

## DECLARATION

1. I know that Plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own.
2. I have used the Harvard convention for citation and referencing. Each significant contribution to, and quotation in this research study from the work or works of other people, has been attributed, cited and referenced.
3. The research study is my own work.
4. I have not allowed and will not allow anyone to copy my work with the intention of passing it off as his or her own.

**NAME: Nonceba Diagretta Meyiwa**

**STUDENT NUMBER: DNKNON001**

**SIGNATURE:**

## TABLE OF CONTENTS

<b>DEDICATION</b> .....	5
<b>ACKNOWLEDGEMENTS</b> .....	6
<b>DEFINITION OF TERMS</b> .....	7
<b>ABSTRACT</b> .....	8
<b>LIST OF ABBREVIATIONS</b> .....	10
<b>1. INTRODUCTION</b> .....	11
1.1. The problem addressed in this study .....	12
1.2. Justification for this study .....	14
1.3. Aims and objectives of this study .....	15
<b>2. LITERATURE REVIEW</b> .....	17
2.1. Mothers care for disabled children .....	17
2.2. Factors affecting the empowerment of parents .....	18
2.3. Disabled children are not accessing available services.....	19
2.4. Relevant legal instruments.....	20
2.5. Disabled children and the Children’s Act.....	21
2.6. Summary of Chapter 2 .....	23
<b>3. METHODOLOGY</b> .....	24
3.1. The case study strategy.....	24
3.2. Sampling strategy .....	24
3.3. Gaining access to participants .....	25
3.4. Data Generation through in-depth interviews.....	26
3.5. Data management and analysis.....	26
3.6. Ensuring trustworthiness .....	27
3.6.1. Credibility.....	27
3.6.2. Dependability.....	27
3.6.3. Transferability.....	27
3.6.4. Confirmability.....	27
3.7. Ethical considerations .....	28
3.8. Preliminary bias and assumptions .....	29
3.9. Limitations of the study .....	29
3.9.1. Venue and time for interviews .....	29
3.9.2. Research design.....	30
3.9.3. The diversity of the mothers.....	30

<b>3.10. The study participants.....</b>	<b>30</b>
3.10.1. <i>Participant 1: Gugu.....</i>	30
3.10.2. <i>Participant 2: Zanele.....</i>	31
3.10.3. <i>Participant 3: July.....</i>	32
3.10.4. <i>Participant 4: Thoko.....</i>	32
<b>3.11. Summary of Chapter 3.....</b>	<b>34</b>
<b>4. FINDINGS.....</b>	<b>35</b>
<b>4.1. Theme 1: Limited information.....</b>	<b>35</b>
4.1.1. <i>“We cannot fight for what we do not know”.....</i>	37
4.1.2. <i>Poor dissemination of information on the Children’s Act.....</i>	37
4.1.3. <i>“We do not know the rights of our children”.....</i>	38
4.1.4. <i>Parents become passive.....</i>	39
4.1.5. <i>Information not reaching the parents.....</i>	40
4.1.6. <i>Inaccessibility of the media to some parents.....</i>	41
4.1.7. <i>Illiteracy.....</i>	41
4.1.8. <i>Stigma.....</i>	41
4.1.9. <i>Poverty amongst parents of disabled children.....</i>	41
4.1.10. <i>Under-resourced centres for disabled children.....</i>	42
4.1.11. <i>Summary of Theme 1: Limited information.....</i>	42
<b>4.2. Theme 2: Mothers collaborating with Government.....</b>	<b>43</b>
4.2.1. <i>Parent representation at all levels of government.....</i>	43
4.2.2. <i>Government to consider the diversity of mothers.....</i>	44
4.2.3. <i>Government to provide appropriate facilities.....</i>	44
4.2.4. <i>Integrated government support.....</i>	45
4.2.5. <i>Summary of Theme 2: Collaborating with the government.....</i>	46
<b>4.3. Theme 3: Building the capacity of parents.....</b>	<b>46</b>
4.3.1. <i>Skills for dissemination of information.....</i>	47
4.3.2. <i>Building the confidence of parents.....</i>	48
4.3.3. <i>Building the leadership skills of mothers.....</i>	49
4.3.4. <i>Building DPO leadership.....</i>	49
4.3.5. <i>Summary of Theme 3: Building the capacity of parents.....</i>	50
<b>4.4. Theme 4: Advocacy and networking across sectors.....</b>	<b>50</b>
4.4.1. <i>Fight for the rights of our children.....</i>	52
4.4.2. <i>Mothers working together as a collective.....</i>	52
4.4.3. <i>Leadership creating awareness on the Act.....</i>	53
4.4.4. <i>Networking across the sectors.....</i>	54
4.4.5. <i>Co-ordinated support.....</i>	54
4.4.6. <i>Involvement of other stake holders.....</i>	55
4.4.7. <i>Summary of Theme 4: Advocacy and networking across sectors.....</i>	55
<b>4.5. Summary of Chapter 4.....</b>	<b>56</b>
<b>5. DISCUSSION OF FINDINGS.....</b>	<b>57</b>
<b>5.1. Awareness-raising about the Children’s Act.....</b>	<b>57</b>
5.1.1. <i>Limited information.....</i>	57
<b>5.2. Responsibilities of the government.....</b>	<b>58</b>
5.2.1. <i>Literacy.....</i>	58
5.2.2. <i>Language diversity.....</i>	60
5.2.3. <i>Use of media.....</i>	60

5.2.4.	<i>Alignment of services.....</i>	60
<b>5.3.</b>	<b>Building capacity of parents .....</b>	<b>62</b>
5.3.1.	<i>Stigma.....</i>	62
5.3.2.	<i>Mothers' feeling of inadequacy.....</i>	63
5.3.3.	<i>Poverty amongst parents of disabled children.....</i>	64
5.3.4.	<i>Under-resourced centres for disabled children .....</i>	65
5.3.5.	<i>Mothers of disabled children as leaders and decision makers.....</i>	65
5.3.6.	<i>Delegates not bringing back information.....</i>	66
<b>5.4.</b>	<b>Integrated services and programmes.....</b>	<b>67</b>
<b>5.5.</b>	<b>Building capacity for advocacy: strategies to promote acquisition of information.....</b>	<b>68</b>
5.5.1.	<i>Skills development.....</i>	68
5.5.2.	<i>Networking.....</i>	71
<b>5.6.</b>	<b>Summary of Chapter 5 .....</b>	<b>72</b>
<b>6.</b>	<b>RECOMMENDATIONS AND CONCLUSION.....</b>	<b>73</b>
<b>6.1.</b>	<b>Collaboration and co-ordination.....</b>	<b>73</b>
6.1.1.	<i>Collaboration between the Department of Social Development and other Government Departments.....</i>	73
6.1.2.	<i>The role of parents in the implementation of the Act.....</i>	75
6.1.3.	<i>Parents' knowledge of how to demand the rights of their children.....</i>	75
<b>6.2.</b>	<b>Ensuring that information on the Act is available to the parents .....</b>	<b>75</b>
6.2.1.	<i>Parents and literacy skills.....</i>	75
6.2.2.	<i>Accommodating parents' diverse literacy levels.....</i>	76
6.2.3.	<i>Dissemination of information to parents through community-based workers .....</i>	76
<b>6.3.</b>	<b>Dissemination of information to DPOs.....</b>	<b>76</b>
6.3.1.	<i>Awareness-raising and training on the Act.....</i>	76
6.3.2.	<i>Securing resources for building the capacity of DPOs to support parents.....</i>	76
6.3.3.	<i>Knowledge about private and public resources and services.....</i>	77
<b>6.4.</b>	<b>Dissemination of information through DPOs.....</b>	<b>77</b>
6.4.1.	<i>DPOs to provide support to parents.....</i>	77
6.4.2.	<i>Strengthening the economic capacity of parents.....</i>	78
6.4.3.	<i>Combating stigma through raising awareness in the community.....</i>	79
6.4.4.	<i>Equipping mothers with specific skills.....</i>	79
<b>6.5.</b>	<b>Networking across the children's disability sector.....</b>	<b>80</b>
<b>6.6.</b>	<b>Summary of Chapter 6 .....</b>	<b>80</b>
<b>6.7.</b>	<b>Conclusion.....</b>	<b>81</b>
	<b>LIST OF REFERENCES.....</b>	<b>82</b>
	<b>APPENDIX A: Interview Guide.....</b>	<b>87</b>
	<b>APPENDIX B: Consent Form.....</b>	<b>89</b>
	<b>APPENDIX C: Information Letter.....</b>	<b>91</b>

## **DEDICATION**

I salute the four mothers of disabled children who participated in this study for their openness in sharing their experiences with me. They painted a clear picture of the barriers which contribute to most of them not taking cognizance of the legislation which is enacted to improve the situation of their children. Their participation will go a long way towards informing both government and the disability sector about how parents may be supported in order to acquire information.

University of Cape Town

## ACKNOWLEDGEMENTS

**I sincerely acknowledge and thank the following people:**

Theresa Lorenzo for accommodating my health condition, for her advice and direction, and for encouraging the production of quality work.

Sue Philpott for helping me to be systematic and consistent throughout my studies. As Theresa would say, “not to mix potatoes with onions”.

To Adri Winckler and Zanele Magwa who helped me with the registration for my studies, ensuring that my documents were in order.

To Rose Mazibuko for encouraging me during my studies and for letting me use her computer and her car to meet with my supervisor.

To DICAG for initially funding my studies.

To DPSA who subsequently funded my studies.

To my sister and her husband, Dr and Mrs Mkhonto, and also my sister Zandile Dineka, for granting me unrestricted use of their laptops, and for providing me with transport when it was needed.

To my children and my nieces Nane, Andile, Nontobeko, Nomvula, Sandile, Nondumiso, Smanga and Boikanyo for putting up with me while studying.

To Theresa’s mother, and her sister and husband for allowing me to meet my supervisor at their homes.

To Sue’s husband and children for allowing me into their home for the purpose of my supervision and accommodation.

## DEFINITION OF TERMS

**Disability:** Schneider (2006) defines disability as an experience that arises out of the interaction between a person with a health condition and the context in which they live. Disabled Peoples International further explains that disability manifests as a person's loss or limitation of opportunity to take part in the normal life of their community on an equal level with others due to physical and social barriers (Priestley, 2006).

**Disabled children:** children whose experiences are determined by the interaction between their health condition and their environments because society fails to include children of difference (Priestley, 2006).

**Health condition:** neuromotor impairments, degenerative diseases and orthopedic and musculoskeletal disorders (Eloff et al., 2002:84). Health condition excludes what Heller et al. (1996:36) define as health impairments, e.g. cystic fibrosis and infectious diseases like HIV/ AIDS.

**Mother:** a mother is traditionally a female biological parent. According to Kayongo-Male and Onyango (1984:21), traditional black Africans often call uncles, aunts and even grandparents "father" or "mother". Mwamwenda (1995:429) attributes this tendency of calling relatives "mother" or "father" to the interdependence of the extended family, resulting in other immediate members of the family taking responsibility for children. For the purpose of this study, mother shall mean the biological mother or aunts, grandmothers and other female relatives of the disabled child.

**Collaboration:** working jointly with others, willingly co-operating with others and sharing goal setting, problem solving and the achievement of goals (Mastropierre & Scruggs, 2000:38).

## ABSTRACT

The purpose of this study is to explore the information that the mothers of disabled children have on the provisions of the Children's Act (CA) (Act no.38 of 2005) and the Children's Amendment Act (CAA) (Act No.41 of 2007). The two Acts were consolidated after the regulations had been adopted<sup>1</sup>.

The Children's Act gives effect to the three specific constitutional rights of children contained in section 28. These are:

- a. The right to social services.
- b. The right to parental or family care or to appropriate alternative care when removed from their family.
- c. Protection from maltreatment, neglect, abuse or degradation.

This Act stipulates the services that are required to give effect to the three State obligations.

The aim of the research was 1) to investigate the nature of information which mothers of disabled children have acquired about the Children's Act, and 2) factors influencing the access to this information by these mothers.

The study population was mothers whose children have a physical or mental disability. The study sample was purposively selected from mothers of disabled children living in a township in Ekurhuleni Metropolitan, in Gauteng Province.

A qualitative research approach was used in this study, and a case study design was adopted. Individual in-depth interviews were held with four participants.

The data collected through the in-depth interviews was analyzed using a thematic content analysis. The findings of this study will raise awareness among mothers of

---

<sup>1</sup>The two Acts shall hereafter be referred to as The Children's Act except when the two Acts need to be distinguished.

disabled children and their organizations of the rights and services to which disabled children are entitled according to the Children's Act. It will therefore enable them individually and through DPOs to more effectively monitor the implementation of the Act by the State and to enforce compliance by the State of its obligations to disabled children in terms of the Children's Act.

University of Cape Town

## LIST OF ABBREVIATIONS

ABET	Adult Basic Education and Training
CBR	Community-based Rehabilitation
CRF	Community Rehabilitation Facilitator
DICAG	Disabled Children Action Group
DoE	Department of Education
DPI	Disabled Peoples' International
DPO	Disabled People's Organization
DPSA	Disabled People South Africa
ECD	Early Childhood Development
HIV	Human Immunodeficiency Virus
LSEN	Learners with special educational needs
MEC	Member of the Executive Council
NGO	Non Governmental Organization
OSDP	Office on the Status of Disabled Persons
RDP	Reconstruction and Development
UN	United Nations

## CHAPTER 1

### 1. INTRODUCTION

Poverty, social fragmentation, a culture of violence and unemployment, and HIV/AIDS have resulted in vast numbers of vulnerable children needing social welfare services (Proudlock et al., 2008). The Child Care Act that was passed more than twenty years ago in 1983 was put in place to provide welfare services to vulnerable children. However, this legislation was developed during the apartheid era and mainly served the interests of the white population. It was an Act which was not pro-active but which was reactionary in that the state only intervened after the child had been harmed. Through the Child Care Act,

the State only provided minimal assistance to individuals or families when the “normal” safety nets such as family and community had failed (Dutschke and Manson, 2008:1).

The new Children’s Act (No.38 of 2005 as amended) is aimed at addressing the need for a new legislative framework which is in line with the Constitution and various international conventions (Proudlock et al., 2008), such as the United Nations Convention on the Rights of the Child (1995) and the United Nations Convention on the Rights of Persons with Disabilities of 2006, which came into force on the 3<sup>rd</sup> of May 2008. For the first time in the history of this country, child care and child protection programmes and services are no longer viewed as charity but as rights.

The Disabled Children’s Action Group (DICAG), an organization of parents of disabled children, learned through experience that the future of disabled children is directly linked to the levels of empowerment of their parents (DICAG, 2001:14). This implies that parent empowerment is central to a disabled child’s likelihood to access services which are provided for in the Children’s Amendment Act and which are available to all children. Accessing information on the Act and knowing the provisions are among the most powerful tools to empower the parents of disabled children, because they provide a critical means with which to monitor and to enforce the rights of their children.

### **1.1. The problem addressed in this study**

The Children's Act makes specific provisions to address the situation of disabled children who are frequently marginalized in terms of service provision and access. This is in line with Howell's observation:

Disability has been equally recognized as a basis of direct and indirect discrimination and a central factor contributing to inequality and the marginalization of people in the past. New laws and policies now make provision for the removal of disability discrimination in key areas and create opportunities for addressing the needs of disabled people as a previously disadvantaged group in society (Howell et al., 2006:79).

Despite this, mothers still face enormous challenges in raising disabled children. This is largely due to most of them being unemployed, semi-literate or functionally illiterate (Emmett, 2006). Most of them are single women who have been deserted by their husbands and lovers, ostracized by their communities and isolated by their extended families. Mothers of disabled children tend to be withdrawn and live in a world of their own. Some professionals such as therapists make this burden even heavier by relying on mothers only and not on both partners to implement the necessary programmes (McKenzie & Muller, 2006). In practice, and supported by the researcher's observation, it is frequently the mothers who care for and worry about their disabled children.

