



NAME	PATRICIA DIMHAIRO
STUDENT NUMBER	200604875
PROPOSED DEGREE	MASTER OF SOCIAL SCIENCE IN RURAL DEVELOPMENT
COURSE CODE	31011
YEAR	2013
TITLE OF RESEARCH PROJECT	CARE DEPENDENCY GRANTS IN A SOUTH AFRICAN TOWNSHIP: AN ASSESSMENT OF ACCESS, CHALLENGES AND CONTRADICTIONS IN BOPHELONG, GAUTENG
MANNER OF OBTAINING THE DEGREE	COURSE WORK AND DISSERTATION
NAME OF SUPERVISOR	PROFESSOR WILSON AKPAN
FULL TIME/PART TIME	PART TIME

DECLARATION

I declare that this dissertation is the product of my work, that it has not been submitted before for any degree or examination in any other University, that all the sources used or cited have been correctly and completely referenced, and that the study adheres to the University of Fort Hare's guidelines on research ethics. I also acknowledge that, as advised by my supervisor, I have fully adhered to the University of Fort Hare's rules regarding plagiarism and that, as advised by my supervisor, the responsibility to do so is mine, and mine alone.

Signed.....
PATRICIA DIMHAIRO (STUDENT NO. 200604875)

SUPERVISOR'S STATEMENT

I hereby confirm that the dissertation of the following candidate has been submitted with my approval.

Name of Candidate: PATRICIA DIMHAIRO

Student Number: 200604875

.....

PROFESSOR WILSON AKPAN
(SUPERVISOR)

Acknowledgements

I am grateful for the guidance I received from Professor Wilson Akpan in the process of writing this dissertation. I also acknowledge the assistance from Mr. De Bees Multi Disability Organisation, who helped me to locate the caregivers of children with disabilities. My gratitude also goes to Ms. Rea Schoeman of the South African Social Security Agency (SASSA) for assisting me with information on grants. The Emfuleni Municipality also played a significant role in this study. I thank my family and friends for their support. Thank you to all the research participants for their contributions.

DEDICATION

To My Loving Son

ABSTRACT

The condition of disability has been part and parcel of many societies, yet the attention given to the issue has been minimal. Most focus on social and economic intervention has been directed on the person living with disabilities and largely ignoring the role played by the caregivers who are involved in the day to day upkeep of the disabled. This has left the caregivers with challenges that remain largely unexplored. The care dependency grants that are offered by the government have been helpful but insufficient. Most families raising children living with disabilities are unemployed thereby shifting their financial dependency to the caregiver grant. This compromises the quality of life of the intended beneficiary.

It is against this background that this study assesses factors affecting access to care dependency grant by children with disabilities, from the perspectives of the caregivers. Data were collected using a mini survey of 19 caregivers (of children with disabilities) in Bhopelong Township, in-depth interviews, an FGD and non-participant observation of how research participants navigated the challenges of caring for children with disabilities against the backdrop of deep poverty.

The study found that some of the children with disabilities remained poverty stricken and without access to care dependency grant. The study further revealed that access to care dependency grant was impeded by factors such as lengthy application process, lack of awareness among some caregivers about the existence of care dependency grant, physical distance to the relevant offices of the Departments of Home Affairs and Social Development, which made it difficult for people to apply for relevant grants. There was the further problem of whole families depending for their survival on the little grant money that was specifically meant for the welfare of the child with disability.

The study concludes from these findings that children with disabilities – and those caring for them - are disadvantaged in quite intricate ways and that only a more rigorous and socially sensitive design of care dependency grant can ameliorate such disadvantage.

Table of Contents

Acknowledgements.....	iii
Dedication	iv
Abstract.....	v
List of Tables	ix
List of Figures	x
CHAPTER ONE: OVERVIEW OF THE STUDY.....	1
1.1 Introduction	1
1.2 Contextual Background of the Research	3
1.3 Study area.....	7
1.4 The Research Problem.....	8
1.5 Research questions	11
1.6 Aim and objectives.....	11
1.7 Significance of the study.....	12
1.8 Theoretical framework	12
1.9 Organisation of the study.....	15
CHAPTER TWO: SOCIAL WELFARE GRANTS AND SOCIAL EXCLUSION – A REVIEW	16
2.1 Introduction	16
2.2 The History of the social welfare model in South Africa.....	16
2.3 Redistributing the economy post 1994.....	19
2.4 The South African social welfare model within the neoliberal nexus	21
2.5 Understanding social exclusion.....	23
2.5.1 Social exclusion of people with disabilities	25
2.6 Relationship between poverty and disability.....	26
2.7 The Social Model of Disability	28
2.8 Conclusion	30
CHAPTER THREE: METHOD OF STUDY	31

3.1 Introduction	31
3.2 Data sources	31
3.3 Qualitative and Quantitative Research	32
3.4 Case study	34
3.5 Data collection techniques	34
3.5.1 Observation.....	35
3.5.2 Individual in-depth Interviews	36
3.5.3 Focus Group Discussions	37
3.5.4 Questionnaires.....	38
3.6 Sampling	38
3.6.1 Purposive sampling	38
3.6.2 Snowball sampling.....	38
3.7 Language	39
3.8 Data analysis	40
3.9 Ethical issues in the research.....	40
CHAPTER FOUR: FINDINGS AND DISCUSSION - DYNAMICS OF ACCESS TO CARE DEPENDENCY GRANTS.....	43
4.1 Introduction	43
4.2 Employment status	43
4.3 Distance to SASSA offices	48
4.4 Access to and Dependency on grants	49
4.5 The burden of women.....	50
4.7 Challenges facing children with disabilities.....	53
4.7.1 Nature of disability	53
4.7.2 Difficult access to education by children with disabilities	54
4.7.3 Health access/medical costs	56
4.7.4 Social pressure and exclusion	57
4.8 Conclusion	59
CHAPTER FIVE: FINDINGS AND DISCUSSION - CHALLENGES FACED BY FAMILIES WITH CHILDREN WITH DISABILITIES.....	60

5.1 Introduction	60
5.2 Disability, vulnerability and citizenship	60
5.3 Economic Exclusion, debt accumulation and disability	64
5.4 Family and disability	67
5.5 Housing dilemmas	69
5.6 The challenges faced by families with children with disabilities that have no access to Care dependency grant.....	71
5.7 Conclusion	73
CHAPTER SIX: SUMMARY, RECOMMENDATIONS AND CONCLUSION.....	75
6.1 Summary.....	75
6.2. Recommendations.....	75
6.3. Conclusion	77
REFERENCES	81
Appendices.....	89
Appendix 1: Caregiver Questionnaire	89
Appendix 2: Caregiver Interview guideline.....	94
Appendix 3: Stakeholder Interview guideline.....	95
Appendix 4: Letter of Introduction.....	97

List of Tables

Table 1: Respondents' Employment Status	45
Table 2: Respondents' educational qualifications.....	46
Table 3: Respondents' Monthly Income	47
Table 4: Number of people in the household	48
Table 5: Distance to SASSA Offices	49
Table 6: Gender of Caregiver	51
Table 7: Marital Status	52

List of Figures

Figure 1: Bophelong Location, Gauteng.....	8
Figure 2: Relationship between poverty and disability	27
Figure 3: The process of stigmatisation.....	58

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 Introduction

The democratic South African government adopted and broadened the apartheid welfare system, making it more inclusive so as to cater for the poor and the needy citizens (Patel, 2008). Having inherited one of the most unequal social systems in the world, the South African government came up with a welfare model to cushion disadvantaged and vulnerable citizens. The apartheid system had previously excluded the black South African citizens from actively participating in the economy. Some of the consequences of the exclusion were illiteracy and unemployment. The remnant patterns of that exclusion are still very visible and can be seen in most poor areas around the country. The introduction of the inclusive welfare grants therefore stepped in to rescue poor families. These social welfare programmes by the government have been hailed as some of the most significant achievements directed at improving the wellbeing of the people (McKinnon, 2004). Although the welfare grant system has achieved positive results in many poor households, its full implementation remains a challenge.