Compounding these challenges, mothers are prone to being uninformed and ignorant of the rights of their children. Their children often do not access available services like day-care centres, where they could be further directed towards more facilities. Disabled children are frequently turned away from these facilities by practitioners and service providers who are not trained to deal with them. Service providers and support services for disabled children fall short of their needs; and they often do not take cognizance of information in the Acts and related policies.

From the researcher's observation in the township at Ekurhuleni Metropolitan, many parents, in particular mothers and grandparents of disabled children are not taking advantage of the services that are available to them and to their disabled children. Nor

are they in a position to advocate for the services which their disabled children need and which are not provided for in the Children's Act. Most of the mothers of disabled children are not members of Disabled Peoples Organizations (DPOs), which play a pivotal role in empowering mothers of disabled children to be self advocating on issues affecting them.

In order for them to be effective disability activists, mothers of disabled children need to know what the Act says. The Children's Act promotes equity in service provision. It provides clarity on the services needed as well as by whom and how that service is to be provided. A broad description of services which will benefit all children are stipulated in the Act. These include:

- Services aimed at preventing neglect and abuse of children
- Services supporting families of children who need early intervention to prevent imminent harm to them
- Protection services to those children who have been abused, to prevent further harm to them, and
- Services placing children in alternative care where it is in the child's best interests to be removed from his/her family.

It is therefore important to determine what information mothers of disabled children have, how it was obtained and how they use that information to the benefit of their children. If they do not have the information about the Children's Act, it is important to identify the factors that prevent them from knowing what the law provides for their children. Knowledge and information about the Children's Act will place the mothers of disabled children in a position to identify the opportunities that are available to them in order to effectively lobby the government to implement the Act (Dube, 2006). It is not sufficient to have an equal opportunities policy, if the beneficiaries of those policies do not know what such policy means or how to implement and benefit from it in practice (Hurst, 1999).

## **1.2. Justification for this study**

The Children's Act introduces numerous beneficial changes for disabled children. The disability-specific clauses are aimed at ensuring that disabled children have equal access to available services as all other children. The clauses further state who is to provide which service for disabled children, including the necessary support for both parents and children.

DICAG observed in the organization's strategic plan (DICAG, 2001) that 98% of caregivers in the organization were women and 58% of them were grandmothers. This explains why this study will exclude men or fathers of disabled children and focus more on the mothers of these children.

It is crucial to investigate whether mothers of disabled children are informed of their disabled children's rights as stated in the Children's Act. Information and knowledge will facilitate the capacity of the mothers to effectively change the situation of their disabled children. The mothers have the duty to monitor that the state implements the Act. This equally applies to other duty bearers who are mentioned in the Children's Act.

There are strategy and provisioning clauses in the following chapters of the Act:

- Partial Care
- Early Childhood Development
- Child and Youth Care Centres and
- Drop-in Centres.

These oblige the Minister of Social Development and Provincial MECs to ensure that disabled children have equal access to these services, by specifically stating that due consideration must be given to these children. The Minister and MECs are further obliged to make facilities accessible and programmes available to disabled children, as well as prioritizing funding for these programmes. The strategy and provisioning clauses read together, promote equal access to services for disabled children.

Information and knowledge of the Act, and the necessary skills and support will enable the mothers to monitor its implementation as well as access services for their disabled children. Although knowledge about the Act is crucial, knowledge on its own will not lead to the enforcement of the Act. Mothers need to know and identify opportunities and platforms that they can use to influence decision makers and policy implementation. Mothers need to be able to monitor budgets as well as the services to which those budgets are allocated. The question to be asked is whether they target services that will also benefit disabled children. This study investigates the information that mothers of disabled children have as well as why they do not have the information on the Act if that is the case. It identifies what skills and support the mothers of disabled children need in order to access and use the information that is in the Act, for the benefit of their children.

This study contributes to raising awareness among mothers of disabled children and their organizations of the rights and services to which disabled children are entitled according to the Children's Act. It enables them individually and through DPOs to more effectively monitor the implementation of the Act by the State and to enforce compliance by the State of its obligations to disabled children in terms of the Children's Act.

### **1.3. Aims and objectives of this study**

The aim of this research is to identify what information and knowledge mothers of disabled children have about the Children's Act.

The objectives are:

- to describe the information and the awareness that mothers of disabled children have about the Children's Act
- to identify factors which facilitate or hinder the acquisition of information on the Children's Act by mothers of disabled children
- to identify the skills which mothers of disabled children need in order to access information from the Children's Act

- to determine how mothers may have benefited or will benefit from the information in the Act
- to elicit from the mothers the nature of the support which they will need in order to access, understand and use the provisions of the Act.

The following chapter will provide a review of relevant literature consulted for this study.

University of Cape Town

## CHAPTER 2

### 2. LITERATURE REVIEW

#### 2.1. Mothers care for disabled children

All parents would like to play an important part in their children's education and development. However, many disabled children are going through experiences of being excluded and discriminated against by society. They largely do not access local schools, pre-schools, or educare centres, either because of being refused admission or because their parents lack information on the existence or the functioning of those facilities (Brummer, 1996).

In the case of disabled children it is largely the mothers who are expected by society to nurture and raise disabled children, as observed by Pokémpner and Roberts:

The impact of disability on women as parents is not only evident in relation to women who are themselves disabled, but also in relation to the role of women as mothers and caregivers. Being a woman implies an increased set of barriers to access and participation on various levels. Nowhere are these barriers more evident than in the case of a woman who has to cope with children who are disabled or who have chronic illnesses. Especially within the context of women-headed households and early pregnancies, women face enormous challenges in raising disabled children (2001).

Mothers of disabled children frequently experience "disablement by proxy", that is the child's impairment is being transplanted onto them (Brett, 2002). A similar experience has been observed in the case of disabled people and their families.

As was previously stated, the Disabled Children's Action Group (DICAG), an organization of parents of disabled children, learned through experience that the future of disabled children are directly linked to the levels of empowerment of their parents (DICAG, 2001). This implies that parent empowerment is central to a disabled child's likelihood to access services which are provided for in the Children's Act and which are available to all children. Accessing information in the Act and knowing the provisions are

among the most powerful ways to empower the parents of disabled children because information and knowledge provide them with critical tools to monitor and enforce the rights of their children.

## **2.2. Factors affecting the empowerment of parents**

Various factors may affect the levels of empowerment of parents of disabled children. Disability has been shown to be associated with low levels of income and an increased likelihood of poverty. Parents of disabled children are likely to have lower educational and literacy levels than the rest of the population (Emmett, 2006). Experiences of parents of disabled children are characterized by lack of opportunities and the physical and emotional strain of caring for a disabled child.

Mothers of disabled children may feel stigmatized by the way that they are perceived and treated. Society is often patronizing towards their children. The mothers are conscious of not being taken seriously because of their children's disability, and they constantly face assumptions that their children are incapable of doing anything for themselves. They feel constantly judged and under pressure to be good parents, in order to prove themselves and to challenge the negative attitudes of society which seek to render them powerless and vulnerable (Brett, 2002).

Some people may conceal their disability status or that of members of their households because of the stigma that is associated with disability (Brett, 2006). These experiences are largely due to limited or lack of information by the parents, family members and their communities on the rights of disabled children. They are also exacerbated by the attitudes which mothers of disabled children experience from the society.

Out of a desire to provide for their children some parents come together to start informal daycare centres where the child can at least be cared for (Brummer, 1996). These parents seldom have the use of proper buildings, and they have to use a home, rondavel or shack as a centre for children. These informal centres often have very little

money to buy toys, apparatus and food for the children because most of them get little or no support from the government (Brummer, 1996).

If parents are to play a significant role in the lives of their children, they need information and support in their groups and in the informal daycare centres, so as to empower themselves in order to meaningfully contribute to the education and development of their children. They need skills to be able to cope with disabled children in their families, care for them, teach them and advocate for better facilities. Often parents only want to give up their responsibility if they feel they cannot manage anymore (Brummer, 1996).

Boxil (2000) observes that the feelings of hopelessness among parents who cannot cope with raising their disabled children have been passed on from generation to generation, with such parents lacking the sense of agency. For generations now, parents are in the position of not knowing how to turn their adverse situation around. This has very serious and adverse effects on the development of their children and on the parent's capacity to nurture and raise her child. According to Nhlapo et al

it is essential that sufficient programmes be implemented to ensure that the knowledge of human rights reaches each individual, if self advocacy is to be facilitated (2006:102).

### **2.3. Disabled children are not accessing available services**

In the White Paper on An Integrated National Disability Strategy it is estimated that 70% of disabled learners of school-going age were outside the general and education training system (ODP, 1997). Taylor (2001) reported that 30% of disabled children of school-going age were not attending school full time, compared with 10% of non-disabled children. Higher education remains out of reach for the majority of disabled people (ODP, 1997).

According to Elwan (1999), disabled people and their families are usually poorer than the rest of the population. They are likely to have lower educational and literacy levels

than the rest of the population. When disabled people are employed, they are likely to be under-employed relative to their level of training.

Emmett (2006) also suggests that educational disadvantages of disabled children may be compounded by racial inequalities:

- 51% of African disabled children were not attending secondary school in contrast with 11% of white disabled children
- white disabled children were more likely to attend special schools than African children
- 32% of white children as compared to 8% of African children attended primary school
- 33% of white disabled children attended special schools at secondary levels compared to only 5% of African disabled children.

Early childhood development holds a particular potential for disabled children as it can enhance their capacity to participate fully in the realization of their rights and abilities. However, disabled children continue to have limited access to Early Childhood Development (ECD) services, as only 1.36% of these children are in ECD centres, including special schools (Biersterker & Kvalsvig, 2007). In addition, most of the ECD sites for Grade R are located in schools, while the majority of disabled children are in informal daycare centres or at home-based sites.

#### **2.4. Relevant legal instruments**

The Children's Act gives effect to Section 28 of the Bill of Rights of the Constitution and to international instruments that have been signed and ratified by South Africa. These include:

- the UN Convention on the Rights of the Child (adopted November 1989)
- the African Charter on the Rights and Welfare of the Child (which came into force in November 1999)
- the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN, 1993)

- the UN Convention on the Rights of Persons with Disabilities (which came into force in May 2008).

## **2.5. Disabled children and the Children's Act**

Several amendments have been made to the Act to ensure that disabled children equally enjoy the rights in the Children's Act. It gives effect to the rights that disabled children have, as well as to the obligations of the State and other duty-bearers in ensuring that these rights are protected. It has provisioning clauses obliging the National Minister and Provincial MECs of Social Development to deliver services to disabled children, including the allocation of resources; and makes special provisions that prioritize provisioning services to children from poor communities and to disabled children. It further provides norms and standards which "will regulate the outcomes and the well being of children" (Bray & Dawes, 2007:20).

In line with the Constitution, the Children's Act entrenches services to children as rights. Children now have rights to parental care, family care or alternative care. They have a right to social services; they have a right to be protected from abuse, maltreatment, neglect and degradation. These are the rights in Section 28 of the Bill of Rights which the Children's Act gives effect to. This legislation creates obligations and provides implementation strategies for the State. However, Dube (2006) observe that even when such good legislation is in place, many disabled people do not know of their rights or how to access them.

The problem is that information is not communicated in either direction, i.e. from the National Government to DPO leadership level, or to grassroots organizations (Dube, 2006). Bray and Dawes note that children cannot access their human rights without the support and intervention by certain individuals. It therefore becomes critical to focus attention on those individuals who are responsible to enable the child's access to her rights.

A rights based approach should not only be concerned with the rights accorded to the child but also to their reciprocal – the duty-bearers responsible to enable the child's access to her rights. Children's enjoyment of and access to their rights

is made possible by the actions of certain duty-bearers. These persons range from those closest to the child (parents or other legal guardians) to more distant personnel and systems (for example clinic staff or teachers, local government), ministers and finally, the president. (Bray & Dawes, 2007:23)

Dube (2006) states that many disabled people are unable to access information due to the high levels of illiteracy among disabled people, and the production of information in formats that are inaccessible. He notes that dissemination of information about progress on government interventions is a crucial tool for communities to understand and gauge the success or failure of the program. This means that disabled people may be prevented by various barriers from accessing information on their rights.

Gariyo (2002) takes this further and states that local governments must develop accountable and transparent systems that enable the communities they serve to access information required to conduct effective monitoring. This requires that DPOs at local levels need to build the capacity at the grassroots, so as to monitor policy implementation within their communities (Dube, 2006).

Literature around the capacity of parents of disabled children to monitor the implementation of the policies and laws which the government enacts in order to benefit their children is scarce. This is particularly so when it comes to the question of whether the parents of disabled children take cognizance of legislation which gives effect to the rights of their children. There is, however, a fair amount of literature written to confirm that it is mostly the mothers of disabled children who, without the assistance or the cooperation of their partners and or family members, solely carry the responsibility of bringing up their disabled children (Mc Kenzie & Muller, 2006; Emmett, 2006).

If disabled children are to benefit from the legislation that is in force, it is imperative to explore factors which prevent parents of disabled children from acquiring information on the existing legislation policies and programmes. This will make it possible to identify methods to facilitate the acquisition of information from the Act by the mothers.

## **2.6. Summary of Chapter 2**

The literature reviewed in this chapter supports the view that many disabled children are not accessing available services which are their right in terms of the Constitution of South Africa (1996). It also stresses that children cannot access their human rights without the support and intervention of certain individuals, for example their parents. This means that parents of disabled children need to know what the Act provides for their children. However, many parents of disabled children are prevented by various barriers from accessing information on the rights of their children from the Act which has adverse effects on their children's development.

In the next chapter I will describe the methodology which was used for this study.

University of Cape Town

## CHAPTER 3

### 3. METHODOLOGY

A qualitative research methodology was chosen for this study. This method views events, actions, norms and values from the perspective of the people being studied (Bryman, 1988), so that it is possible to describe human actions (Mouton, 2001). The qualitative approach is consistent with the aims of this study design, namely to explore the information that mothers of disabled children have about the Children's Act.

#### 3.1. The case study strategy

The research strategy adopted in this study is the case study. Case studies have the potential to maximize the gathering of highly descriptive information on the phenomenon being studied (Merriam, 1998). Mouton (2001) describes case studies as an intensive investigation of a single unit. Case studies serve the purpose of gaining an in-depth understanding of the problem under investigation as well as of the meaning that the objects of the study attach to it. This was achieved by focusing attention on a single entity or unit which is immersed in the problem situation.

Case studies can be descriptive, interpretive or evaluative, depending on their intent or purpose (Merriam, 1998). This study adopted a descriptive case study. Descriptive case studies offer a detailed account of the research problem so as to give descriptive and basic information about the phenomenon being studied. Merriam (1998) maintains that descriptive case studies are helpful in producing basic information where research has been scarce, which is the situation in this study. The researcher intended to explore and describe the information which mothers of disabled children have about the Children's Act.

#### 3.2. Sampling strategy

The sampling strategy used by the researcher was snowballing, which is a form of purposive sampling. It requires that criteria selecting the sample be determined. Merriam (1998) states that this sampling strategy is based on the assumption that the

researcher intends to discover, understand and gain insight from a sample that is able to give the most relevant information. It is about identifying and selecting rich informants for in-depth study, i.e. people who are articulate, reflective and willing to share experiences with an interviewer as well as being able to provide detailed information about the phenomenon under study (Morse, 1999).

In accordance with this strategy, four mothers of disabled children were selected according to the following criteria:

- they should be mothers whose children are disabled
- they must be staying in a township in the Ekurhuleni Metropolitan area
- the children must have a physical or intellectual disability
- they must be willing to freely share their experiences in the interview.

### **3.3. Gaining access to participants**

A local clinic at a township in Ekurhuleni provides weekly stimulation programmes for disabled children and their caregivers. This clinic was selected as a base for the sampling of the six mothers of disabled children. The researcher verbally explained to the nursing sister the purpose of the research and why she would like to interview mothers of disabled children about their knowledge of the Children's Act. The nurse agreed to give the researcher permission to sample the mothers from those who bring their disabled children to the clinic on Wednesdays. It was initially planned that the researcher would hold individual discussions with the mothers who were selected to be a part of the study. However, due to participant attendance problems which the researcher had not anticipated, the times and the venue for conducting interviews with the participants was changed. The clinic proved to be unsuitable because it required the interviews to be conducted only after working hours. Participants found it very difficult to come to the clinic again after they had been there earlier.

All participants sent their children to an informal stimulation centre in their township for care. The principal of the centre was approached by the researcher for a suitable room in which to conduct the interviews. A room was made available to us, which we used for

interviews during the morning when the mothers brought in their children, or in the afternoon when they fetched the children.

### **3.4. Data Generation through in-depth interviews**

Data in this study was generated through in-depth interviews. De Vos defines interviewing as “a conversation with a purpose” (1998:207). The quality of the information obtained during an interview is largely dependent on the interviewer (Patton, 1990). The researcher serves as the instrument through which the data is generated, probing for further information as needed for depth and clarity (Boyd, 1993).

Each in-depth interview was conducted in the language of the participant and lasted for one and a half to two hours per participant. An interview guide is attached (Appendix A). The in-depth interviews were recorded for the purpose of transcription and analysis. To ensure clarity of statements, copies of transcripts of the first interview were given to the participant to make any desired changes. A second interview was conducted with each participant to gain clarity on issues or follow up on gaps identified in the analysis as well as member-checking the initial themes identified.

### **3.5. Data management and analysis**

Data was analyzed according to qualitative content analysis (Henning et al., 2004). Each tape-recorded in-depth interview was transcribed and it was carefully translated into English. The transcription was shared with the interviewees during the second interview for verification. The researcher again listened to the tapes and re-read the transcripts to acquaint herself with the data. During the re-reading of transcripts, emerging themes or topics were identified and noted on the margins of the transcript record. Themes were then coded whilst also clustering similar themes for coding. The coded themes were then re-read and clustered under main headings. The identified themes then became sub-headings of the main themes (Lathlean, 2006). In short, topics were clustered into categories from which main themes emerged.

### **3.6. Ensuring trustworthiness**

Trustworthiness refers to the reliability of the study. Qualitative researchers employ certain techniques to ensure trustworthiness. Guba and Lincoln (Kreftig, 1991:215) propose what they call “an alternative model method” to ensure reliability of the study. This involves four criteria, which are credibility, transferability, dependability and confirmability.

#### **3.6.1. Credibility**

This criterion refers to the extent to which the researcher is confident that the findings from the available data reflect the actual meanings communicated by the participants. In this study, credibility was ensured through peer debriefing, where the researcher discussed the research process and findings with an impartial colleague who has a research background. Member-checking was also done where the researcher solicited the reaction of the participants to the researcher's reconstruction of what transpired in the first in-depth interview.

#### **3.6.2. Dependability**

Dependability refers to the consistency of the findings. If the study is replicated within a similar context, the findings should be the same (Brink, 1991). This was ensured by giving a detailed account of all the steps or progression of events, how data was analyzed and interpreted and how findings and conclusions were reached.

#### **3.6.3. Transferability**

This criterion of trustworthiness refers to applicability of the research to other contexts and settings. Narratives about the context in which the research happened are given. This facilitates judgment about the degree of fit or similarity to be made by others who may wish to apply the findings elsewhere.

#### **3.6.4. Confirmability**

This criterion encompasses the “neutrality” of the researcher. Findings should be free from bias and other perspectives of the researcher (Krefting, 1991). The researcher,

being a parent of a disabled child and a mother, acknowledged and analyzed her pre-conceptions and beliefs in relation to this study through keeping a diary of her feelings and thoughts during the data collection and analysis processes.

### **3.7. Ethical considerations**

Before commencement of the research, an accessible venue for the interviews was secured and arrangements were made to ensure that participants would reach the venue. An information letter was prepared that explained the purpose and the objectives of the research, which was given to the participants (Appendix B). Issues of confidentiality, informed consent, beneficence, anonymity and voluntary participation were explained in the language which is understood by the participant. It was further explained to the participants that they could withdraw from the research at any stage without any consequences. Data would be collected by recording the interview, using a tape recorder, with their permission. Informed consent (Appendix B) was obtained from the six mothers of disabled children prior to their participation in the study. They were asked to sign a consent form or give verbal consent which would be signed by a witness. Arrangements were made to refer for help any participants who might show signs of distress or a need for any other support when sharing their experiences in the course of the research.

Arrangements for a suitable venue in which to conduct interviews were initially made with a local clinic staff member. This was subsequently changed to accommodate the participants, and instead interviews were held at the local day-care centre in the township.

To ensure the accuracy of statements, participants were given hard copies of transcripts of the first interview at the time of the second interview. They were able to make any desired changes. Where the participant found it difficult to understand the transcript, the researcher explained the contents to them in a simpler language, but without distorting the actual meaning.

The research proposal was submitted to the Faculty of Health Sciences Research Ethics Committee for approval and clearance, where after the research commenced.

### **3.8. Preliminary bias and assumptions**

The participants and the researcher live in the same township and at times meet at disability meetings and events. The participants to be sampled are all mothers of disabled children. This, as Lathlean comments,

gives a researcher a social identity and background which may have an impact on the research process, especially in the interpretation of the research findings (2006:420).

He emphasizes that the researcher will need to “reflexively bracket” experiences so that they do not unduly bias the process of research. The researcher may be aware of the tendency of mothers of disabled children to be ignorant of the rights of their disabled children contained in various Acts. The researcher had to be cautious and set aside her own beliefs so as to see and hear the participant’s experiences as undisturbed as possible, without having to validate her own beliefs (Munhall, 1994).

### **3.9. Limitations of the study**

#### **3.9.1. Venue and time for interviews**

Initially it was planned that the interviews were to be conducted at the local clinic. However after the participants had been sampled, the clinic proved to be unsuitable because it required the interviews to be conducted only after working hours. Participants found it very difficult to come to the clinic again after they had been there earlier.

All of them sent their children to an informal stimulation centre for care in the township in which they live. The principal of the centre availed to us a room which we could use for interviews during the morning when the mothers brought in their children or in the afternoon, when they fetched the children.

Two of the mothers who were identified for interviewing did not show up at the centre. Due to time constraints and because the research question had sufficiently been answered by the four participants, they were not replaced.

### **3.9.2. Research design**

A qualitative approach was used in this study. This methodology does not fully reflect the magnitude of the problem being studied. The cases of four participants, all of whom were mothers, were explored to gain in-depth understanding of their context. More research, both quantitative and qualitative, would have to be conducted with a broader sample to draw generalization for the greater population.

### **3.9.3. The diversity of the mothers**

The mothers interviewed for this study differed in terms of age, marital status, education, and disability status. A mother with an intellectual disability was not as vocal as the others. She was however still recruited for the study so that it could be appreciated that mothers are not the same and they may relay their needs in different ways. This was a big challenge in that the researcher had to try and follow up on one sentence answers, so as to make sense of what this participant intended to say.

## **3.10. The study participants**

What follows is a brief description of each of the study participants.

### **3.10.1. Participant 1: Gugu**

This participant was the first to be interviewed. She is a 40-year-old mother of a 4-year-old girl who has cerebral palsy and epilepsy, and who is blind and also deaf. She has two other children who were born outside her marriage to the father of the disabled child. She is staying at her parent's house due to problems she experienced from her husband after the birth of her third and disabled child.

The disabled child's father deliberately abandoned work, where after the mother became solely responsible for raising the child. According to the mother, the father does

not visit the child and he does not care for this child. The participant is unemployed and she gets assistance from her sisters, family members and friends.

The child attends a local parent daycare centre at a township in Ekurhuleni. This is an informal daycare centre which was started by its chairman who is also a parent of a disabled child.

### **3.10.2. Participant 2: Zanele**

Participant two is a 24-year-old lady who stays in a township at Ekurhuleni Metropolitan with her partner who is the father of the disabled child. She is not the biological mother of the disabled child, and she is not married to the father of the child. She is originally from a rural area. She however is a caregiver to the child, and she says that she is coping very well. She has developed a healthy relationship with the child. The child sees physiotherapists every month at a nearby Clinic.

The participant is teaching at a local primary school. When she explained the child's disability, she stated that the child has an intellect which could be equal to that of a five year old, and yet he is ten years old.

The child's biological mother stayed with the child's father and the child in a township in Ekurhuleni Metropolitan until a quarrel ensued between them and she left with the child to stay in a nearby township. The child goes to a special school which is situated in the neighbouring suburb. The participant pays R250.00 per month for the transport which takes the child from home to school. There are no special schools in the township where the child lives.

The participant states that they received letters of complaint from the school about the child coming to school not having washed and in dirty clothes. His lunch box was not right and the child was under-performing at school. She states that they then linked up with the social workers who called all of them including the biological mother to discuss the matter. The mother stated that she was now overwhelmed by the burden of giving

care to her child. She was not emotionally coping anymore. She then agreed to release the child to go and stay with the participant. The participant further stated that the child visits the biological mother whenever the mother requests those visits.

### **3.10.3. Participant 3: July**

Participant three is 26 years old, and she stays in a township in Ekurhuleni Metropolitan. She is a single parent who is unemployed and who is the mother of a 4-year-old boy. She does not stay with the biological father of her child. She is renting a room in an informal settlement where she stays with her child.

The child has cerebral palsy. He sees therapists as per arranged appointments at a nearby clinic. The child also attends an informal daycare centre in the township in which they live which the community refers to a “stimulation centre” because it cares for disabled children. It is the only facility in the township that accommodates disabled children. It was established by a concerned parent who is disabled and has a disabled son. It operates from a rented garage and does not receive any form of support from the government, despite the fact that a municipal social worker visits occasionally.

The father visits his son although he is no longer in a relationship with the mother.

The participant is the deputy chairperson of the centre which has been described above and which her son attends.

### **3.10.4. Participant 4: Thoko**

Participant four is a 26-year-old mother of a disabled child, a boy who is five years old. She stays with the child’s father although they are not married. They stay at the informal settlement in a township. Describing her child’s disability, she stated that doctors informed her that her child would not be able to walk. The problem they said was at the spinal cord. The bones did not close properly.

The child attends an informal day-care centre which has been described in respect of participants one and two above. The child does not receive any stimulation from the clinic or the hospital as is the case for the other disabled children who go to a clinic at the nearby suburb or a hospital at the neighbouring township. The participant said that the child stopped when he started attending at the centre. She does not see the value of getting the child stimulated, and she thinks that because the child now comes to the centre that is sufficient. She seems to be putting all her trust for guidance in the centre chairperson.

The chairman is the founder member of the stimulation centre, which is situated in the township. The centre operates from her daughter's house which is a two roomed RDP house (government subsidized house). She extended this house and added a garage, which is now a daycare centre for disabled children.

Both the chairman of the stimulation centre and the participant went to school up to standard four. The participant was identified as having a learning disability and was referred by her primary school to an informal daycare centre in the township, which at the time was the only place which cared for disabled children in. The centre was closed due to lack of capacity and resources. The participant receives a disability grant for herself.

**Table 1: Summary of the demographics of the four participants**

Name	Gugu	Zanele	July	Thoko
Age of participant	40	24	26	26
Age of child	4	10	4	5
Place of residence	Township in Ekurhuleni	Township in Ekurhuleni	Township in Ekurhuleni	Township in Ekurhuleni
Child's impairment	multiple	developmental delay	Cerebral Palsy	Cerebral Palsy

<b>Services accessed by child</b>	Care Dependency Grant Physiotherapy treatment Daycare centre	Care Dependency Grant Physiotherapy treatment Special school	Care Dependency Grant Physiotherapy treatment Daycare centre	Care Dependency Grant Daycare centre
<b>Participant's relationship to child</b>	Biological mother	Stepmother	Biological mother	Biological mother
<b>Mother's employment status</b>	Not employed	Teacher	Not employed	Not employed
<b>Mother's disability status</b>	No disability	No disability	No disability	Intellectual disability
<b>Father's support</b>	None	full	full	full

### 3.11. Summary of Chapter 3

This chapter reviewed the methodology which was adopted for this study. It introduced the snowballing and the case study strategies which enabled the researcher to select information-rich informants.

Data generation and management systems were also reviewed. A definition of trustworthiness of the data was provided, and adherence to ethical requirements was described.

The next chapter will look at the findings which emerged from the interviews.

## CHAPTER 4

### 4. FINDINGS

This chapter reflects the themes that emerged from the cross analysis of the four individual interviews with the participants related to the study objectives, namely

- to describe the information and the awareness that mothers of disabled children have about the Children's Act
- to identify factors which facilitate or hinder the acquisition of information on the Children's Act by mothers of disabled children
- to identify the skills which mothers of disabled children need in order to access information from the Children's Act
- to determine how mothers may have benefited or will benefit from the information in the Act
- to elicit from the mothers the nature of the support which they will need in order to access, understand and use the provisions of the Act.

These themes give a full picture of the unifying force which would assist parents to access, understand and use the provisions of the Children's Act. They are reflected in the following table:

**Table 2: Key themes emerging from participant interviews**

Themes	Gugu	Zanele	July	Thoko
Theme 1: Limited information	X	X	X	X
Theme 2: Mothers collaborating with the government	X	X		X
Theme 3: Building capacity of parents	X	X	X	X
Theme 4: Advocacy and networking	X		X	X

#### 4.1. Theme 1: Limited information

This theme seeks to explain why mothers have limited information on the Children's Act. Various factors were identified.