The current South African welfare grants are varied and include the child support grant, the old age grant, the disability grant and the care dependency grant. Briefly, the child support grant is a monthly payment of R280 given to a caregiver, a parent, a grandparent or a child over sixteen heading a family. The income of the caregiver, if single, should not be above R33 600 per annum. If the caregiver is married, the combined salary should not be above R67 000 per annum. They receive this support grant until the children attains the age of 18. The old age grant is given to those beyond the age of 60 years. The care dependency grant is given to a parent, guardian, foster parent or custodian who has under their care any children between the age of one and eighteen who needs full time care because of either mental or physical disability. This is a cash transfer or monthly payment of R1 200 It is a conditional grant given to those who meet a certain criterion through a means test. Only those people whose financial situation is below a certain level can access the grant. The means test for the care

dependency grant takes into cognisance the income of the entire household. For instance, this grant could only be accessed by couples whose joint income was less than R288 000 per annum. A single parent with a child with a disability under their care could also access the grant if their income was less than R144 000 per annum. However, the income of foster parents is not taken into consideration. Means testing is sometimes problematic as will be further discussed in section 1.2. One cannot get the grant if the child is in a psychiatric hospital or receives care from a treatment centre. Only one type of these grants can be accessed for the child; however it is possible to get a care dependency grant as well as a foster child grant for the same child. The care dependency grant is obtained through the process of applying and filling in an application form at the nearest District Welfare office. The application form is completed in the presence of an officer from the South African Social Security Agency (SASSA). The grant becomes void and is cancelled if the child dies; is admitted into a psychiatric care or rehabilitation centre or any other institution. Hence the grant is reviewed from time to time to check this (Mail and Guardian 2009)

These welfare grants have gone a long way in bridging the gap between those who have and those who do not have. Although the welfare grant money is not very substantial considering the economic reality of escalating standard of life in South Africa, it has nevertheless assisted families to raise healthy children, take care of the disabled and the elderly. To those that have been excluded from the economy for various reasons, the welfare money has gone a long way catering for the needs of those without other sources of income.

Although the social welfare grant model has made positive changes in many lives of the poor people that have no other income alternative, the model has also experienced implementation challenges. For example the care dependency grant which is the focus of this study has been a challenge to many potential beneficiaries who have experienced problems in accessing it. Although some have failed to access the grant because of the flaws in the welfare grant system, others have failed to access the grant because of lack of knowledge and exposure to such options that are available to them. The lack of access to care dependency grants has therefore mainly impacted negatively

on the welfare of the children with disability whose condition makes them very vulnerable.

Everyone in South Africa has the right to access social security. Furthermore the South African Constitution obliges the government to pass laws and have policies that provide welfare assistance for the people who need it the most. Despite the above protective measures people with disabilities remain poverty stricken (Hatton, 1995). Graham was quoted by SAPA saying that, 'many disabled South Africans are living in poverty without access to the government's disability grant' contrary to common beliefs that the disabled live on social grants. A study conducted in Gauteng Townships actually found that 61% of the respondents interviewed in eight of the poorest townships in Gauteng were not accessing the disability grant," (SAPA, 2010). Bophelong was one of these townships where people were not accessing disability grant.

Although the majority of South African township residents are disadvantaged in many ways, their situation is similar to people residing in the rural areas. This phenomenon is not limited to South Africa but is a global feature. Worldwide, the pervasiveness of poverty and poor delivery of basic services in rural areas of developing countries continue to constrain development efforts.(Hatton 1995;45) This present study focuses on the factors affecting access in Bophelong, a township in Gauteng province in South Africa. Although the study is about children with disabilities, the empirical data will be collected from parents, caregivers, and legal guardians in Bophelong.

The section below offers a historical background in order to gain a better understanding of disadvantaged South African communities.

1.2 Contextual background of the research

South Africa underwent a dark period of apartheid which meant separate development for different races. This translated to different access to government services with black people being the worst affected due to deliberate exclusion. The history of apartheid has therefore meant that poverty has affected some people more than others. Black

people were confined to low income jobs and were most affected by unemployment and landlessness. This was not a historical accident, but the result of deliberate policies that deprived people of their land, kept them out of skilled work and confined them to urban ghettos and Bantustans¹. There was little attention to issues that affected black people and the vulnerable of society suffered even more discrimination. The township in most South African cities were meant to house cheap labour and little attention was paid to the needs of the people in these areas by the apartheid government. Although the social security nets were in place at that time, they were not meant to uplift the black people but were mainly meant to cushion whites from falling into the category of poverty. Blacks were viewed as cheap and reserve labour for the white economy. (Brown and Neku 2005;56)

The year 1994 ushered in the dawn of a new era in South Africa. It saw South Africa emerge from a system that was discriminatory based on racial lines to become Africa's last independent and democratic country after decades of apartheid rule. The results of this legacy still remain evident today in all sectors of its society. Although South Africa has travelled a long route of democracy, the foot prints of apartheid are still evident in many sectors. The apartheid system was structured in a discriminatory way such that government spending was solely directed to the development of minority white population and urbanized areas. The majority of South Africans were marginalised from many services that government-of-the-day was providing. People and children with disabilities were among the worst affected victims of the apartheid government. However, strategies have been formulated post-1994 to redress the imbalances of the past, for example, the shift to a developmental local government which was established to better the lives of all South Africans. One of the strategies is the formulation of the local government sphere that is very close to the people, whose mandate is to deliver services to its area of jurisdiction. Although there are many initiatives that the present government has introduced to reduce the burden on the previously disadvantaged, many challenges still persist with many communities in South Africa languishing in poverty. This then problematises the incorporation of poor South Africans into the

¹ Read more about social grants on <http://www.etu.org.za/toolbox/docs/government/grants.html>

mainstream society.

The International Labour Organisation (ILO) and the United Nations' Development Programme (UNDP) state that a key indicator of poverty is the degree to which people are excluded from accessing basic goods and services². Previous literature dealt with access to social services skewed in favour of privileged households. Consequently, access to education housing, transport, health and water, for instance, generally depended on one's race, gender and location.

As a result, according to the study conducted by the University of Johannesburg it was found that many respondents did not know about the disability grant or how to apply for it, while others claimed they did not have identity documents which would allow them to qualify for the government grant. It was further discovered that people with disabilities were still experiencing discrimination and were being pushed to the margins of society. The Department of Education briefed the committee on the quality and accessibility to compulsory education of children with special needs, including children with disabilities, street children that several hurdles are faced by such learners. The main problem identified was that not all these children are placed in schools that appropriately cater for their disability (White Paper 2009).

South Africa is also a signatory to the UN Convention on the Rights of the Child, which states that every child has the right to a standard of living adequate for his/her development (UNCRC, date). The Constitution of South Africa of 1996 is the supreme law of the land any conduct or law inconsistent with it is therefore invalid. Section 27 of the Constitution states that

1. Everyone has the right to have access to:

- a) A health care service, including reproductive health care
- b) Sufficient food and water and
- c) Social security, including if they are unable to support themselves and their

² More information on the exclusion of the disabled can be obtained from;
<http://www.independentliving.org/docs5/SANatIDisStrat1.html#anchorNote12>

dependants, appropriate social assistance

2. The state must take reasonable legislative and other measures within its available resources, to achieve the progressive realisation of each of these rights.