**Table 3: Categories and codes for Theme 1**

<b>Categories</b>	<b>Codes</b>
4.1.1 We cannot fight for what we do not know	<i>I did not know about it [the Act]</i>
	<i>I heard about it from you</i>
	<i>the little that I have heard from you</i>
	<i>know that the child has a right to education</i>
	<i>to live with children who are not disabled</i>
	<i>that the Act includes disabled children</i>
	<i>[parents] must care for their disabled children</i>
4.1.2 Poor dissemination of information on the Act	<i>[physiotherapist] brushes through the law [the Act] does not go into detail</i>
	<i>they make it [law] and it ends there in parliament</i>
	<i>we do not see it on TV</i>
	<i>down there it is not known</i>
	<i>in passing they tell parents that they have this right and that right</i>
	<i>indeed we do not know the rights of our children</i>
4.1.3 We do not know the rights of our children	<i>we shall know what it says about our children and their rights</i>
	<i>it will make us realize the rights of our children</i>
	<i>be aware of the rights of our children</i>
	<i>you explained that disabled children have rights</i>
	<i>we shall know what to do and not to do for our children</i>
	<i>you become stereotyped</i>
4.1.4 Parents become passive	<i>parents... doing nothing</i>
	<i>you feel inferior</i>
	<i>always complains that her child is disabled</i>
	<i>do not feel comfortable</i>
	<i>your mind just gets blocked</i>
	<i>one has to think alone about what needs to be done</i>
	<i>I do not know the reason for not having information</i>
	<i>Disabled children have no representatives to bring back information from the national meetings to the centres.</i>
<i>how will she understand or communicate [in English]</i>	
4.1.5 Information is not reaching the parents	<i>when the law is passed it must not only be in English</i>
	<i>others are old and they do not understand English</i>
	<i>I can read a little but not English</i>
	<i>they can read [the Act] but if it is not only in English</i>
	<i>there must always be an interpreter</i>
4.1.6 Inaccessible media	<i>we do not see it on TV</i>
	<i>we do not hear it on the radio</i>
	<i>...but others do not have them</i>
4.1.7 Illiteracy	<i>many did not go to school</i>
	<i>they are illiterate</i>
	<i>we need to take parents for ABET training</i>
	<i>some parents cannot read</i>
	<i>they do not know the door of a school</i>
	<i>I went as far as standard 4</i>

	<i>I can read a little...</i>
4.1.8 Stigma.	<i>Some parents are ashamed of their disabled children</i>
	<i>Some hide their children in shame</i>
	<i>belonging to such groups [of parents] identifies them in the community</i>
	<i>most parents do not love their disabled children</i>
	<i>how can you belong to such a group [of parents]</i>
4.1.9 Poverty among parents of disabled children.	<i>organizations...do not have money</i>
	<i>the majority of people who are poor are disabled people and parents of disabled children</i>
	<i>if you do not work you become stereotyped</i>
	<i>you are poor</i>
	<i>obviously your mind will be poor</i>
4.1.10 Under-resourced centres for disabled children.	<i>we need a place to meet</i>
	<i>we need buildings for such things as teaching each other about laws</i>
	<i>there are no stimulation centres</i>
	<i>although we have this centre, it does not serve our needs</i>
	<i>there are just no resources</i>
	<i>right now here we do not have meeting places</i>
	<i>I do not know where organizations of parents are in our community</i>
	<i>if you do not work you become stereotyped</i>
	<i>you are poor</i>
	<i>obviously your mind will be poor</i>

#### 4.1.1. "We cannot fight for what we do not know"

As part of this study, the interviewer had to establish the extent of information which mothers possessed. Their responses were similar and all indicated that they were not aware of the Children's Act. However, parents had some information about the rights of their children. Gugu understood

*[...] that a child has a right to education, to live with children who are normal and to go to school with normal children [...] this Act is inclusive in that even our disabled children have rights which cover them [...] to care for our children irrespective of their disability.*

The following factors were identified by mothers as those which hinder them from acquiring information on the Children's Act:

#### 4.1.2. Poor dissemination of information on the Children's Act

Gugu talked about her experience with white therapists and other health professionals:

*She [the physiotherapist] likes to talk about rights of children when she teaches and she just brushes through the law [the Children's Act]. She does not get into details. She just talks and rushes past the groups of Mamas [mothers of disabled children] [...] Therapists think that at the centres we will get all the information. For them, their duty is to show us how to raise our children. So in passing they tell us that as parents we have this right and that right.*

Thoko noted that after the law has been passed, it is not made known to the people:

*They make it [law] and it ends there in parliament [...] we do not see it on TV.*

Zanele stressed the need to disseminate information to the communities and suggested that forming support groups would be beneficial as they would receive information on the Act in those support groups. They in turn would spread it to the community thus raising awareness of disability:

*With support groups, information can spread easily because more people will be informed in the community.*

#### **4.1.3. "We do not know the rights of our children"**

Zanele felt that one of the benefits of parents having information was that they would know what rights their children have. This would guide their behaviour and attitude towards their children:

*Since you have explained to me that this Act is inclusive in that even our disabled children have rights which cover them, if it can reach us, and government play her part and support us and give our NGOs resources, we can know the rights of our children. We can benefit a lot knowing what we can do and what we cannot do for our children [...] indeed we do not know the rights of these children.*

July and Thoko confirmed that information about the Act, would enable parents to be aware of the provisions of the Act in respect of the rights of their children:

*We shall know what it says about our children and their rights. [...] From the little that I have heard from you [about the Act], it will make us realize and be aware of the rights of our children.*

Gugu felt that parents do not know the rights of their disabled children because there are no representatives of parent organizations at government structures to bring back information to the parents:

*I think that they do not have information at the centres [...] sometimes you find that disabled children have no representatives to bring information to the centres.*

#### **4.1.4. Parents become passive**

In terms of the Children's Act, the government has certain obligations towards all children and specific obligations to fulfil towards disabled children. Because of limited information about the Act, most mothers do not know the State's obligations with regard to their children. For example, the MEC is obliged to prioritize funding of Early Childhood Development (ECD) in favour of disabled children and those in poor communities [Clause 93 (4) (a) and (b)]. In addition, mothers are not aware of who is responsible for the provisions of the Act, and therefore they are not able to demand the implementation of the specific services to which their children are entitled.

Mothers feel the strain of looking after their disabled children without the support from government. This, combined with lack of information, results in the mothers being passive and doing nothing about the situation of their children. Passivity perpetuates their exclusion in such a way that their children do not benefit from the Act. Gugu stressed that often parents of disabled children feel daunted with regard to their children. This instils in them the feeling of inferiority and passivity which causes them to withdraw into a world of isolation. As a result they do not participate in activities that will benefit their children. She felt that this is the core reason that:

*[...] parents of disabled children have this thing of doing nothing but always complain that their children are disabled. They feel inferior because their children are disabled. They do not feel comfortable.*

July's view was that one of the reasons for parents not to be organized and for centres for disabled children to be in conditions which do not promote the development of their children is that parents do not know what to do. In this way, lack of information of their children's rights limits the capacity of parents to think of what they need to do to promote the rights of their children:

*We are not organized as parents [...] although we have this stimulation centre, it does not serve our children's needs [...] always one has to think alone about*

*what needs to be done. There is no chance to think about other things. The mind just gets blocked.*

The interview with Thoko confirmed the attitude of passivity among parents. They do not know about the Act and they do not know the reasons why they do not know about it. They do not question why they do not know or seek answers. They remain passive and do nothing:

*I really do not know the reason why I do not know about the Act.*

#### **4.1.5. Information not reaching the parents**

Mothers identified several factors that prevent information about the Act from reaching them. One of them is the use of the English language. Most parents do not understand English, the language in which the laws are usually written and explained. They may need an interpreter in order to understand what the Act says:

*English is the medium of communication in most places. How will she [the mother] understand or communicate? There must always be an interpreter to explain 1,2 and 3 [...]. The Department of Social Development must take up the responsibility to give skills to those parents who are not educated. (Gugu)*

*I can read a little but not English. (Thoko)*

*I think that they can read [the Act] if it is not only in English but in other languages as well. (July)*

Another factor is that representatives from the centres are not bringing back information. Gugu cited the importance of having representatives of parent organizations who advise government on the issues of disabled children at all levels of government. These representatives are to bring back information to the parents at the centres. However, information does not reach the centres due to the limited capacity of the representatives to participate effectively in the meetings:

*I think that there is no information [on the Act] at the centres. This is because disabled children have no representatives to attend and bring back information from the national meetings to the centres.*

#### **4.1.6. Inaccessibility of the media to some parents**

Zanele felt that the media are not adequately utilized to disseminate information to the parents:

*We do not see it on TV and others do not have those [TVs]. We do not hear it on the radio [...].*

#### **4.1.7. Illiteracy**

Gugu and Zanele observed that many parents lack education and saw this as a hindrance to acquiring information. These are their views:

*We need to take staff to ABET because many did not go to school and they are looking after our kids [...] some of us went to school and can read and explain to those who did not go to school what the Act says. (Gugu)*

*[...] some parents cannot read [...] they do not even know the door of a school. They are illiterate. (Zanele)*

Some parents are themselves disabled. They have lower levels of education and were taken out of the mainstream system for not coping:

*I went as far as Standard 4. They took us to an informal day-care centre in the township because we were failing our grade. I can read a little but not English. (Thoko)*

#### **4.1.8. Stigma**

Zanele felt that parents were so overwhelmed with the disability of their children that they did not want to be associated with it:

*The problem is that some parents are ashamed of their disabled children. Belonging to such groups identifies them in the community. How can they belong to such a group? Some even hide their children in shame. If only parents can be taught what to do. Most do not love their children. If NGOs can support parents so that they can appreciate their children and come to parent groups and organizations.*

#### **4.1.9. Poverty amongst parents of disabled children**

Zanele and Thoko felt strongly that poverty among parents of disabled children played a big role in information not reaching them. With no adequate resources and finance,

parents cannot organize themselves into viable parent support groups which are needed to inform and educate the parents on the Children's Act:

*The problem with organizations is that they do not have money. If you look, the majority of people who are poor are disabled people and parents of disabled children. They need money to eat. They need to work. If you work you wake up [become active]. If you do not work you become stereotyped and this is because you are poor. Obviously your mind will be poor. Your mind sleeps because you are hungry and if you are hungry you do nothing. This is what happens with many parents, mostly those who are single. (Zanele)*

#### **4.1.10. Under-resourced centres for disabled children**

Centres bring mothers together, making it possible for them to meet and to share information. However, such centres do not exist in most communities, which means that children and parents cannot meet to acquire or to share information. Some of the centres are informal day-care centres which are under resourced in terms of trained leadership, staff, proper structures and finances:

*There are no stimulation centres in our township. Although we have this centre, it does not serve our needs except to care for our children. (July)*

Zanele highlights the importance of having proper structures in which parents can meet.

*We need to come together as a group and tell government that we need buildings for such things as teaching each other about laws. We need a place to meet.*

#### **4.1.11. Summary of Theme 1: Limited information**

This theme identifies the factors which prevent parents of disabled children from acquiring information on the Children's Act and benefiting from its provisions. These range from illiteracy, passivity, lack of skills and capacity among parents, insufficient support from government, poor dissemination of information by health officials, inaccessible media, poverty, DPOs having no leadership skills, parents lacking confidence in themselves and stigma resulting from being a parent of a disabled child.

## 4.2. Theme 2: Mothers collaborating with Government

This theme explores the factors that facilitate mothers gaining information about the Act.

**Table 4: Categories and codes for Theme 2**

Categories	Codes
4.2.1 Parent representation at all levels of government	<i>there must be representatives coming from the centres</i>
	<i>government must support them to go and get information as well as training on the law</i>
	<i>for NGOs to be right, government must give something.</i>
	<i>government must do something to help parents to "wake up" and go to NGOs</i>
	<i>it must be the responsibility of the centre to approach Social Development to give parents skills</i>
	<i>the social worker called us to elect the chairman for the centre</i>
4.2.2 Government to consider the diversity of mothers	<i>but others do not have them [TVs]</i>
	<i>some parents cannot read</i>
	<i>I am disabled</i>
	<i>government has to do something</i>
	<i>some of us are single parents</i>
	<i>some children are severely disabled</i>
	<i>mothers cannot go to work</i>
	<i>be able to go to work</i>
	<i>government [...] play her part</i>
<i>I can read a little</i>	
4.2.3 Government to provide appropriate facilities	<i>as a group [...] tell government that we need buildings for such things as teaching each other about laws</i>
	<i>there are no resources</i>
	<i>they [centres] do not serve our needs</i>
	<i>we need a place to meet</i>
	<i>we do not know where organizations of parents are</i>
4.2.4 Integrated government support	<i>get guidance from government</i>
	<i>get guidance from those who know it [the Act]</i>
	<i>meet as leadership as well as with social worker</i>
	<i>government must do something</i>
	<i>see how we can improve our situation regarding the act.</i>
	<i>NGOs need support from government</i>

### 4.2.1. Parent representation at all levels of government

Gugu sees collaboration with government happening through having representatives of disabled children at all levels of government. Their role would be to participate in

discussions about disability issues, get information from interacting with government and bring that information back to the mothers:

*There must be representatives coming from the centres who represent disabled children nationally and provincially [in government discussions] [...] it must be the responsibility of the centre to approach Social Development to give parents skills.*

Zanele's position was similar. She stressed that parents must be supported by the government to go and get information:

*Government must support them to go and get information as well as training on the law [...] the problem with organizations is that they do not have money [...] for NGOs to be right [...] government must give something.*

*Government must do something to help parents to "wake up" and go to NGOs. NGOs also need support from government to be able to build the parents. If government can meet these parents halfway, and government play her part and support us and give our NGOs resources, we can know the rights of our children.*

#### **4.2.2. Government to consider the diversity of mothers**

The participants indicated that if information on the Act is to effectively reach mothers, government must recognize the fact that they are not a homogeneous group. Differences occur in terms of literacy levels, age, languages, disability status and poverty levels. For example, Thoko confirmed the diversity of parents in terms of their literacy skills and disability. She can read a little but not English. This means that language difference can create a barrier to some mothers acquiring information. Some of the parents are themselves disabled. They did not go far at school and they were taken out of the mainstream system for not coping at school. Government therefore needs to ensure that the information reaches a variety of mothers in different ways:

*We spoke with the chairman that we need a place to accommodate our children while we go to work. (Thoko)*

*Government has to do something. Some of us are single parents. Other children are severely disabled and the mother cannot go to work. (Zanele)*

#### **4.2.3. Government to provide appropriate facilities**

Zanele stressed the need for government assistance:

*Right now here we do not have meeting places, no organizations that we know. There are just no resources [...] We need to come together as a group and tell government that we need buildings for such things as teaching each other about laws.*

July gave an example of her township which does not have adequate and appropriate stimulation centres, to highlight the effects of lack of facilities for parents of disabled children. The centres are not well resourced, and they do not serve the needs of disabled children. They only offer care to the children, who are routinely brought in the morning for care and fetched in the afternoon:

*Like now, there are no stimulation centres. We do not know how to start them. We do not know which door to open for centres to be built. We do not know who to approach [...].*

Thoko stated that even where centres are running parents do not know where the centres are. Parents need to meet in order to share information:

*I do not know where organizations of parents are in our community. I only meet some parents at the centre but not in a formal and organized way.*

#### **4.2.4. Integrated government support**

However, this collaboration is not taking place. Although government departments are obliged to render services to disabled children, they often do not make contact with the parents and the centres for disabled children:

*[...] was early in the year when [the social worker] called us to elect the chairman for the centre. (Thoko)*

Participants felt that parents needed support in order to be able to build their capacity to get information on the Act:

*Yes, there are many who hide their children. If NGOs can make us to meet and share views, then that can build the parents [...] Government must do something to help the parents to "wake up" [be alert] and go to NGOs [...] NGOs also need support from government to be able to build the parents [...]. (Zanele)*

This has an effect on those centres functioning without government support. Mothers need government officials who are knowledgeable on the Act, to interact with them, and to give them information in support of their actions as a group:

*I hope we will get guidance from government and from those who already know about it [the Act] [...] We need to meet as leadership as well as with our social worker to see how we can improve our situation regarding the Act. (July)*

*Some of us are single parents, you find that some children are lying flat on the bed being severely disabled, and the mother cannot go to work. (Zanele)*

#### 4.2.5. Summary of Theme 2: Collaborating with the government

Collaboration with the government was identified as a factor that would facilitate dissemination of information to the parents. This requires parents having representatives at all levels of government to facilitate collaboration. Collaboration will promote recognition by government that mothers are a diverse group with diverse needs. It will further ensure the provision by government of appropriate facilities which mothers need in order for them to meet. It was clear to the parents that government has a role to play to support them in the acquisition of information on the Act.

#### 4.3. Theme 3: Building the capacity of parents

Parents identified various skills as necessary to obtain information and knowledge on the Act.

**Table 5: Categories and codes for Theme 3**

Categories	Codes
4.3.1 Skills for dissemination of information	<i>we need to take staff [leaders] to ABET training</i>
	<i>many did not go to school [...]</i>
	<i>they cannot read</i>
	<i>we call the parents and educate them</i>
	<i>Social Development to give those parents who are not educated the skills</i>
	<i>parents be taught what to do</i>
	<i>to meet, share views</i>
	<i>to build the parents</i>
	<i>people who are educated and who can communicate</i>
	<i>be able to ask questions and be answered</i>
	<i>we want people who will explain [the Act]</i>
	<i>government must support parent organizations to go get information training on the law</i>
	<i>some children are severely disabled and the mother cannot go to work</i>

4.3.2 Building the confidence of parents	<i>parents to “wake up” and go to NGOs</i>
	<i>parents feel inferior</i>
	<i>they do not feel comfortable</i>
	<i>stand for my child</i>
	<i>if I become brave [confident]</i>
	<i>everything I want I will get, even information</i>
4.3.3 Building leadership skills of the mothers	<i>I am the Chairman</i>
	<i>have our own groups</i>
	<i>decide on the issues of our children</i>
	<i>mothers be taught what to do</i>
	<i>we must workshop them [mothers]</i>
	<i>educate them [mothers]</i>
	<i>give skills to the parents</i>
<i>parents decide for themselves</i>	
4.3.4. Building DPO leadership	<i>we have leadership at the centre</i>
	<i>the social worker called us to elect the chairman</i>
	<i>people who are educated [in leadership]</i>
	<i>nobody is assembling us</i>
	<i>we do not have information on how to come together</i>
	<i>we do not know what to do</i>
	<i>[the chairman] should speak to us about it [the Act]</i>
	<i>speak to us about what we can do</i>

#### 4.3.1. Skills for dissemination of information

Gugu identified the need to develop literacy and communication skills among the parents and the organizational leadership, if they are to acquire any information from the Act:

*Our centres lack education. We need to take staff to ABET training because many did not go to school [...] they cannot read [...] the leadership must be responsible [...] we call the parents and educate them [...] it must be the responsibility of the centre to approach Social Development to give those parents who are not educated the skills.*

The following are seen as the specific skills that are required:

1. communication skills to share information on the Act between parents and for them to empower each other:

*[...] parents of disabled children are ashamed of their disabled children. Belonging to such organizations identifies them in the communities [...] if only parents can be taught what to do [...] if only NGOs can make us to meet, share views, then that can build the parents. (Zanele)*

*[...] must be people who are educated and who can communicate with other people [...]. (Gugu)*

2. skills to obtain information and to get explanation on the Act from the people who are knowledgeable:

*We need to be able to ask questions and be answered [...] we want people who will explain [the Act]. (Gugu)*

3. legal literacy skills which will enhance their advocacy skills in order to make sure that the rights of their children are observed:

*[...] government must support parent organizations to go and get information as well as training on the law. (July)*

4. skills to be able to work:

*Government has to do something. Some of us are single parents. Some children are severely disabled and the mother cannot go to work. Government has to meet these parents half way [...]. (Zanele)*

Thoko observed that parents who know the rights of their children will be better placed to realize their economic potential and exercise the rights of their children in a way which allows them to go to work:

*We spoke with [the child's] mother [the chairman] that we get a place where our children would be accommodated [...] to be able to go to work.*

5. skills to convene and to conduct meetings:

Thoko stated that the meeting to elect the chairperson at the centre was convened by the social worker. Although having organizational structures in place is positive, this reflects lack of skills on the part of parents to convene meetings and conduct elections:

*[The social worker] called us to elect the chairman for the centre.*

#### **4.3.2. Building the confidence of parents**

Parents felt that most mothers were not confident enough to advocate for their children. They were withdrawn, feeling inferior and not confident to even express themselves in meetings:

*If I became brave [confident] and stand for my child, everything I want I will get [...] [but] they [parents] do not feel comfortable. (Gugu)*

*Parents feel inferior [Gugu]... [and] Government must do something to help the parents to "wake up" and go to NGOs [...] NGOs also need support from government to be able to build the parents. (Zanele)*

#### **4.3.3. Building the leadership skills of mothers**

Mothers felt that their empowerment as leaders in issues of their children could be achieved by giving them information on the Act:

*Mothers must be taught what to do [...] then that can build the parents. (Zanele)*

*I think that centres do not have information [...] we [must] workshop them [mothers] and educate them [...] Department of Social Development to give skills to the parents [...] [and] let parents decide for themselves [...]. (Gugu)*

*We do need as parents of disabled children to have our own groups where we can come together, talk and decide on the issues of our children. (Gugu)*

#### **4.3.4. Building DPO leadership**

Zanele felt that although mothers are in leadership positions within the disability sector, they are making very minimal contributions towards empowering and supporting each other to address the adverse situation of their disabled children. This is because they have limited information on the provisions of the Act. If they are to succeed as leaders, mothers need to be informed and knowledgeable on the Act. The leadership within the disability sector must be able to acquire information on the Act and give directions on what needs to be done by the other parents at the centre:

*I think that centres do not have information [...] It must be people who are educated [in leadership positions] [...] who can communicate with others.*

The result is that the disability sector has a leadership which does not adequately protect the rights of disabled children and does not deliver on its mandate due to lack of information and knowledge on the Act and because it lacks the necessary skills:

*We have leadership at the centre which my child attends and I am the chairman. Like now. There are no stimulation centres in our township [...] We do not know how to start them. We do not know which door to open for centres to be built. We do not know who to approach [...]. (July)*

July emphasized the importance of having an empowered leadership. Even if parents get information on TV, they will not know what to do in response. If they acted collectively, they may be able to make demands on the government to get services for their children; but they do not have the capacity to come together. The leadership in most parent organizations has very limited capacity to mobilize parents of disabled children to form viable support groups:

*Nobody is assembling us and we do not have information on how to come together. We do not know what to do.*

If they are to succeed as leaders, mothers need to be informed and knowledgeable on the Act. The leadership within the disability sector must be able to acquire information on the Act and give direction on what needs to be done by the other parents at the centre:

*I do not think that they [leaders] have any information because they have never discussed it with us [...]. (July)*

Thoko has much confidence in her chairman. She feels that she will be better supported if the chairman speaks to them about the Act:

*The chairman should speak to us about it [the Act] and about what we can do.*

#### **4.3.5. Summary of Theme 3: Building the capacity of parents**

Mothers need certain skills to acquire information from the Act. Leadership in parent organizations has to possess the skills which they can then transfer onto the other parents. The required skills range from literacy, communication skills, legal literacy skills, confidence building, leadership skills and skills to enter the labour market and work, while the children are being developed and cared for in appropriate facilities.

#### **4.4. Theme 4: Advocacy and networking across sectors**

Mothers identified certain strategies which are necessary to enable them to effectively advocate for the fulfilment of the rights of their children. The theme also looks at how mothers and their children would benefit from networking.

**Table 6: Categories and Codes for Theme 4**

<b>Categories</b>	<b>Codes</b>
4.4.1. Fight for the rights of our children	<i>fight for the rights of their children</i>
	<i>if we are informed, we will sit down, strategize</i>
	<i>know that now we are fighting for 1,2,3</i>
	<i>if we are not informed, we cannot fight for what we do not know</i>
	<i>government must support them [mothers] to go and get information, training on the law</i>
	<i>must know where to go, which door to knock at to make sure that the rights of our children are observed</i>
	<i>have our own groups, come together, talk about the issues of our children</i>
	<i>will give us "tools" to go out and fight for the rights of our children</i>
4.4.2. Mothers working as a collective	<i>NGOs are so much needed in communities; get full information; form a group to discuss on such things as laws</i>
	<i>if NGOs can make us to meet, share views, then that can build the parents</i>
	<i>come together as a group, tell government that we need buildings</i>
	<i>we are not organized as parents; it's each one for herself one has to think alone</i>
	<i>I do not think that [...] we must place people who do not have education</i>
4.4.3 Leadership creating awareness on the Act	<i>they go and come back with something; we call the parents</i>
	<i>we workshop and educate them</i>
	<i>if only NGOs can be taught what to do</i>
	<i>make us to meet, share views</i>
	<i>we need to come together, talk about the issues of our children</i>
	<i>the disability leadership should be well informed on the Act be knowledgeable about what needs to be done</i>
	<i>give information and education to the other parents at the centre</i>
4.4.4 Networking across sectors	<i>disabled children are neglected; they are not considered; disabled children will be accommodated in the community</i>
	<i>disability is not recognized</i>
	<i>we will get guidance from those who know</i>
4.4.5. Co-ordinate support	<i>get guidance from government officials</i>
	<i>get guidance from those who already know about it</i>
	<i>see how we can improve our situation</i>
4.4.6 Involvement of other stakeholders	<i>stimulation centres in our areas</i>
	<i>disability is not there [in awareness campaigns]</i>
	<i>get information we need</i>
	<i>we are not organized as parents</i>

	<i>it is each one for herself</i>
	<i>ask therapists about our children's disability</i>
	<i>the more the therapists come to the centre, the more the information</i>

#### **4.4.1. Fight for the rights of our children**

Gugu stressed that parents need to fight for the realization of the rights of their disabled children. To do so successfully requires them to be informed and knowledgeable on the provisions of the Act so as to know what rights to advocate for.

*Parents need to fight for the rights of their children. If we are informed, we will sit down, strategize and know that now we are fighting for 1, 2, 3, but if we are not informed, we cannot fight for what we do not know.*

Zanele stated that they need literacy and advocacy skills as well as knowledge about who to target for advocacy:

*[...] also government must support them [mothers] to go and get information as well as training on the law [...] We must know where to go and which door to knock at to make sure that the rights of our children are observed.*

However, targeting the right people without clear information and knowledge will not assist the advocacy strategy:

*We need as parents of disabled children to have our own groups where we can come together and talk about the issues of our children. Those at the centre [who have information] to go out to the parents in the community and tell them about the Act. In other words, acquiring information on the Act will give us "tools" to go out and fight for the rights of our children. (July)*

#### **4.4.2. Mothers working together as a collective**

Participants in the study emphasized the need for the disability sector to speak as a collective. This can be facilitated by

- having well resourced centres in the communities
- government supporting delegates to go out and get information and knowledge
- government supporting initiatives aimed at developing the capacity of mothers
- by ensuring that NGOs for disabled people exist and are sustainable.

Zanele's view was that well resourced community facilities are needed where mothers of disabled children can meet, share views, get information on the Act as well as support from each other, the government and NGOs:

*NGOs are so much needed in communities where we can get full information and form a group to discuss such things as laws.*

July confirmed that parents are not working together as an organized group. It is each one for herself. They do not know each other as parents and the decisions and thoughts they have about their children are taken individually. This deprives parents of an opportunity to learn from each other and give each other support. July saw this as one of the causes of stress for the parents. Although they share common challenges in relation to their disabled children, due to lack of information and lack of collective action they do nothing in response.

*We are not organized as parents. It's each one for herself [...] this causes stress as one has to think alone about what needs to happen to her child. There is just no chance to think of other things. The mind just gets blocked.*

Working as a collective, discussing issues together, sharing views and approaching government together on their identified common needs will enhance the capacity of mothers to acquire and to disseminate information on the Act. The government has the duty to support organizations of disabled people, but because of the limited information which mothers possess, they may not be aware of this government obligation as well as its implications. They cannot therefore strategically position themselves as a unified voice of parents that demands delivery by government on its obligations.

*We [need to] plan [...] with government [...] come together as a group and tell government that we need buildings for such things as teaching each other about laws.*

#### **4.4.3. Leadership creating awareness on the Act**

In order for the parents to advocate successfully on the Act, leadership needs to be knowledgeable and accountable to members:

*Leadership must be responsible. I do not think that [...] we must place people who do not have education. They give us problems [...] When they go and come back with something, we call the parents. We workshop and educate them. (Gugu)*

July stressed that

*the disability leadership should be well informed on the Act, be knowledgeable about what needs to be done, and give information and education to the other parents at the centre.*

Zanele states that NGOs must be supported by government in their attempts to teach parents what to do in terms of the Act to appreciate their children. NGOs must encourage parents to meet and share views on their children.

*[...] NGOs must support parents so that they appreciate [mothers acknowledging the disability of their children, loving them] their children. They must make us to meet, share views, then that can build the parents.*

This will ensure that parents have “tools to fight”.

#### **4.4.4. Networking across the sectors**

Mothers felt that networking across sectors will enhance the acceptance and the recognition of their disabled children in the community, thus creating awareness on disability issues:

*[...] disabled children are neglected. They are not considered. It's only now in 2009, maybe because of 2010 that disability looks like it is in fashion. Disabled children will be accommodated in the community. (Gugu)*

#### **4.4.5. Co-ordinated support**

Government departments are obliged to render services to disabled children, but often they do not make contact with the parents and the centres for disabled children. This has the effect that these centres function without government support. Government needs to interact with parents, and to give them information in support of their actions as a group:

*I hope we will get guidance from government and from those who already know about it [...] We need to meet as leadership and see how we can improve our situation [...]. (July)*

#### **4.4.6. Involvement of other stake holders**

Advocacy and information sharing networks would enhance the acquisition of information by the disability children's sector at large and the distribution of information on the Act to the public. These networks would therefore have the effect of

- creating awareness on the provisions of the Act to the broader children's disability sector
- integrating and including disability issues in advocacy initiatives of the broader children's sector, thus strengthening the voice of the children's disability sector
- sharing of information on children's issues and learning from each other's experiences and good practices on how best to acquire and disseminate information on policies and laws, thus building the capacity of the children's disability sector. It will also promote the involvement of other stake holders who should be integrating disability into their programmes.

The interview participants stressed these points:

*We are not organized as parents. It's each one for herself. (July)*

*The more the physios come to the centre, the more we gain information. We can ask the about our children's disability. (Gugu)*

#### **4.4.7. Summary of Theme 4: Advocacy and networking across sectors**

Parents identified the barriers which prevented them from acquiring information from the Act. They share common challenges in relation to their disabled children. However, due to lack of information and lack of advocacy skills and support, nothing constructive is done in response. This is due in part to lack of support from the government. They proceeded to identify what would facilitate their acquisition of information from the Act. However, without government support and guidance, and without joining hands with other children's organizations, their aspirations to turn their situation around will never be realized. This theme has looked into ways in which parents can best demand compliance by the government with its obligations in terms of the Act. Parents need to be informed on the rights of their children in terms of the Act, speak with one voice on their demands, act as a collective and continually create awareness on the Act. This theme therefore speaks to the broad strategies which organizations of parents must

employ in order to learn from each other. This should result in disability being embraced by all parents and their children being included and benefiting from the services. Governmental support of children's disability networks is therefore crucial.

#### **4.5. Summary of Chapter 4**

This chapter has described the findings which emerged from the five themes that were identified from the interviews of the participants. The findings have indicated that there are various factors which hinder the acquisition of information from the Act by the mothers. The next chapter will discuss the findings.

University of Cape Town

## CHAPTER 5

### 5. DISCUSSION OF FINDINGS

This chapter discusses the key themes that emerged from the findings gained from the interviews with the four participants as presented in Chapter 4, namely:

- limited information
- mothers collaborating with the government
- building capacity of parents
- advocacy and networking.

#### 5.1. Awareness-raising about the Children's Act

##### 5.1.1. Limited information

The Population Policy for South Africa (DoSD, 1998) in its guiding principles acknowledges that all people have the right to be informed about all matters relating to their daily lives. Consequently the South African public should have access to relevant information concerning government policies, and the appropriate understanding of this information and its implications for all facets of their lives.

It is not sufficient to have an equal opportunities policy (such as the Children's Act) if the beneficiaries of those policies do not know what such policy means or how to implement and benefit from it in practice (Hurst, 1999). This theme emerged from the interviews with all the participants who showed little knowledge about the existence of the Children's Act. Some mothers heard about it for the first time during the interviews. One parent had heard the doctors and therapists talk about it at the hospital, but she too did not have detailed information about the Act.

Some parents know that disabled children have rights which emanate from the Constitution. Parents are however not aware how the limited information which they have on the rights of disabled children can be linked to the Children's Act. This explains why most of them feel inadequate as parents of disabled children and why their children

continue to be discriminated against and excluded. This poor level of awareness of available intervention programmes which are provided for in the Children's Act could be turned around to change the situation for the better.