3. No one may be refused emergency medical treatment.

Looking closely at section 27(2) it is clear that the state has an obligation to ensure that these rights are progressively realised, the children with disabilities are part of the people who cannot support themselves.

Despite these constitutional clauses that guarantee rights and access to social security, bureaucratic processes often hinder people from accessing these benefits. For instance, the means test approach on accessing care dependency grants has proved elusive for many would-be beneficiaries. It is rarely used correctly

The Means test approach in practice is rarely used correctly, is administratively demanding causes delay and can be demeaning. The costs of administering the means test could be better spent on providing a universal grant to more recipients. Poor people usually cannot meet the administrative requirements and this excludes those most in need (Streak, 2002).

The Constitutional entrenchment of social security rights has significantly strengthened the mandate of the state to provide comprehensive social protection; the right to have access to social security, including if they are unable to support themselves and their dependants, appropriate social assistance. Be that as it may, the Constitution goes further to state that “the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights” (South Africa Constitution, 1996). This is a clear and unambiguous undertaking by the drafters of the Constitution to develop a comprehensive social security system based on, amongst others, two important paradigms: right of access for everyone and financial viability.

According to Olivier, compared with their non-disabled peers, fewer children with disabilities and young people are likely to engage in positive activities and the range of

activities participated in is smaller. Children and young people with learning disabilities, autism or multiple impairments are least likely to participate in positive activities. (Olivier 2004; 43) There are gaps which have been identified and the main argument of the study is exemplified by taking for instance children with disability who tend to have absolutely no access to education at pre-school and otherwise due to discrimination and unawareness by the community on how to relate to them. The reality is that, some areas are well resourced and developed while others remain under-serviced with major developmental needs.

1.3 Study area

Bophelong is a township located in Gauteng province. Like most South African townships, it was established in 1948 to house black people that provided labour to the towns of Vereeniging and Vanderbijlpark. This coincided with the period when the racist Nationalist party came to power, and fostered separate development based on race. This was also a time when Gauteng was undergoing massive industrialisation drive and experiencing growth that was being fostered by massive mine development. Bophelong falls under Sedibeng District and Emfuleni Local Municipalities respectively. The Emfuleni local Municipality contains approximately six large peri-urban townships of Evaton, Sebokeng, Sharpeville, Boipatong, Bophelong and Tshepiso (Emfuleni IDP 2007/2012). The Emfuleni Local Municipality has a population of 726 298 and contributes 80% of the Sedibeng District Municipality Population. Of that population, 37 779 reside in Bophelong (Slabbert, 2004). More than 99% of the population is black and only a small fraction of colored population is found in that area. It is a historically disadvantaged location and still suffers from the effects of apartheid.

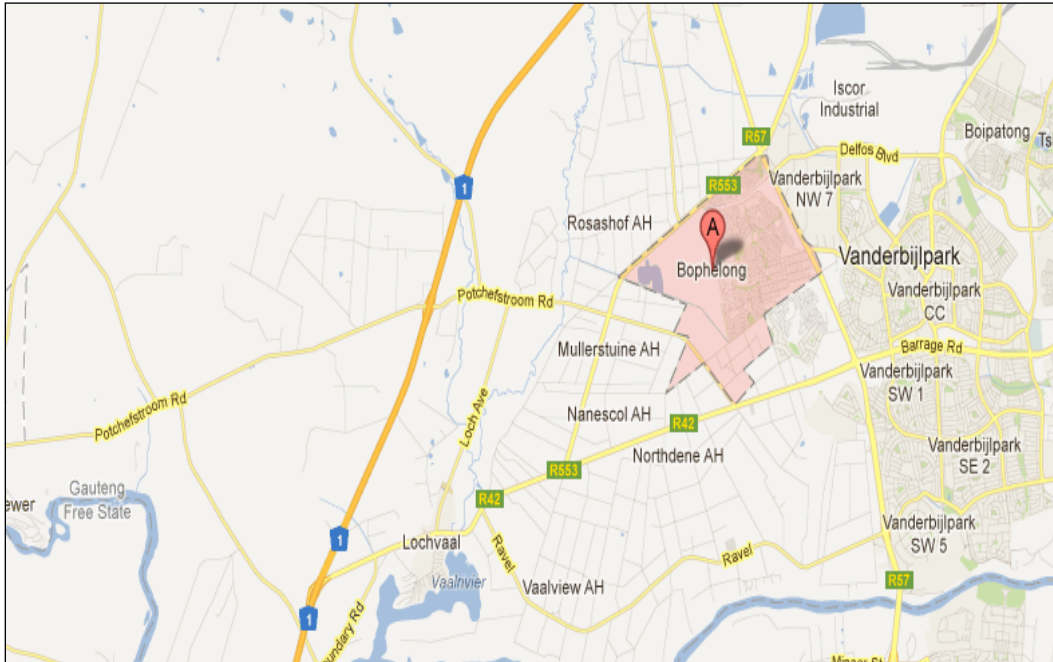


Figure 1: Bophelong Location, Gauteng

Source: Map Data c 2012 AfriGIS (Pty) Ltd

1.4 The research problem

Contrary to the popular belief that the poor and the vulnerable are covered and also benefit from the government welfare programmes, many poor and vulnerable households remain without access to the welfare grants. In many cases access to such programmes remains precarious. Theoretically, the families with children with disabilities should be able to access care dependency grants but in reality this is a problematic terrain. The democratic dispensation in South Africa continues to be challenged by various negative forces that become an obstacle to the full implementation of welfare programmes. The children with disabilities silently suffer although the outer impression is that they are benefiting from government support and therefore their lives are normal. Besides the difficulties in accessing the grants meant to cover children with disabilities, forces of exclusion have also been very prominent in the

lives of people with disabilities. Some forms of exclusion are not immediately evident and silently discriminates and pushes people with disabilities to the periphery. The silent exclusion worsens their predicament (Morris, 2001). The severity of the financial constraints in families with children with disabilities cannot be overemphasised. Most children with disabilities need specialised care on day to day basis. For most families with such a challenge, the additional dilemma becomes that of lacking enough money to take care of the disabled child. The difficulties faced by families of children with disabilities can be attributed to the current social security system which appears to be fragmented, limited in coverage and non comprehensive. The system also suffers from exclusion in that many groups of children are not covered, or cannot access assistance; these include children with moderate disabilities. (Olivier 2004;78)

It has further been observed that the care dependency grant is limited in its scope and suffers from unclear eligibility criteria by targeting only children with severe disabilities in permanent home care. It excludes children who may have moderate disabilities but due to their socio economic situation become severe handicaps. The exclusion experienced by people with disabilities and their families is the result of a range of factors. In most cases families with children with disabilities have to spend their lives carrying a social stigma which consequently discriminates them from access to a variety of social capital. The attitude that society has towards people with disabilities or having children with disability is negative. People with disabilities are usually seen as the 'Other' who should not be part of the mainstream society. (Pam 1997:24) Disability especially in the African context is interpreted badly and the disabled are viewed as not 'belonging' or not supposed to belong and be incorporated in society as full human beings. The complexities that stem out of such a world view have long lasting consequences that sometimes spill into other avenues of life. People with disabilities start their lives from on an unequal footing to the disadvantage and detriment of their wellbeing in comparison with people without disabilities.

The legislative framework of South Africa although highly regarded internationally for its democratic principles does not offer full protection to the disabled who due to their vulnerability require such intervention. There has also been a general tendency of

people who receive welfare grants to be totally dependent on them and not explore other livelihoods.(Olivier 2004:67) In some provinces of the country such as the Eastern Cape ranked the second poorest province in South Africa, people are overly dependent on grants to the extent that the province has been described as characterised by a 'grant economy'. The Gauteng province on the contrary is ranked as having a giant economy not only in terms of South African ranking but also in the African continent. Although Gauteng has been glorified as an economic giant, this does not mean that all is well within the wings of supposedly economic glory. Many families are yet to have their share of the Gauteng economic pie. The realities of life in Bophelong Township serve as testimony that people with disabilities are forgotten in most instances and their participation in the economy is very limited. The question remains as to why they are yet to be fully recognised as deserving to be part and parcel of society with full benefits. The disabled continue to suffer and have many difficulties and disadvantages in society. Their immediate families who have to care and support their disabled members also go through trials and tribulations of prejudice, exclusion and discrimination. The psychological weight placed on family members of people with disabilities sometimes translates to a plethora of other challenges to the detriment of the disabled.

It has been observed that in many instances, parents with children with disabilities do not register their birth early. According to the Legal Resources Centre (LRC) Non registration of birth has negative consequences on children. Birth registration not only gives a child recognized legal existence and identity, but supposedly opens the door to other rights such as access to health and education services³. The implementation of policies concerning children with disabilities are not always interpreted and applied uniformly or in the best interests of the child. Children and young people with learning disabilities, autism or multiple impairments are least likely to participate in positive activities (Olivier 2004; 43).

This research therefore advances an argument that access to care dependency grant by families of children with disabilities is problematic. There are serious gaps in terms of

³ More information on protection of children's rights can be accessed from; www.lrc.org.za/children

access to welfare by those with disabilities in comparison to those with none. The person with disability has to face multiple social obstacles that might make it impossible for them to lead a more fulfilling life. Although the current government inherited an excellent physical infrastructure from the apartheid era, the country is still faced with imperatives such as social and economic development, chronic unemployment, and persistent poverty (Olivier 2004; 56). People with disabilities have appeared a little more clearly on the development map, raising unsolved issues of definition, enumeration, self-representation, goals and strategies⁴ (Miles 2003; 03). This research endeavours to understand the challenges facing those with disabilities in accessing the care dependency grant and how these in turn negatively affect their wellbeing.

1.5 Research questions

The study seeks to answer the following questions:

- i. What factors affect access to care dependency grant?
- ii. To what extent does care dependency grant assist children with disabilities in Bophelong Township?
- iii. What are the challenges faced by families with children with disabilities?

1.6 Aim and objectives

The central aim of this study is to examine the dynamics of access to care dependency grant, based on the narratives and experiences of caregivers in Bophelong.

The specific objectives of the study are as follows:

- i. To examine the factors that affect access to care dependency in the study community with regard to children with disabilities.
- ii. To examine the extent to which care dependency grant assists children with disabilities in the study community.
- iii. To examine the challenges faced by families with children with disabilities.

⁴ See Disability world on; http://www.disabilityworld.org/12-01_06/povertydisability.shtml

1.7 Significance of the study

People with disabilities have been left out of the social systems in many cases. This disadvantage mainly emanates from their very physical makeup of which society shows little pity for. It is generally taken for granted that those with disabilities have the state to provide for them. But in reality is this really the case? Whilst theoretically it is easy for one to say that the children with disabilities have access to care grants, little attention is given to the difficulties faced by the potential beneficiaries in accessing such grants (Johannsmeier, 2007). Although the state says the children with disabilities can have access to care grants, there are many such cases that suffer the deep effects of poverty with grants not anywhere near sight to rescue them. These children with disabilities are not in a position to personally fight but depend on the help from others. As noted by Herring (2005) children with disabilities cannot go to court on their own to challenge decisions made on their behalf or to contest when they are not happy with certain decisions. There is also scholarly gap in addressing issues faced by those with disabilities within social sciences.

This research therefore seeks to generate knowledge and contribute to policy debates which will ultimately lead to a better treatment and care of the vulnerable children, thereby helping South Africa to better care for its children who are the future. This study will fill the void left by scholarly contributions on the challenges faced by children with disabilities in accessing care dependency grants. The study will then suggest any possible interventions of addressing these challenges faced by the children with disabilities.

1.8 Theoretical framework

Theories are formulated to explain, predict, and understand phenomena and, in many cases, to challenge and extend existing knowledge, within the limits of the critical bounding assumptions. The theoretical framework is the structure that can hold or support a theory of a research study. The theoretical framework introduces and describes the theory which explains why the research problem under study exists.

There is a social model, medical model and legal approach welfare. According to the medical model, disability is a medical category. The legal approach model includes welfare, mental health, and guardianship law. The social model conceptualises disability as a socially constructed category. Access to social assistance for disabled people is undermined by a number of common and often well documented factors across different schemes. In applying the international and national theoretical framework to access to disability grants to children with disabilities a number of critical shifts can be witnessed in how services to children with disabilities are to be perceived namely: an emphasis on their rights to access the care dependency grant, the right to protection development and participation in society (Dawes 2007, 13). The equalisation of opportunities for children with disabilities through the provision of additional support so that they can realise their full potential; to enjoy a full and decent life in conditions which ensure dignity, promote self reliance and active participation in society. The acknowledgement that children with disabilities should as far as possible have a say in decisions which affect their lives and should no longer be seen as passive recipients of welfare.

The rights based theoretical approach has it that action is mandatory and children with disabilities are entitled to help as the subject of their rights. Rights are universal and inalienable; they cannot be diluted or taken away. This shows that access to social security is a right that children with disability are entitled to. The term access and equality address some of the most fundamental concepts in social sciences. While equality can be defined as "the same as" "equivalent" and " matching", in a human rights context the term is used to mean that we are all the same in one fundamental way: regardless of our differences we all possess inherent worth. This implies that whether one is born with a disability or not we are all the same in one fundamental way. A number of different approaches can be taken when applying the principle of access. The first theoretical framework is referred to as formal equality. According to Anderson formal equality can occur when laws and policies call for different groups of people to be treated the same, perhaps by saying disadvantaged people like children with disabilities should access governmental resources and should be treated equally (Anderson 1999; 23). In the South African context this would be access to care dependency grant.

However this theory is not enough by itself to ensure that children with disabilities can enjoy true equality and access. Additional steps may need to be taken in order to account for the different circumstances those children with disabilities face and to address the artificial barriers to their access.

Kate Gooding (1997) put forth another theory to access; she says that another approach to access is what is often referred to as "access of opportunity." This approach recognizes that disadvantaged people may face limitations in their lives resulting from factors and circumstances entirely outside of their control, such as their race, gender, disability. Ensuring access to resources therefore requires specific actions to be taken to move beyond formal access, and ensure that children with disabilities can enjoy the same opportunities as other children. Such actions may include accessibility of transportation, combating stereotypes and attitudes that lead to failure to access by children with disabilities, and providing reasonable accommodations in educational and other contexts (Gooding 1997).

The third approach can be referred to as "access in fact" "substantive access" or "defacto access". This approach seeks to ensure equality of results and not just access and equal opportunity. In other words, de facto sees each person as equally entitled to full enjoyment and access of their human rights of their conditions. Although a properly implemented "access of opportunity" approach is typically sufficient to ensure that most children with disabilities are able to enjoy their human rights as they wish, and an additional commitment by the State to "de facto access" can be of great assistance in ensuring enjoyment of human rights by children with disabilities. For example by ensuring that children with disabilities are not discriminated against.