Insufficient awareness of the rights of disabled children by their mothers is evident when the mothers refer to mainstream schools and to children who are not visibly impaired as "normal". The use of the word "normal" indicates the extent to which the medical model of disability is entrenched. This model attributes some form of deficiency and abnormality to disabled persons and entrenches the belief among parents of disabled children that a different appearance and behaviour of their children is an abnormality. In contrast to the charity mode of the medical model of disability, the Children's Act adopts a rights-based approach which recognises the inherent value and equality of all children. That is why it is important for parents to know about the rights of their children.

## **5.2. Responsibilities of the government**

The United Nations Standard Rule 5 on the Equalization of Opportunities for Persons with Disabilities requires States to undertake measures to provide access to information and communication (UN, 1993). The United Nations Convention on The Rights of Persons with Disabilities (UN, 2008) obliges State parties to take measures to promote appropriate forms of assistance and support to persons with disabilities to ensure their access to information. The findings in this research study revealed that a large number of parents of disabled children have limited information on the Act which is attributable to various factors. Mothers stated that the government first has to determine what the barriers of access to information are in order to make appropriate interventions. This process has to take into account the fact that mothers of disabled children are a heterogeneous group in terms of age, income, education, self confidence and literacy levels.

### **5.2.1. Literacy**

Illiteracy emerged as a barrier to acquisition of information as mothers who cannot read have limited opportunities of getting information. Many mothers have never been to

school and are totally illiterate, while some can read a little but not English. Of great concern is that the leadership in most parent organizations was also found to be largely illiterate or semi-literate, and yet the mothers rely on them for information. This means that both the leadership and the mothers have limited literacy capacity. Interview participants felt that those parents who are literate should explain the Act to those who cannot read.

The issue of low literacy levels is a national concern. The review of literature on the subject found that among children aged 15 to 19, girls tend to drop out of school earlier than boys, often due to teenage pregnancy. In comparison to other race groups, Africans still lag behind in educational achievement. In 1994, 25% of Africans aged fifteen to nineteen had not passed Standard 4. The majority of members of very poor households aged forty-five and over have no formal education at all. The literacy levels of African adults are considered lower than for other race groups (DoSD,1998). This finding supports the high rate of illiteracy found among black mothers of disabled children and the leaders of their organisations. This suggests that a large portion of mothers are deprived of obtaining information through text reading.

Mothers felt that this could partly be remedied by training through Adult Basic Education and Training ABET. This may be good because after expert explanation mothers may need to read further on the Act. The Department of Social Development needs to work with the Department of Education to ensure that ABET also focuses on legal literacy. This suggestion should not create an assumption that the only way in which parents can obtain information from the Act is through reading. The Department of Social Development together with DPOs must find other innovative ways of communicating and imparting information to the illiterate mothers. This could be done for example through word of mouth from those mothers who are informed and through the composition and broadcasting of information-rich songs. Such initiatives need the joint participation of all the parties involved with disabled children, with government providing the necessary support. Disabled children need to be at school and at appropriate day-care centres while their mothers receive training on ABET.

### **5.2.2. Language diversity**

Related to literacy is the language difference which emerged as a barrier to acquisition of information on the Act. All participants felt that the Act must be available in languages other than English so that it is also accessible to those mothers who can understand only other languages. The United Nations Standard Rule 5 on access to information makes it a right for persons with disabilities, their families and advocates to have access to full information on the rights and available services and programmes. Such information should be presented in various languages. The Children's Act has been translated into languages such as Zulu, Sotho and Afrikaans in order to ensure accessibility of the Act to those who only understand languages other than English.

But even if all mothers were able to read and translations of the Act into other languages were available, this would not be sufficient as it does not per se facilitate the understanding of the acquired information from the Act. The Government needs to ensure that user-friendly versions and not only verbatim translations of the Act are published.

### **5.2.3. Use of media**

The use of the media was suggested by some mothers who felt that information will spread if more is said about it in the radio and on TV. This may also inform those parents who are illiterate about the Act. However, there may be limitations regarding use of the media. Mothers in rural areas may not have electricity while others may not have the money to buy a TV. Illiteracy, poverty and lack of infrastructure development in rural areas may all be barriers to acquisition of information on the Act.

### **5.2.4. Alignment of services**

Various government departments provide services to disabled children and their parents. Government departments need to work together with DPOs in order to identify the barriers which prevent parents to acquire information on the Act. Participants expressed the need for parents to come together as a group and decide on what they should take to the government as their needs. Government also needs to find out from

the parents what they need and then together plan on what can be done. There was even a suggestion that the leadership must meet with the social workers to discuss how information on the Act can reach the parents. For the collaboration to be a success, all parties must feel that they are equal, must show respect towards each other and be conscious of each other's limitations.

The services which were identified by mothers as being needed, and which government is obliged to provide in terms of the Children's Amendment Act No.41 (2007) are the following:

- partial care centres which are accessible to children with disabilities [Clause 78 (4) (b)]
- Early Childhood Development with programmes which are available to children with disabilities [Clause 93 (4) (b)]
- Prevention and Early Intervention Services, which may include programmes providing families with information to enable them to access services [Clause 144 (2) (c)]
- Prevention and Early Intervention Services which focus on developing appropriate parenting skills and the capacity of parents and caregivers to safeguard the wellbeing and best interest of children with disabilities [Clause 144 (1) (c)].

The Children's Act No. 38 of 2005, Section 5 states that

To achieve the implementation of this Act in the manner referred to in section 4, all organs of state in the national, provincial and where applicable, local spheres of government involved with the care, protection and wellbeing of children must co-operate in the development of a uniform approach aimed at coordinating and integrating services delivered to children.

What emerges from the findings is that the services of the different departments do not complement each other. Health professionals often have limited information on disability issues, resulting in parents who come into contact with these therapists not receiving detailed information on the Act. ABET does not focus on legal literacy, often resulting in parents reading but not understanding the text. All departments have an equal duty to

align their services to the Children's Act. They are all dealing with the same disabled child, but in isolation from each other.

The Department of Social Development bears the responsibility to ensure the co-ordination of government services to children. This requires planning and a strategy for extensive collaboration between all the stakeholders. Co-ordination of services for children and collaboration between government departments would ensure that more comprehensive programmes are designed for all government departments who are involved with disabled children and their parents.

### **5.3. Building capacity of parents**

Rule 18 of the United Nations Standard Rules (UN, 1993) makes it the duty of the State to support the formation and the strengthening of organizations of persons with disabilities. DPOs in turn have a duty to share information with their members and to build their capacity. Stigma, poverty, under-resourced centres for disabled children, delegates not feeding back information to the parents, mothers feeling inadequate and mothers not fulfilling their leadership role all contribute to lack of capacity by parents to demand compliance by government with its obligations.

#### **5.3.1. Stigma**

Zanele cited the issue of parents who did not want to belong to parent support groups. These parents hide their disabled children in fear of being stigmatised by association in their communities. It is a continuing experience that mothers of disabled children who are not impaired become "disabled by proxy" where the child's impairment is "transplanted" onto them as parents (Brett, 2002). This has the effect of isolating the stigmatised mother.

The future prospects of disabled children are directly linked to the levels of empowerment of their parents (DICAG, 2001). This implies that parent empowerment is central to a disabled child's likelihood to access services which are provided for in the Children's Amendment Act. Accessing information in the Act and knowing the provisions

are among the best tools to empower the parents of disabled children because they enable them to monitor and to enforce the rights of their children. If parents are not empowered to deal with negative attitudes towards disability, they disassociate themselves with disability and distance themselves from their children. This deprives the parent of access to information and training on dealing with negative attitudes because they will not join parent organisations.

Stigmatisation takes place in the communities where mothers and disabled children live. More aggressive community awareness campaigns are necessary in order to change the mindset in the community. Awareness-raising per se may not be sufficient to change behaviour. The integration of disability-specific programmes into general community programmes may promote the sense of oneness in the community and dispel the myth of “us, parents of disabled children” and “them, the normal community members.”

### **5.3.2. Mothers’ feeling of inadequacy**

Feelings of inadequacy emerged from all the mothers that were interviewed. Their views of themselves are likely to emanate from the feelings of shame and inferiority for being mothers of disabled children. This feeling in turn results in mothers having very low self-esteem. In the context of being a mother of a disabled child, feeling adequate is based on accepting and appreciating one’s disabled child and appreciating one’s role as a mother of that child.

The manifestation of feeling adequate and a proud mother is self-esteem. An inferiority complex and feelings of inadequacy push mothers into a world of isolation and ignorance, which accentuates in them the tendency to be passive and inactive due to lack of confidence. Lack of confidence instils fear in the mothers to interact with authorities to solicit information on what they can do to get the information. In summary, lack of confidence also deprives the mothers of information.

The findings show that parents expect their leaders to bring information to the centres. To do so, leaders need certain skills and to be knowledgeable about the information which is contained in the Act. There is therefore a need for capacity building of the representatives of disabled people in order to improve their ability to effectively influence policy and development processes (Dube, 2006). Capacity building includes and should focus on confidence building as well as be adaptable to the capacity of understanding in participants to ensure that they follow proceedings (Harknett, 2006). For parents to acquire information it will be necessary to first boost their self-esteem by building their confidence, making them believe in their children and in themselves and by arming them with information.

### **5.3.3. Poverty amongst parents of disabled children**

Although the state of poverty among members of parent organizations was raised only by Zanele and partly by Thoko, it is an observable reality that most of the organizations of parents of disabled children are led by single black leaders who are largely unemployed and who have very low regard of themselves. They mostly survive on the Care Dependency Grants and in some cases on their own Disability Grants.

Poor single and unemployed mothers are likely not to have the requisite resources for the formation and development of their centres. They are also likely not to have the means to attend discussion and information sessions to acquire information, knowledge and skills and to play their advisory role on issues of disabled children. With no adequate resources and finance, they cannot organize themselves into viable parent support groups which are needed to inform and educate the parents on the Children's Act. It is imperative to look into existing poverty alleviation programmes and legislation and to establish how they include parents of disabled children, as well as to identify additional or special measures which may be needed in order for those programs to have a positive impact on the lives of disabled children.

#### **5.3.4. Under-resourced centres for disabled children**

Related to the issue of poverty are the centres for disabled children and their parents. They do not exist in most communities, which means that children and parents cannot meet. A few centres which exist are informal day-care centres which are under-resourced in terms of trained leadership and staff, proper structures and finances. The leadership in those centres is largely comprised of poor, illiterate, single unemployed mothers who do not know what to do to turn this situation around. Parents and their leadership do not know where to go and who to approach for resources which are scarce. Organizations require strong leadership. Lack of organised centres and government support weakens the morale of the mothers. Most of the mothers cannot reach the centres because of lack of taxi and bus fares both for themselves and their children. The low morale negatively affects the seriousness with which organisations of disabled children are viewed both by the mothers and the members of their communities. This may affect the level of commitment which mothers give to building and development of their centres, which accounts for the poor attendance of those centres. Centres bring mothers together, while the absence or inappropriateness of centres disperses the mothers and disorganises them, making it difficult for them to get information and training.

Most community-based organizations of parents cannot afford to recruit the services of high calibre, skilled and well-trained staff to build the capacity of their organizations (Dube, 2006). Out-sourcing of skills must be done with caution, because where the staff members are themselves not disabled or parents of disabled children, there is a lack of insight and commitment to the development of the disabled child and their parents. This fact points to the need for parents to be trained and placed in all leadership positions in order to strengthen their organisations.

#### **5.3.5. Mothers of disabled children as leaders and decision makers**

While government support is critical, there is a tendency for government officials to “own” and control projects to which they give support and skills. In the process parents become disempowered while social workers maintain their dominance (Brett, 2002).

The findings of this study confirm that social workers are seen as experts who control the operations of centres.

Gugu, Thoko and July acknowledged that mothers are leading the disability centres as chairpersons. However, despite the fact that parents are in leadership positions in their organisations, they are not making decisions for themselves. This was confirmed by Thoko who stated that they met only once as parents of disabled children at the centre to elect the chairperson. The convener of the meeting was the social worker and not parents. This shows the imposing relationship by some professionals on parents who lack capacity to be decision makers on issues of their children.

What disabled children need is best known by their mothers as parents. Parents often hold the key in accessing their child's experiences and provide essential insight into their child's world (Brett, 2002). Knowledge of their children's world puts them in a better position to be clear about the purpose of their participation, consultation or inclusion in the decision-making processes (Miller & Albert, 2006). The participation of mothers in matters affecting their children creates a feeling of being taken seriously, thereby increasing the sense of belonging to the process which enhances the spirit of co-operation and collaboration with government, promoting trust and joint planning. These are some of the elements of a viable partnership between government and the mothers.

#### **5.3.6. Delegates not bringing back information**

Having limited information and low self-esteem raises a challenge for mothers to participate as equals in meetings with their counterparts in government who are well trained and knowledgeable and who often have little patience with the comparatively slow pace of the DPOs (Dube, 2006). Parents or representatives of disabled children who largely have limited information on the Children's Act cannot be expected to participate confidently in discussions. This emphasizes the need for representatives and leaders to be trained on the provisions of the Children's Act. This will enhance their confidence to engage with their counterparts in government and to be able to follow and understand discussions so as to be able to report back to the other members.

There are various factors which result in the lack of feedback from representatives to their organisations. These include:

- representatives who do not understand the proceedings and therefore cannot give feedback
- leaders and members of organisations who do not hold the representatives accountable by requiring reports of meetings which they attended
- representatives who may attend meetings without a clear mandate from the organisation on the issues to be raised so that there is no clear focus on what feedback is required.

#### **5.4. Integrated services and programmes**

All mothers in the study had frequent encounters with health professionals, especially physiotherapists, but only Gugu outlined the role which the physiotherapists played in those encounters. This becomes relevant when one considers Gugu's assumption that therapists think that the mothers will receive information at the centres. This is indicative of the general perception of the public about therapists that they are responsible to render only health-related services to disabled children. This might have influenced the other three mothers to mention the role of physiotherapists only in relation to the stimulation of their children and how they should care for them.

Therapy is still perceived as being medically-oriented, focussing mainly on medical rehabilitation with little emphasis on equalization of opportunities and social integration. This explains why physiotherapists in the hospital parent groups do not give mothers detailed information on the Children's Act. This is caused by the streamlined training which therapists receive which confines them to medically-oriented services to disabled children and their parents. The result is that physiotherapists have limited information on disability issues.

Others have already emphasized that rehabilitation is a means to an end and not an end in itself (see Rule et al., 2006). There is a critical need to broaden the training of service providers in order to link rehabilitation personnel with other disability services

and programmes and embrace the social model of disability. Community-based rehabilitation (CBR) is a strategy to implement the social model of disability as it stresses the empowerment of disabled people as well as equalization of opportunities. Philpott and McLaren (1997) argue that health policy-makers and planners need to ensure that rehabilitation services are given due recognition and status as a tool for the empowerment and enhancement of disabled people. This opinion is equally shared by some of the participants in this study who saw great potential for the parents of disabled children in the training of therapists and community rehabilitation facilitators on the Children's Act. For this purpose, CBR would be the approach of choice (Lorenzo & Cloete, 2004).

However, in the township at Ekurhuleni Metropolitan where the study was conducted, two Community Rehabilitation Facilitators (CRFs) are performing the rehabilitation tasks of merely stimulating disabled children in the community. This reduces them to being assistants to physiotherapists who perform the same tasks at the hospital. CRFs should be targeted to fill in the gap of linking health professionals with other disability services and ensuring that the mothers receive detailed information on disability issues, where they can be reached.

## **5.5. Building capacity for advocacy: strategies to promote acquisition of information**

Although participants expressed the view that they would like to “[...] *become brave and stand for my child*” (*Gugu*), they experienced many challenges in doing so. They cited various factors which prevented them from obtaining information on the Act and recommended interventions which could assist them to be informed about it. Mothers cited skills development, speaking as a collective and networking across sectors as some of the strategies to promote acquisition of information on the Act.

### **5.5.1. Skills development**

The following skills were identified as being important:

### **1. Leadership skills**

There is a need for a deliberate effort to build the capacity of leadership and of the representatives of disabled people in order to improve their capacity to effectively influence processes. This includes giving leaders appropriate skills and technologies to acquire and disseminate information on the relevant laws and policies (Dube, 2006). Leadership skills of mothers were found to be very limited in disability centres. The leaders did not know how to mobilise and inform mothers about the Children's Act because they do not have information on it. They do not know what to do. Poorly informed leadership leaves most of the mothers ignorant on the provisions of the Act. This lack of leadership skills impacts negatively on the ability of mothers to acquire the information needed to be able to monitor the implementation of the Act.

### **2. Communication skills**

These were found to be lacking among the mothers and advocates of disabled children. Fear of authority due to lack of confidence, awareness and knowledge of the Act results in mothers being passive doing nothing to engage relevant people in order to obtain information. The findings revealed that many mothers of disabled children had experienced a high degree of negative social attitudes from other community members and so had very low expectations of their own capabilities. Even their training may be handled in a very "top down" manner (Lang, 1999). This suggests that training in communication must include training in confidence building. Effective participation by the mothers is further hampered by the absence of information and knowledge on the Act. This knowledge is a necessary tool if mothers are to communicate their needs in acquiring information effectively and as equals.

### **3. Literacy and language skills**

Most of the mothers in the centres who were included in this study were found to have limited or absolutely no literacy and language skills. Most Acts are available only in written form. Gugu suggested that illiterate mothers must receive adult education. This requires a deliberate effort by the mothers to lobby the Departments of Social

Development, Education and Transport to intensify the availability, accessibility and awareness of adult education in the black communities.

This does not mean that illiterate mothers cannot acquire information and continue to play a critical role in the dissemination of the acquired information. However, unless some methods are used to disseminate information, large numbers of mothers shall continue to be excluded.

Literacy skills are critical and coupled with the appropriate understanding of the literacy capacity of the mothers so as to diversify the training offered to them. DICAG (2008) recognised the need to build the literacy skills and legal understanding of the mothers through workshops which are facilitated by knowledgeable people on the provisions of the Act. This should be done through methods which would make the mothers feel comfortable to participate, for example through role plays.

#### **4. Self advocacy skills**

Mothers indicated that they need "*tools to go out and fight for our children*" (July). They understood that by obtaining information on the Children's Act, they would have knowledge on what the rights of their children are. Knowledge of rights gives the mothers a tool with which to advocate for the respect, promotion and the implementation of these rights. Legal literacy further would inform mothers of the responsibilities of the various duty-bearers towards their children. It is therefore important to provide the mothers with the capacity to obtain information which will inform and enhance their advocacy skills, giving them the capability to monitor the implementation of the provisions of the Act and to influence decisions which aim to include their disabled children.

#### **5. Skills to mobilise**

Parents expect their leaders to give direction on how to advocate for the rights of their children. However, most leaders in children's disability organisations lack leadership skills and knowledge. This fact impacts negatively on both the parents and the children

who remain trapped in ignorance and isolation. Compounding the leadership problems is the fact that parent organisations are not adequately supported by government. The result is that they do not have adequate resources and finances with which to organise themselves into viable parent support groups and to build their organisations. Parents and their leadership do not know where to go or who to approach for resources, or how to mobilize the membership. Lack of organised centres and lack of government support perpetuates the passivity and low morale of parents.

The study found that mothers were not organised into viable support groups but tended to be isolated and not working collectively. Most organizations of disabled children did not engage in collaborative advocacy strategies when they approached government for interventions. This portrays the children's disability sector as being disorganised with each organisation focusing on its own interests. This is a missed opportunity because, as Frost (1999) observes, government and policy-makers are more likely to listen to a single unified voice representing the interests of all disabled children.

#### **5.5.2. Networking**

Information-sharing networks would enhance the acquisition of information by the children's sector at large and the distribution of information on the Act to the public. These networks would therefore have the following effects:

- creating awareness on the provisions of the Act to the broader children's sector
- integrating and including disability issues in advocacy initiatives of the broader children's sector, thus strengthening the voice of the disability children's sector
- sharing of information on children's issues and learning from each other's experiences and good practices on how best to acquire and disseminate information on policies and laws, thus building the capacity of the children's sector to be self-advocates on issues of the children.

Ensuring that strong organizations do not drown the voices of the smaller and weaker organizations is one of the challenges that need attention through intensified capacity building. Speaking with one voice has the advantages of identifying the common needs and strategies.

The sustainability of network formations is largely dependent on the capacity of the co-ordinating office to efficiently monitor and enforce proper planning of the operations of the groups, the availability of resources and the support from various groups, including from organizations for disabled children and government.

Unfortunately networking has been given very low status by most organizational development funders. Hurst (2006) observes that funding for networking, leadership support or for the straightforward “core costs” of running an organisation is not available. Poor organisations may have very limited opportunities of being part of the networks which in turn may perpetuate and sustain the existing state of mothers of disabled children not getting support, not knowing what to do in challenging situations or where to go to obtain information on the Act.

#### **5.6. Summary of Chapter 5**

This chapter has discussed the findings of the study. In the discussion it emerged that although there were challenges which mothers faced in the acquisition of information from the Act, certain interventions and support from government and other stake holders could mitigate those challenges.

In the next chapter an overview of the study, recommendations and a conclusion to the study will be presented.

## CHAPTER 6

### 6. RECOMMENDATIONS AND CONCLUSION

It has been suggested in this study that the empowerment of parents of disabled children is a powerful tool which ensures that disabled children are included and anticipated in all service delivery areas. This entails acquisition of information by the parents of disabled children from the Children's Act.

However, the findings revealed that most parents of disabled children and the leadership in their organizations had limited information on the provisions of the Act. The recommendations which are suggested below are based on the findings and aim to ensure that information on the Act reaches the parents.

#### **6.1. Collaboration and co-ordination**

Various factors emerged in this study as being barriers to the acquisition of information on the Act by mothers of disabled children. It is also evident that children's needs are complex and fall under the responsibility of different departments. Therefore government should be working closely with parents in protecting the rights of children, if they are to make appropriate interventions. The following interventions are recommended:

##### **6.1.1. Collaboration between the Department of Social Development and other Government Departments**

Section 4(1) and (2) of the Children's Act requires all government departments to collaborate with each other and plan for services and programs for children. Section 5 specifically requires

all organs of state in the national, provincial and where applicable, local spheres of government involved in the care, protection and well-being of children to co-operate in the development of a uniform approach aimed at coordinating and integrating the services delivered to children.

The Act does not state how the co-operation between departments should be initiated. The lead department, Social Development, should ensure the coordination and the formulation of a uniform approach to the implementation of services by all the departments. Parents need to know what government departments are obliged to do and are to be empowered to demand delivery of services by the various departments.

**Table 7: Summary of responsibilities of various duty bearers**

<b>Duty Bearer</b>	<b>Responsibility</b>	<b>Problems</b>
Department of Social Development	Consider diversity of mothers and have translated and user friendly versions.	The Act is written in English which some parents do not understand.
	Support parents to have own centres, stimulation centres, and trained leadership and staff. Provide services.	Under resourced centres.
	Support parents to run their centres.	Lack of collaboration between parents and government.
	Guide parents on the implications of the provisions of the Act.	
	Support networks of parent organizations.	
Department of Education	Ensure that ABET training focuses content on legal literacy.	Illiteracy among parents and their leaders.
	Train parents through ABET programmes.	
	Make reading and learning material available	
	Ensure that trained staff are available.	
Department of Health	Community health workers are trained on the Act and disability.	Community Health Workers are not aware of the Act.
Department of Labour	Reasonable accommodation of parents of disabled children in the labour market.	Poverty among most parents of disabled children.
Department of Transport	Ensure that parents can reach venues where ABET programmes are run.	Transport is not available.
	To facilitate the meeting of community health workers with parents.	
DPOs/ Parent Leadership	Mobilise parents.	Passivity among parents, limited information on the Act, stigmatization of parents.
	Equip mothers with advocacy skills.	
	Raise disability awareness in the community.	

	Inform and educate mothers on the Act.	
	Build self empowerment skills among parents.	
	Promote networking within the disability sector.	Parent organizations are stagnant.

### 6.1.2. The role of parents in the implementation of the Act

Parents require information on the provisions of the Act if they are to play a role in support of implementation. This requires the relevant government departments to remove the barriers which hinder the acquisition of information by the parents regarding the obligations of various government departments towards children in terms of the Act.

### 6.1.3. Parents' knowledge of how to demand the rights of their children

The Department of Social Development together with the Department of Education should

- ensure that ABET focuses content on legal literacy. This means educating parents about law making processes and how as parents they can be involved in lobbying and advocating during those processes for the inclusion of the rights of their children.
- include making parents aware of the oversight roles of government committees which they can approach in the event of non-delivery.

## 6.2. Ensuring that information on the Act is available to the parents

### 6.2.1. Parents and literacy skills

The Department of Education together with the Department of Social Development and the Department of Transport must ensure that

- parents are trained through ABET so that they can read documents like the Act
- parents have the required reading and learning materials
- trained staff (which includes parents) are available. This is possible in the current Adult Basic Education which is offered through a program known as KHARI GUDE meaning "let us learn"

- parents can reach the venues where ABET programmes are run.

### **6.2.2. Accommodating parents' diverse literacy levels**

The Department of Social development should

- find and support other innovative ways of disseminating information to mothers who cannot read. For example, they could make use of role plays, recorded videos, word of mouth, songs in traditional or familiar tunes, and workshops.
- ensure that user-friendly versions and not only verbatim translations of the Act are distributed. This includes pictorial materials and making the Act available in other languages besides English
- ensure that more is said in radio and TV programmes about the Act. This should be done in different dialects and formats such as Sign Language.

### **6.2.3. Dissemination of information to parents through community-based workers**

The Department of Health and Social Development must ensure that Community Rehabilitation Facilitators, rehabilitation therapists and other personnel working at the community level are trained on the Act so as to give information to the parents they come into contact with, be it at the centres or local clinics.

## **6.3. Dissemination of information to DPOs**

### **6.3.1. Awareness-raising and training on the Act**

DPOs are required “to provide capacity building to the parents on legislation and policy advocacy [...] through leadership [...] and training programs [...] at residential and other facilities” where parents can be reached (DoSD, 2009). The Department of Social Development must therefore train the DPO leadership and other selected people as trainers. What has been gained in the training may then be passed onto others in different organisations.

### **6.3.2. Securing resources for building the capacity of DPOs to support parents**

Training the parents on the Act may require DPOs to engage the services of trainers who may be parents or CRFs. It is the responsibility of the following departments to

support DPOs with resources they may need in order to disseminate information to the parents:

- the Departments of Social Development which is to ensure that the training venues are available and accessible and that people are aware of the training
- the Department of Education which is to formulate appropriate training materials and together with Social Development train the facilitators
- the Department of Transport which is to ensure that parents can reach the training centres.

### **6.3.3. Knowledge about private and public resources and services**

It was revealed in the findings that most parents were not accessing services which are available in their communities because they are not aware of them. Social Development should frequently inform DPOs about the availability of resources and services which are available to the community and which they can access. This may require quarterly information sheets and meetings, and social workers and community facilitators informing centres.

## **6.4. Dissemination of information through DPOs**

Parents play a significant role in the areas of care and advocacy on behalf of their children. In order to do so, parents need to be informed about their rights and those of their children. However, parents tend to be overwhelmed by the negative attitudes of society towards their children and they disassociate themselves from disability.

DPOs should therefore mobilize and encourage parents of disabled children to belong to parent organizations, support groups and disability forums so as to empower themselves about their rights.

### **6.4.1. DPOs to provide support to parents**

DPOs need to provide support to parents in the following areas:

- to educate parents about the Act so that they know the rights which the Act provides for their children which they can then demand from government
- boosting mother's self esteem by building their confidence. This entails

- building on what parents already know about the rights of their children and linking it with the Act
- giving value and recognition to what they are currently doing well to improve the situation of their children.

#### **6.4.2. Strengthening the economic capacity of parents**

Hunger and poverty among most parents who need information and whose confidence may need boosting often undermine those efforts. Economic independence gives parents an acceptable social standing. It is therefore recommended that the Departments of Social Development, Education, Labour, and Transport and representatives of parent organizations should meet to outline their respective roles to support efforts to build parents' confidence and self worth:

- Department of Social Development: to ensure the availability of partial care centres to accommodate children while parents are at work or are engaged in income generating projects. Partial care centres must be well resourced in terms of trained staff, appropriate buildings and finances.
- Department of Education: to ensure that children of school-going age are not discriminated against at mainstream schools so as to allow their parents an opportunity to empower themselves economically while they are at school.
- Department of Labour: to ensure that parents of disabled children enter the labour market and that their situation as parents of disabled children who are discriminated against, is taken cognizance of.
- Department of Transport: to ensure accessible public transport so that parents can participate in skills development opportunities as well as seek employment opportunities.
- Parent representatives: to play an advisory role to the Departments.
- The abovementioned institutions: to conduct an audit on how poverty alleviation legislation, labour laws and programs include disabled children and their parents.

Economic independence gives parents social acceptance and this helps to build their self-esteem which is necessary if parents are to come out and go to places where they can obtain information without fear of being stigmatized.

### **6.4.3. Combating stigma through raising awareness in the community**

It is recommended that:

- DPOs conduct community information awareness campaigns on the Act
- be integrated into other community programs to promote the spirit of the community which works together, and to demystify the belief by many people that disability issues cannot be integrated and fused into community programs and should be dealt with separately
- this may have more impact on changing behavior and negative attitudes aimed at stigmatizing disabled people and parents of disabled children.

### **6.4.4. Equipping mothers with specific skills**

Various skills were identified as necessary to enable parents to access information on the Act. These include:

#### **Leadership skills**

The Department of Social Development must run workshops with the leadership of DPOs on skills and strategies to mobilize its membership and on how to acquire and disseminate information on the Act to its membership. For this, membership mobilization and facilitation skills are required.

#### **Communication skills**

The Department of Social Development must equip DPOs with skills to

- communicate among themselves and with the membership so as to reach decisions which are shared and endorsed by all
- draw up agendas which reflect that parents are aware of their rights and which address their concerns
- train leadership to communicate with authority and to communicate as equals in discussions.

#### **Legal literacy and advocacy skills**

The Department of Social Development must work with the DPO leadership to ensure that parents know what to do with the information after acquiring it. This includes skills to

- monitor the implementation of the Act by various government department, monitor the quality of service which is given to disabled children, and examine the profiles of services to which budgets are allocated as to whether they target services that will also benefit disabled children
- understand what budgeting in government means and make input into budget allocations for services to children in terms of the Act
- monitor that the strategy and provisioning clauses in the Act are complied with by all duty bearers.

### **6.5. Networking across the children's disability sector**

Organizations of disabled children have not developed as yet, and the only way to promote self organization is through networking, leadership training and learning from others (Hurst, 1999).

It is therefore recommended that the Disabled Children Action Group (DICAG), an organization of parents of children with disabilities, shall have to engage the South African Disability Alliance (SADA), an umbrella body of organizations of and for disabled people, to assist and support the meeting of organizations of parents of disabled children to discuss the following issues:

- the role of existing disabled children's networks
- how parents feel that the status of children's networks can be enhanced
- what form the network should take, including the composition of the secretariat, means of communication and meetings between members, priorities advocacy as well as strategies and funding.