Although different schools of thought exist to conceptualise the welfare grant system, this study will align more with the social model and the human rights model. The social model explains the discrimination of the disabled as emanating from their categorisation in society as the 'other'. Society consciously establishes such categories in order to offer an explanation and differentiation between the normal and the abnormal. This

conscious discrimination is also a way society isolates itself from responsibility in caring for the vulnerable and pushing them to become a state responsibility. The fact that people with disabilities are viewed as abnormal serves to legitimise the inherent and structural discrimination suffered by the disabled.

The human rights model will strengthen the argument of this dissertation by advocating that the care dependency grant is not only about a few hundred Rands that the state gives to the 'lucky few' but is a human rights issue as the access to care money improves the wellbeing of the disabled and saves lives in some instances. Since the rights of people with disabilities are protected by the constitution, it is therefore within acceptable standards that user friendly channels are provided to cater for the needs of the vulnerable within South African society. There should therefore be deliberate effort to get the services to all the people especially the vulnerable who due to many reasons fail to have access to services that can make their lives better.

1.9 Organisation of the study

This dissertation will be organised as follows; Chapter One is an Overview of the study. The background to the study is concentrated in this chapter. Chapter Two reviews relevant literature which highlights the contribution that has been made by other scholars on the issue of care dependency grants. In this chapter, the gaps in literature are highlighted whilst at the same time showing how these gaps have been filled by this study. The literature discussion is presented under the title; Social welfare grants and social exclusion. Chapter Three focuses on research methodology used to conduct this study. Chapter Four looks at the dynamics of access to care dependency grants in Bophelong Township. Chapter Five looks at the challenges of families with children with disabilities and Chapter Six recommends and concludes the study.

CHAPTER TWO

SOCIAL WELFARE GRANTS AND SOCIAL EXCLUSION – A REVIEW

2.1 Introduction

This chapter looks at the literature on issues related to social welfare grants in both South Africa and the global context. It has been noted that a sizable literature already exists in this context focusing on various facets of the grants. Most perspectives on social welfare grants in the South African contexts are agreed that the deliberate social construction of the past apartheid government left huge social inequality footprints of which the current government has been struggling to erase. The social landscape of the country remains marred in deep poverty and enduring structural inequality. It has been highlighted in many academic works that the majority of blacks continue to experience high rate of poverty. Although there are many causes that can be attributed to this grim picture, the apartheid pillars of discrimination have continued to silently foster suffering and poverty amongst the majority of black citizens. As such, it is this background that informed the adoption of social welfare grants by the current government to cushion the poor, weak and vulnerable members of society. In order to avoid human tragedy the government of South Africa adopted various categories of social welfare grants to assist the poor to cope with their life circumstances. The various types of grants available in the South African context have already been alluded to in chapter one of this dissertation.

2.2 The History of the social welfare model in South Africa

The social welfare model has a long history in South Africa and can be traced to the early white settlement period. It has been noted that as early as 1657, the Dutch reformed church and the Dutch East India company distributed relief to indigent white farmers (Boers) whose crops failed (Brown and Neku, 2005:301). At that time such relief was specifically targeting whites and excluding blacks. The exclusion was informed by the Calvinist ideas of predestination and the views that whites were chosen by God to be superior. Africans were viewed as having certain sets of beliefs and way of life which was particularly marked from that of the white people. In the same way, whites had their own sets of beliefs and way of life which was regarded to be superior

and civilised. In this context, the welfare was therefore provided by the Dutch reformed church but only limited to whites. Brown and Neku (2005:302) argue that;

As social welfare services for whites progressed under the authority of the Dutch Reformed Church, institutional welfare resources for children and persons with disabilities were also established, but the church did not help the indigenous population which also experienced social and economic difficulties.

From the onset of the welfare services in South Africa, there was discriminatory distribution which used race as a variable of exclusion. The failure of white crops coincided with the period of industrialisation which changed the face of South Africa. This was when minerals were discovered in 1860 (Brown and Neku, 2005:302). The failed white farmers and poorer whites began to move into the cities that were rapidly urbanising. The lure of mining activities were not only limited to whites but also blacks began to migrate from their rural homes in search of better living in the city. Poverty was already becoming a major problem in the rural areas thereby pushing people to the urban areas to work in the mines. It has been observed that only men were moving into the mines in search of wage labour leaving behind their impoverished families who needed support. The money earned in the mines was however not sufficient to cater for the needs of the labourer and the extended family. The economic situation however put pressure on the meagre wages that became a lifeline to the whole family.

At this same period, whites in the city were also enduring difficulties as they had to compete for opportunities with other urban dwellers. Brown and Neku (2005: 302) contend that;

Many white urban migrants with no educational and trade skills that would allow them to compete with immigrant mining employees or with blacks whose low wage jobs they did not want also continued to experience poverty.

In face of this growing urban poverty, the church became increasingly involved with welfare activities whose access was only limited to white people. Black families that had migrated to the city had to invent creative ways to escape poverty. Black women began to form stokvels as income saving measures (Brown and Neku, 2005: 302).

The discriminatory practices in welfare access were taken to a higher level during apartheid. When the Nationalist party won the elections in 1948, it instituted apartheid which already had foundations in the previous era. Apartheid meant that development, in its multiple senses was to be implemented based on race. Each and every race within the borders of South Africa was supposed to develop in its own direction. This meant that whites, coloureds, Indians and blacks had different systems in place for their development. The welfare services have been singled as having been very harsh towards black people. In 1928, the elderly were already getting state pension. The benefits however were biased towards white people. In 1944 limited grants were made available to blacks at a lower rate. The state then was little concerned about the plight of blacks but was biased towards the welfare of the white people. As such the poorer whites had the state to look towards for security and general provision. They were secured jobs, better education and better housing. The disabled had institutions to care for them at the cost of the government. In 1950 the state started ceding its responsibility for black by creating departments that were to look after their welfare. The Department of Social Welfare is noted to have transferred its responsibilities for black people to the Department of Bantu Administration and Coloured Affairs. In 1961 the Department of Indian Affairs was also established (Brown and Neku, 2005: 303). The budget allocations were to follow a hierarchical pattern, with whites getting the biggest share of social welfare budget. The needy in that racial group were therefore taken care of with decent allocations. Blacks on the other hand were the lowest in racial classification and they were also allocated the smallest budget which could hardly cater for their needs. Brown and Neku (2005:303) citing Lundi (1992) allude to the flowing discriminatory patterns of social welfare distribution:

1. Coloureds, Indians and whites received payments monthly and blacks were given their allowance every second month;
2. Coloureds, Indians and whites were paid by check through the post office and blacks were paid in cash at various mobile sites, such as schools, under trees or in stores;
3. Pensions for the minority were payable from the date of application, while those of the black majority were payable from the date of approval.

The discrepancies in the allocation of budgets and the general treatment of different racial groups and ordering them in hierarchical order created enduring inequalities during apartheid. The white people benefited immensely from the apartheid machinery and this put them a step ahead of other racial groups. Poverty amongst blacks increased to alarming level yet the state cared less about the situation, justifying it on inferiority of blacks. The inequalities that resulted from the apartheid era have continued to impact negatively on blacks who suffer the highest level of unemployment and lead a poor quality of life because of lack of income. It has been noted that at the demise of apartheid, the new government led by the African National Congress (ANC) party sought to rectify the racial inequalities that were created by the apartheid government.

2.3 Redistributing the economy post 1994

The democratic government of South Africa that came into power in 1994, realizing the deep negative effects created by the apartheid machinery, sought to rectify some of its effects through transformation. There was a realisation that besides the political freedom that the country had achieved, there was a need to gradually redistribute the economy that remained largely in control by the white minority. Since transformation was not an absolute but a gradual process, there was need to find creative ways of arresting the situation from spiralling out of control. It has been observed that the ANC led government guided by democratic principles embedded in the constitution made the access to decent living one of its obligation. As such the poor to some extent became the responsibility of the government. The social welfare grants became one immediate solution. Those that could not generate enough income to sustain themselves and their families were given access to several types of grants. It has been noted that the government adopted a neoliberal approach to the economy after 1994 and experimented with different approaches in addressing issues of the economy. First the ANC led government came up with the Reconstruction and Development Programme (RDP) in 1994 as an approach to the economic plight of the blacks (ANC, 1994). According to Brown and Neku (2005: 304). The major tenets of the RDP model were to;

1. Redressing past imbalances through a deliberate process of affirmative action with respect to those who were historically disadvantaged, that is, women, children and people in rural communities and informal settlements.
2. Establishing umbrella legislation that provided the underpinnings for a development-oriented social welfare system based on the principles of equality, equity, access and empowerment.
3. Ensuring the greatest coverage for the poorest through a restructured, integrated social welfare delivery system at the national, provincial and local levels of government.
4. Developing professional standards to guide the training, education and employment of social service personnel.

The initial imagination of the RDP programme was that it would improve the lives of the people after a long era of apartheid's mismanagement of the country. It was envisaged that it would bridge the deliberately created gaps between different racial groups of South Africa. This policy direction was considered as people driven and a road map to improving the socio-economic status of South Africans. William (2000) notes that the RDP policy initially became a watermark that was developed with intentions of driving South Africa to another direction, away from its apartheid past. There was an urgent need in meeting the basic needs of the poor, democratizing the state, and dismantling apartheid structures (Harrison et al, 2008). RDP was meant to rebuild the skewed economy that was a result of apartheid planning. Moderate in its outlook, the RDP gained popularity during its maiden stages. It also gave ANC an identity of a progressive and democratic state (Lester et al, 2000). As further argued by Lester (2000) the RDP later ran into implementation problems and failed to achieve what it had intended to do. The poor continued to be out of jobs and housing still remained a big challenge especially to poor urban dwellers. Romanticized as a progressive model in its initial stages, the challenges that faced RDP were overwhelming and that led to its replacement by another model (Maharaj, 2005).

The RDP model was followed by Growth, Employment and Redistributive Policy (GEAR) in 1996 which was meant to stimulate the economy and share the proceeds later on. The GEAR policy that was initially intended to reinforce the weaknesses of RDP has however been condemned for its inadequateness in improving the lives of the poor. The GEAR model emphasized economic growth, a shift away from socially driven RDP (Bond, 2002). The employment opportunities that seemed to be moving at a snail's

pace within the context of the RDP have not been miraculously accelerated within the GEAR policy. The GEAR policy has actually been described as very close to capitalist values and therefore a mainstay of neoliberalism. There was also an adoption of Black Economic Empowerment affirmative action policies to give employment and business priority to the previously discriminated groups. Although these policies have assisted in reversing some of the inequalities, they have not been adequate in uprooting the majority of blacks from their poverty status. Poverty is still prevalent. There have been several debates on the system of grants in South Africa. The debates have been around the effectiveness of grants in poverty reduction and their sustainability in terms of the economy. Others have pushed a discourse around the structural dependency created by these grants. However, there has been little debate on the limitations in terms of accessibility to the intended beneficiaries.

The social welfare system has therefore ushered a notion that South African state is a distributional regime. Through such a system, the economic benefits trickle down to all the citizens of the country. It has been noted that the welfare grants consume a sizable amount of the social services budget. With spiralling unemployment and an uncertain future facing the people of productive ages, the pressure on the welfare system is set to increase with the state having to carry the burden of the growing army of the unemployed and the vulnerable. It is noted that in poorer provinces such as Limpopo and the Eastern Cape, the social welfare services have played a very pivotal role as lifeline to desperate households. Interestingly the Eastern Cape has actually been cited as carrying a very visible grant identity, meaning that, a big share of the population relies on grants for day to day survival.

2.4 The South African social welfare model within the neoliberal nexus

The social welfare model was informed by the RDP national social policy direction. The 1997 White paper for Social welfare reflected these values (Brown and Neku, 2005: 304). This framework sought to redress the past biases in the social welfare model, by prioritizing access to these services by vulnerable people and families in need. Housed under the Department of Social Development, the social welfare adopted in post

apartheid era was strengthened to provide services in a redistribution pattern, eradicating the social biases that were fostered by the apartheid government. This model was also designed to erase absolute poverty in families that have no access to income and those that are earning too little to be in a position to cater for all their needs. Poverty has continued to negatively affect both rural and urban dwellers and the social welfare assistance has gone a long way towards arresting the drastic effects of poverty. However the long term solutions to people's economic problems seem to be far from being over. The economy is still marred by vast discrepancies to such an extent that the poor are generally kept within the poverty bracket. The question could be what has maintained vast inequalities within the context of a democratic dispensation? This question takes this research back to the neoliberal economic model that the ANC government embraced when taking over power.

The neoliberal approach is an economic model that has a global appeal and seeks to manage the economy in a more open way by allowing free flow of capital and business competition at various levels (Massey, 2005). The market forces are basically left to determine economic activities. There is less involvement of the state. Its role actually becomes that of facilitating economic activities in a non interference fashion and creating institutions that are conducive to the free flow of the capital. The market is deregulated and there is free flow of global capital. The economy also becomes integrated into the global economy (Harvey, 2005). In the broader sense, the neoliberal approach calls for liberalisation of the economy from state control and interference. The theory argues that the economy is able to regulate itself and as it stabilizes and grows, there will be trickle down benefits to everyone (Barchiesi, 2007). What is striking within this theory is the absence of a clear explanation on how the poor and the previously excluded groups can be incorporated within the model without state assistance.

In the context of South Africa where the ANC government inherited an unequal capitalist economy that had for so long operated on racial-Fordist terms which ensured white accumulation of wealth, neo-liberalism is not far from controversy. Since the state is required not to interfere, who then represents the vulnerable and the marginalized? What happens to those that have always been denied access to the economy through

political means? If the political discrepancies are not to be resolved through political intervention, how far can the economy address such issues? How neutral and fair are the economic forces? These are questions one has to battle with in trying to re-imagine the poor's position within the neoliberal space. As noted by Comaroff and Comaroff, (2001) by buying into the liberal notion, the state ceases political interference on the market. This in other words means that the state through its central position is paralysed in terms of protecting the poor from the market forces which have little to offer them. Exploitation of the poor within the neoliberal context is in most cases let loose, to the detrimental effect on the poor and the vulnerable. It is within such an economic context that the poor and the vulnerable, with very limited opportunities available to them, continue to struggle to improve their lives. It is within such economic context that the social model can be conceptualised. What fosters the continued treatment of the vulnerable in society as the 'Outsider'? The Constitution is very clear on the protection of the rights of South African citizen, but just how practical are some of the progressive and democratic principles in face of the neoliberal environment. These are some of the questions that this study seeks to establish. The following section explores some of the mechanisms that have been actively at play, discriminating the vulnerable people that are with disabilities.