### **6.6. Summary of Chapter 6**

Recommendations which were based on the findings of the study were presented in this chapter. Suggestions were made for the roles of various relevant government departments, DPOs, and the disability sector at large.

In conclusion, I will briefly discuss whether the purpose of this research study has been realized.

## **6.7. Conclusion**

This case study aimed to describe the information that mothers of disabled children possess about the Children's Act. The purpose was firstly to determine what factors facilitated or hindered the acquisition of information about the Act by the mothers, and secondly, to identify the skills and the support that mothers need in order to acquire information from the Act.

It is apparent from the findings that mothers face certain barriers in acquiring information. These barriers result in them having limited information on the Act. Compounding the problem is that the leadership in disability organizations has insufficient information on the Act. The result is that the information is not reaching the parents of disabled children.

However, mothers have identified various factors which could facilitate the acquisition of information from the Act, as well as the skills and the support they need. The findings clearly indicate the need for building the capacity of DPOs, the disability leadership and the parents of disabled children.

In conclusion, it appears that the main aims and objectives of this research study have been achieved.

## LIST OF REFERENCES

- Biersterker, L. & Kvalsvig, J. (2007). Early childhood development and the home-care environment in the pre- school years. In *Monitoring child well-being: a South African rights-based approach*. Edited by A. Dawes, R. Bray, & A. van der Merwe. Cape Town: HSRC Press.
- Boxil, B. (2000). The culture of poverty. In *Culture and subjective well-being*. Edited by Biener & Eunock. Cambridge: MIT Press.
- Boyd, C. (1993). Toward a nursing practice research method. *Advances in Nursing Science*, 16 (2):9-25.
- Bray, R. & Dawes, A. (2007). Monitoring the well-being of children: historical and conceptual foundations. In *Monitoring child well-being: a South African rights-based approach*. Edited by A. Dawes, R. Bray, & A. van der Merwe. Cape Town: HSRC Press.
- Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairments: is it time for an alternative model of disability? *Disability and Society*, 17(7):825-843.
- Brink, H. (1991). Qualitative vs quantitative research. *Nursing*, 6(1):14-16.
- Brummer, L. (1996). *Teach us too: a DICAG Guide for the teaching of young children with disabilities*. Cape Town: Disabled Children Action Group (DICAG).
- Bryman, A. (1998). *Quantitative and quality in social research*. London: Routledge.
- De Vos, A.S. (1998). *Research at grassroots: a primer for the caring professions*. Pretoria: Van Schaik Publishers.
- Department of Social Development. (1998). *Population policy for South Africa*. Pretoria: Government Printers.
- Department of Social Development. (2009). Strategy for the Integration of Services for children with Disabilities. Interdepartmental Technical Task Team. Revised draft August. Pretoria: DoSD.
- Disabled Children Action Group (DICAG) (2001). *Strategic Plan*. Cape Town: DICAG National Office.

- Dube, A.K. (2006). Participation of disabled people in the PRSP/PEAP process in Uganda. In *In and out of the mainstream: lessons from research and disability and development*. Edited by B. Albert. Leeds: The Disability Press.
- Dutschke, M. & Manson, J. (2008). Children's Constitutional right to social services. In *South African Child Gauge 2007/2008*. Edited by P. Proudlock, M. Dutschke, L. Jamieson, J. Monson, & C. Smith. Cape Town: Children's Institute, University of Cape Town.
- Eloff, I., Engelbrecht, P. & Swart, E. (2002). Including a learner with physical disabilities: stressful for teachers? *Koers* 67(1):77-99.
- Elwan, A. (1999). *Poverty and disability. A survey of the literature of social protection*. Discussion Paper Series No.9932. Washington D.C: The World Bank.
- Emmett, T. (2006). Disability, poverty, gender and race. In *Disability and Social Change: A South African Agenda*. Edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Cape Town: HSRC Press.
- Frost, B. (1999). Action on disability and development: working with disabled people's organisations in developing countries. In *Disability and development: learning from action and research on disability in the majority world*. Edited by E. Stone. Leeds: The Disability Press.
- Gariyo, Z. 2002 Participatory Poverty Reduction Strategy Papers (PRSPs) The PRSP Process in Uganda. Discussion Paper No. 5, December, ISBN 9970 838 08 X. Uganda Debt Network Available on web: <http://www.udn.or.ug/pub/prsp-zie.pdf>
- Harknett, S. (2006). Improving participatory appraisal approaches with rural disabled people: a pilot project in Pursat province, Cambodia. In *In and out of the mainstream: lessons from research and disability and development*. Edited by B. Albert. Leeds: The Disability Press.
- Heller, K.W., Alberto, P.A., Forney, P.E. & Schwartzmann, M.N. (1996). *Understanding physical, sensory, and health impairments*. Boston: Brooks/Cole.
- Henning, E., van Rensburg, W & Smit, B. (2004). *Finding your way with qualitative research*. Pretoria: Van Schaik Publishers.
- Howell, C., Chalklen, S. & Alberts, T. (2006). A history of the disability movement in South Africa. In *Disability and Social Change: A South African Agenda*. Edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Cape Town: HSRC Press.

Hurst, R. (1999). Disabled People's Organisations and development: strategies for change. In *Disability and development: learning from action and research on disability in the majority world*. Edited by Stone, E. Leeds: The Disability Press.

Kayongo- Male, D. & Onyango, P. (1984). *The sociology of the African family*. London: Longman.

Krefting, L. (1991). Rigour in qualitative research. The assessment of trustworthiness. *American Journal of Occupational Therapy* 45(3):214-221.

Lang, R. (1999). Empowerment and CBR? Issues raised by the South Indian experience. In *Disability and development: learning from action and research on disability in the majority world*. Edited by E. Stone. Leeds: The Disability Press.

Lathlean, J. (2006). Qualitative analysis. In *The research process in nursing*. Edited by K. Gerrish & A. Lacey. Oxford: Blackwell Publishing.

Krefting, L. (1991). Rigour in qualitative research. The assessment of trustworthiness. *American Journal of Occupational Therapy* 45(3).

Lorenzo, T. & Cloete, L. (2004). Promoting occupations in rural communities. In *Transformation through occupation*. Edited by R. Watson, & L. Swartz. London: Whurr Publishers.

Mastropierre, M.A. & Scruggs, T.E. (2000). *The inclusive classroom: strategies for effective instruction*. Upper Saddle River, N.J: Merrill.

Mc Kenzie, J. & Muller, B. (2006). Parents and therapists: dilemmas in partnership. In *Disability and Social Change: A South African Agenda*. Edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Cape Town: HSRC Press.

Merriam, S.B. (1998). *Qualitative research and case study applications in education*. San Francisco: Josey-Bass Publishers.

Miller, C. & Albert, B. (2006). Mainstreaming disability in development cooperation: lessons from gender mainstreaming. In *In and out of the mainstream: lessons from research and disability and development*. Edited by B. Albert. Leeds: The Disability Press.

Morse, J. (1991). *Qualitative nursing research - a contemporary dialogue*. USA [City?]: Sage Publications.

Mouton, J. (2001). *The practice of social research*. Oxford: Oxford University Press.

Munhall, P.L. (1994). *Revisoning phenomenology nursing and health science research*. New York: National League for Nursing.

Mwamwenda, T.S. (1995). *Educational psychology. An African perspective*. 2<sup>nd</sup> edition. Durban: Butterworth Publishers.

Nhlapo, C.M., Watermeyer, B. & Schneider, M. (2006). Disability and human rights: the South African Human Rights Commission. In *Disability and Social Change: A South African Agenda*. Edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Town: HSRC Press.

Office of the Deputy President. (1997). *White Paper on an Integrated National Disability Strategy*. Pretoria. Available from:  
[http://www.polity.org.za/govdocs/white\\_papers/disability1.html](http://www.polity.org.za/govdocs/white_papers/disability1.html) (Accessed April, 2006).

Patton, M.Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage Publications.

Philpott, S. & McLaren, P. (1997). *Disability in Health Systems Trust*. Durban: South African Health Review.

Pokempner, J. & Roberts, D.E. (2001). Poverty, welfare reform, and the meaning of disability. *The Ohio State Law Journal*, (62). Available from  
<http://moritzlaw.osv.edu/lawjournal/issues/volume62/number1/pokempner.pdf>. (Accessed October, 2007).

Priestly, M. (2006). Developing disability studies programmes: the international context. In *Disability and Social Change: A South African Agenda*. Edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Cape Town: HSRC Press.

Proudlock, P., Dutschke, M., Jamieson, L., Monson, J. & Smith C. (Editors). (2008). *South African Child Gauge 2007/2008*. Cape Town: Children's Institute, University of Cape Town.

Republic of South Africa. (1996). *Constitution of the Republic of South Africa, Act No. 108*. Pretoria: Government Printers.

Republic of South Africa. (2005). *Children's Act No. 38*.

Republic of South Africa. (2007). *Children's Amendment Bill No 41*.

Rule, S., Lorenzo, T. & Wolmarans, M. (2006). Community- based rehabilitation: new challenges. In *Disability and Social Change: A South African Agenda*. Edited by B.

Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Cape Town: HSRC Press.

Schneider, M. (2006). Disability and the environment. In *Disability and Social Change: a South African agenda*. In *Disability and Social Change: A South African Agenda*. Edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley. Cape Town: HSRC Press.

United Nations. (1993). *Standard Rules on the Equalization of Opportunities for Persons With Disabilities*. New York: United Nations.

United Nations. (1995). *Convention on the rights of the child*. Geneva, Switzerland: United Nations.

United Nations. (2008). *Convention on the rights of persons with disabilities*. New York: United Nations.

Welman, J.C. & Kruger, S.J. (2002). *Research Methodology*. 2<sup>nd</sup> edition. Oxford: Oxford University Press.

University of Cape Town

## **APPENDIX A: INTERVIEW GUIDE**

This is a list of topics or aspects of the topics which are to be covered in the interview. They are not specific questions (Welman & Kruger, 2002).

### **Introduction:**

- Introductions to each other
- Explanation of the purpose of the interview
- Gaining informed consent: Explanation about issues of confidentiality, answering of questions she wishes to answer, no right or wrong answers and can change answers as we go along, permission to record information manually and on tape, opportunity to read what is recorded and make corrections, no financial gain for participating and no prejudice for not participating.

### **General biographical profile of the interviewee:**

- Name of participant
- Age
- Schooling and education
- Current work status and family situation

### **History of disabled child's disability:**

- Impairment type, cause and period that the child has been disabled
- Name of child
- Age of child
- Whether child attends school, day-care centre

### **Mother's Awareness of the Children's Act:**

- What do you know about the Children's Act?
- How do you know?
- What value is the information of the act to you as a parent of a disabled child?
- How have you or your child benefited from the Children's Act?

### **If the mother is not aware of the Act:**

- What do you know about the rights of your disabled child?
- Do you belong to an organization of disabled people?
- If yes, do they talk about the laws which give rights to disabled children?

- What suggestions or recommendations do you have to make mothers aware of the Act?

University of Cape Town

## **APPENDIX B: CONSENT FORM**

### **INFORMED CONSENT FORM**

You are invited to participate in a research study conducted by Nonceba Meyiwa in partial fulfillment of her studies for a Masters in Philosophy in Disability Studies, in the School of Health Sciences at the University of Cape Town.

I hope to explore more about what mothers of disabled children know about the Children's Act and the Children's Amendment Act, as well as the skills and the support which they may need to benefit from these Acts.

You were selected to participate in this study due to your being a mother of a disabled child. Your participation will include being interviewed once for a one and a half to two hour long interview. The researcher will interview you separately and in a private room at a suitable and mutually agreed to venue, at a time suitable to you. Arrangements will be made for you to reach the venue. To ensure clarity of statements, I will give you copies of transcripts of the first interview. You will be able to make the desired changes. A second interview of the same length of time will be done as a follow up to cover any gaps or seek clarification as well as member checking of initial themes of findings. You will likewise be entitled to ask me for more clarity or simplification when you do not understand.

The information shared in the interview session will remain confidential, as it is regarded as your private property and will be disclosed only with your permission.

By signing the consent form or by giving verbal consent, you indicate that you are voluntarily agreeing to participate in the study and as confirmation of your consent, please give your full signature to the declaration attached to the consent form. If you give me permission, I promise to protect your confidentiality so that no reports that

result from this study will identify you as having been a participant. If you decide not to participate, you are free to withdraw from the study at any stage without prejudice.

---

### SIGNED INFORMED CONSENT FORM

I \_\_\_\_\_, have read the Information Sheet. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no bad consequences for me.

If you have any questions about this research, please call Nonceba Meyiwa at 0732731126 or come to 252 Nojekwa Street, Duduza, or send someone to alert Nonceba that you want to see her.

Signed:

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date and Place

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date and Place

\_\_\_\_\_  
Witness (if necessary)

\_\_\_\_\_  
Date and Place

## APPENDIX C: INFORMATION LETTER

Dear \_\_\_\_\_ (Participant)

I am Nonceba Meyiwa, mother of a disabled child. Thank you for taking the time to participate by reading this letter. You were selected to participate in this study as a mother of a disabled child. I am aware that as a parent of a disabled child your time is valuable. I would therefore ask you to carefully read this letter, which I shall gladly verbally communicate to you should you have problems reading it or understanding its contents.

I will be conducting a research study in partial fulfilment of my Masters in Philosophy in Disability Studies, in the School of Health and Rehabilitation Sciences, at the University of Cape Town. I hope to explore more about what mothers of disabled children know about the Children's Act which has been passed by parliament and which will replace the old Child Care Act of 1983, after the Regulations to the Children's Act have been passed.

Your participation will include being interviewed once for a one-and-a-half to two hour interview. The researcher will interview you separately and in a private room at a suitable and mutually agreed to venue, at a time suitable to you. Arrangements will be made for you to reach the venue. To ensure clarity of statements, I will give you copies of transcripts of the first interview. You will be able to make the desired changes. A second interview of the same length of time will be done as a follow up to cover any gaps or seek clarification as well as member checking of initial themes of findings. You will likewise be entitled to ask me for more clarity or simplification when you do not understand.

The in-depth interview technique will be used. By this I mean that it will be more like a conversation, with humble requests should there be a need for clarity. You will be asked

to share what you know about the Children's Act. The entire interview will be recorded by means of a tape recorder with your permission.

The information shared in the interview will remain confidential as it is regarded as your property and will be disclosed only with your permission. You may be vulnerable to someone determining who you are and what has been said by you, but the researcher will protect you from this possibility by using a pseudonym for each participant.

Prior to an interview, you will be given an explanation of the purpose of the research and what will be done with it. You will then be requested to sign a consent form which is included with this information letter.

The results of this study will form the basis of recommendations to DPOs and the State on issues which hinder or facilitate the acquisition of information and knowledge of what the Children's Act provide for disabled children, by their mothers in order to build the capacity of mothers of disabled children to improve the situation of their disabled children by enforcing their children's rights which are in the Children's Act.

### **Your rights as a participant**

If you agree to sign the consent form, the following conditions are guaranteed and will be met by the researcher:

- Your participation in this research is voluntary.
- There will be no right or wrong answers and you will be at liberty to choose not to answer any questions.
- You may withdraw from the study at any stage without prejudice to you.
- The interviews will be approximately one-and-a-half to two hours in the language of your choice.
- The findings of this study will not identify you as having been a participant.
- There will be no financial reward for participating.
- The interview conducted with you will be tape recorded with your permission.
- Light snacks will be served during the interview.

Should you have questions about the research, or any aspect of this letter, please call Nonceba Meyiwa at Cell: 0732731126 or come to 252 Nojekwa Street Duduza, or send someone to let me know that you wish to see me.

Thank you once again for taking time to read this information letter.

Nonceba Meyiwa

MPhil in Disability Studies student

University of Cape Town