2.5 Understanding social exclusion

Social exclusion is identified as having emanated from industrializing societies in the 19th century. It has been noted that, modernisation and industrialisation resulted in a new type of poverty that affected the working class (Saith, 2001:3). This was seen as a danger as the social order was being threatened. Saith (2001:3) contends that 'this resulted in the introduction of factory legislation, social insurance and institutionalisation of industrial relations to counter these social tensions'. This culminated in the introduction of the modern welfare state. The term 'social exclusion' then referred to those who failed to access the welfare state and were labelled as social deviants and social misfits. It has been noted that the "socially excluded included the mentally and physically handicapped, the aged and invalid, drug users, delinquents and suicidal people" (Saith, 2001:3). In the 1970s and 1980s with the advent of globalisation and neoliberal approach to the economy, the European unemployment rates began to

escalate, affecting those that had been job secure for a long time. This resulted in the extension of the definition of exclusion to include the unemployed and those cut from various social networks resulting in their vulnerability. This meant that the socially excluded were being ex-communicated from the industrial societies. A person is therefore excluded if they cannot access their rights as citizens due to various obstacles. This development pattern has parallels within the South African context. As alluded to earlier on, the industrialisation in South Africa was accompanied by racial capitalism that included and excluded people on the basis of their racial orientation.

It has been observed that a similar notion of exclusion is inherent in the developing countries. What has been noted is that within the developing countries, the excluded are normally in large numbers. In relation to social security that the state extends to its weaker citizens, the actual implementation is very limited. Saith (2001:6) observes that:

Of the social security schemes that exist, coverage is very low: state support for the infirm and disabled is negligible; education support limited and does not usually extend beyond primary school; state pensions cover a minority and health care which although subsidized is spread very thinly and haphazardly.

Such challenges that face most developing countries tend to have huge negative bearings on those in need of the services. Social security is intended to arrest the drastic effects of poverty by rescuing the vulnerable from very low standards of living. The failure to access such assistance results in social exclusion, which in turn, can lead to very poor standards of living due to lack of income. In this study, an attempt is made to relate social exclusion to the consequences that it generates. What happens to the families that are being excluded because of variable disabilities and what impact does that have on the overall wellbeing? It would be interesting to understand the overarching reason that facilitates the social exclusion of people that are already in a vulnerable state. The section below provides some insights into what motivates social exclusion of people with disabilities.

2.5.1 Social exclusion of people with disabilities

Morries (2001) in his study of the dynamics of exclusion of the youths with disabilities in Britain theorized that social exclusion was one way the youth was kept shut out from the main stream society. As such this was informed by deliberate motives to offer limited access to livelihood to these people with disabilities. In a similar way, the current South African model of social welfare grant provision does not provide a clear vision on how issues of social exclusion can be dealt with. It has been observed in most cases that the plight of people with disability is at the mercy of the able bodied who are more privileged and are in a better position to take and implement decisions. The case is limited for the disabled who in most cases are not able to decide upon their life paths. Morris discusses the context of social exclusion within the British context where a policy aimed at addressing such an issue is already in place. The government has a social exclusion unit which he condemns as being vague. Morries (2001) further quotes Burchardt who identified the indicators of social exclusion for children and young people as follows:

- a) standard of living: growing up in a household with an adequate level of material well-being;
- b) education, work and play: having the opportunity to develop skills and knowledge to enable them to play a socially useful role later in life;
- c) nurturing and socialisation: receiving love and attention in a secure environment, and having opportunities to socialise with other children; and
- d) participation in decision-making: developing the capacity to make informed decisions through increasing involvement in decisions which affect their lives.

Interestingly, these indicators of social exclusion were similar to those identified by young people themselves. Morris further observes that in most cases social exclusion has to do with the failure of people to access jobs and in most cases children with disabilities come from families that are unemployed. Relating this with the South African situation, the job market has been under enormous pressure and seems to be dwindling, this means that the lowly educated and minimally skilled will continue to struggle for incorporation into the economy. The South African realities of the poor exceed the above indicators of social exclusion. The poor are in the townships which

have generally been a source of neglect historically, providing limited advancement opportunities relative to middle class children in low density suburbs around Gauteng. Adequate care to children with disabilities becomes a big challenge as the care dependency grant is stretched to provide for the whole family often neglecting the needs of the intended beneficiary. In most cases, the person with the disability is not consulted even if they are capable to contribute. In the case of children, the situation is even worse as they are still considered to be under the guardianship of their parents. There is no platform where they can voice their concerns even if they have plausible and genuine grievances.

2.6 Relationship between poverty and disability

The unequal opportunities that are available to people with disabilities and their families to advance in society has exacerbated the problem of poverty in most families. The condition of disability coupled with society's perception and treatment of people with disability creates an environment of unequal life processes and outcomes. In most cases, this creates a fertile environment for the perpetuation of a poverty cycle in the family. The treatment of people with disabilities as the 'Other' that is different from the 'Us' normal people overshadows people with disabilities, turning them into the 'invisible other' that is of less significance. Although the system of social grants is one way of fighting poverty, some social structural pillars keep poverty in an activated mode. The continuous discrimination and dwindling life opportunities of the people with disabilities make them vulnerable to poverty. As shown in Figure 2, poverty perpetuates itself in individuals and in families that are vulnerable. The vulnerability is facilitated by society.

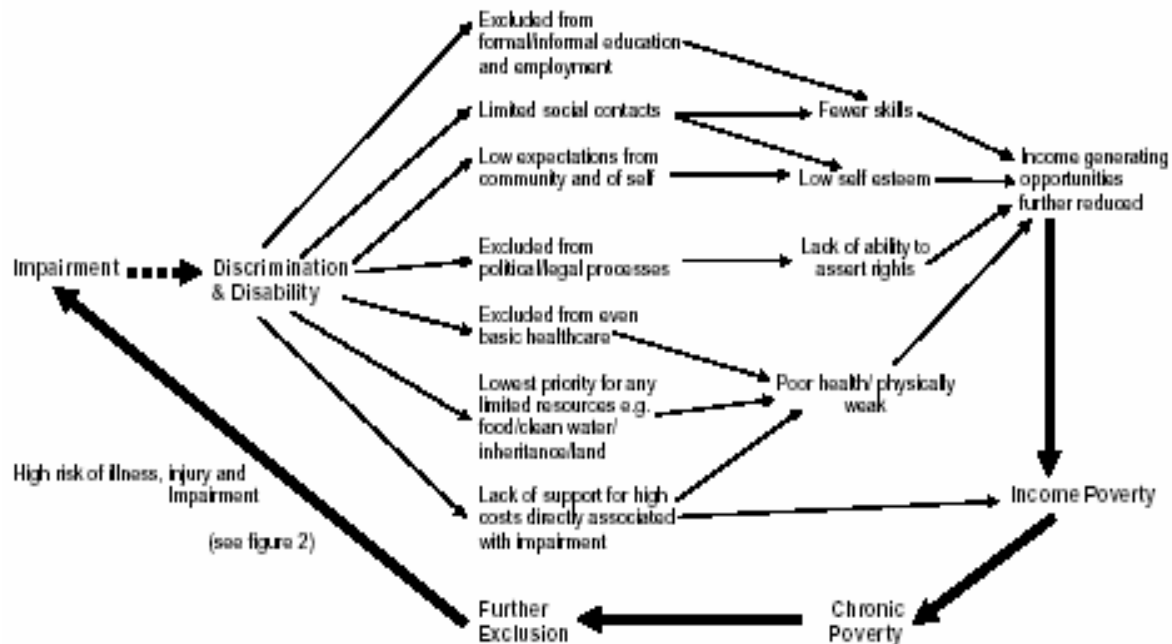


Figure 2: Relationship between poverty and disability

Source: Christa Johannsmeier , 2007:7

The above cycle of disability and the one below show the relationship between disability and poverty and vice-versa. As can be seen above, the exclusion of people with disabilities from education opportunities limits their employment prospects and this leads to chronic poverty. Johannsmeier (2007:7) contents that there is a close relationship between disability and poverty. These variables have a bearing on each other;

Poverty increases the risk of disability, for example through lack of healthcare, poor nutrition, greater exposure to injuries or lack of knowledge about prevention. Disability also adds to the risk of poverty, for example due to the costs associated with the disability, discrimination in the labour market or exclusion from education.

The above quotation highlights the fact that in most cases the poor are the ones who become victims of disability. Because of the poverty status, most poor people become further vulnerable due to lack of access to various social capitals. People with

disabilities and their families are often excluded from access to jobs and employment. That further exacerbates their situation. Most people that have not received formal education may lack adequate knowledge about their rights and have limited access to services that are available. When they fail to be gainfully employed, such families have no means to provide food, shelter and other household needs.

2.7 The Social Model of disability

People with disability have faced numerous problems instigated by society. For a long time, disability has been conceived an abnormal medical condition. As such, people with disabilities have been viewed as being of little worth and their cases as invalid. To some extent, they are generally viewed as a problem. The difference between them and the non disabled people have always been projected into a level of significance. As noted by Barnes (2005:528), the people with disabilities were historically viewed as going through a personal life tragedy. Reid-Cunningham (2009) concurs to this view by stating that disability was viewed as a personal experience to individuals and their families. Barnes further notes that ‘the focus on individual, functional limitations effectively legitimated the wide-ranging inequalities and exclusion from mainstream society experienced by disabled people’ (Barnes, 2005:528). The person with disabilities was therefore largely viewed as a helpless victim who had been unfortunate. As such because of their condition, people with disabilities had to depend on assistance of family and friends and welfare grants. They also relied heavily on medical intervention. In countries like Britain and America, people with disabilities had to form pressure groups in order to earn their recognition as people with equal rights in society. In the United States of America, the ‘Independent living’ is one such pressure group that pressured for change in the treatment of people that were with disabilities (Barnes, 2005:529). This pressure group was informed by the following fundamental principles:

1. Human beings, regardless of the nature, complexity and/or severity of impairment, are of equal worth, and have the right to participate in all areas of mainstream community life.
2. Whatever the character and severity of impairment, individuals should be empowered to make choices and exercise control in their everyday lives

The above quotation shows that people with disability have been perceived as less human than those with no disability. Depending on the level of their impairment, their integration with the main stream society has always been a challenge. This is because society refuses to recognise people with disability as human beings that are able to contribute positively in their communities. Because of exclusion based on the limitations of impairment, in most cases people with disabilities have been conceived as medical objects that require medical intervention to be normal people (Mackelprang, 2010, O'Grady et al, 2004). This treatment of people with disabilities as helpless medical patients has in most cases disempowered them and further disabled them, worsening their cases by putting systematic social barriers of exclusion. Barnes (2005: 531) further explores the tenets of social model that serves to strengthen the role it plays in facilitating better treatment of people with disability:

1. First, unlike the conventional, medical view of 'disability' as incapacity, the social model directs the analytical focus away from individual functional limitations to the barriers to social inclusion created by disabling environments, attitudes, and cultures.
2. Second, it is an holistic approach that emphasizes the interrelationship of these barriers across everyday life, such as inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and negative cultural and media representations.
3. Third, a social model perspective does not deny the importance or value of specific individual interventions in the lives of disabled people, for example, medical, rehabilitative, educational, and employment initiatives, but emphasizes that they are insufficient to achieve inclusion in a society pre-eminently constructed by and for non-disabled people.

It is therefore the social perceptions of society regarding a person with disabilities that prejudices the value of life for persons with conditions that mark them as different. This prejudice champions the idea that the body of a person with disability has to be fixed like a machine for it to operate optimally. The medical treatment, medication and the medical machines are projected as the solution to a 'disabled body'. The categorisation of people with disability that is actively pursued by society at times leads to unnecessary

isolation and exclusion. As observed by Charlton (2001) the prejudiced treatment of people with disabilities lead to their degradation, dependency and powerlessness. He further notes that such traits of exclusion compares well with similar variables such as racism, sexism and colonisation. In this vein, disability is therefore seen as some form of discrimination and social oppression (Thomas et al, 1997). The fact that they are viewed as the other marginalizes them (Reid-Cunningham, 2009).As such, this study will look at how the attitudes of society serves to 'disable' people with impairments leading to some form of discrimination from full social participation.

2.8 Conclusion

Having discussed various models of examining the social welfare system in South Africa, this study applies the social model as an analytic tool for the empirical enquiry. It will investigate the social construction of disability in everyday discourse and the embedded conceptualisation that affect the relationship between society and those with disabilities. Furthermore, the social model will be applied to analyze different forms of exclusions, be they social; psychological or physical, that the people with disability experience.

CHAPTER THREE METHOD OF STUDY

3.1 Introduction

This chapter details the data collection methods that were used in this study. It also gives an explanation to justify the choice of methods. It also highlights the experiences that the researcher went through during data collection at Bophelong Township. The data collection methods that were used in this study were a triangulation of qualitative and quantitative approaches. As such, interviews, observation and focus group techniques were used under qualitative approach. The quantitative approach utilized a structured questionnaire that was distributed to selected informants to gather quantitative data. The triangulation of qualitative and quantitative methods reinforced the data collection process and allowed for diverse information to be collected on various issues that impact on people with disabilities and their caregivers.

3.2 Data sources

Various sources, both primary and secondary, were consulted in the data collection stages in order to meet the objectives of the study. The secondary sources that were consulted included journal articles, book chapters, theses, newspapers and internet sources. The information obtained from these sources was used to review the literature and to contextualise the study. It also highlighted what other previous research on similar studies had unearthed and what procedures were followed to obtain such data. The fieldwork activities were informed by this information gathered from various sources.

The empirical data gathered through fieldwork utilised both qualitative and quantitative data collection methods. Hence, in-depth interviews, focus group discussions and observations were utilised. The interviews were conducted at the homes of the informants and offices of selected government officials. Observations were carried out at Bophelong Township in order to capture silent registers that impact on the lives of people with disabilities. A structured questionnaire was also used to generate quantitative data on disability issues.

3.3 Qualitative and Quantitative Research

This study utilized qualitative approach that gives the researcher access to information by listening to informants talk and also through observation of their actions. This method relies on evidence in order to understand what is taking place (Gillham 2000) . The informants are given space to say their side of the story unhindered, in that way enabling the researcher to gain deep knowledge on issues being investigated. As summarized succinctly by Gillham (2000), qualitative research allows the researcher to go deeper in digging for the information and actually, getting under their skin to understand their way of life in their own perspectives, to understand their own culture and way of doing things and general perspectives on a variety of issues. It actually captures the lived world in its natural setting (Schwandt, 2001: 84). Through this method, this study was able to gather information from those affected by disability, understanding the nature of their lives, their joys and their challenges. It was also enabled to understand deeply what the people with disabilities and those that care for them think about their treatment in contemporary South Africa.

The qualitative approach therefore allows a researcher an entry into the realities of other people in order to make sense of their experiences (Krueger, 1998). As such this enables detailed information to be collected, information that is intimately connected to those that are given an opportunity to tell their side of story and express their views openly without being constrained by predetermined categories. This point is strengthened by Babbie and Mouton (2001) who contend that the insider perspective can be better understood through qualitative methods as it allows the researcher to give space to those studied to express their views. This study argues that qualitative enquiry allows the researcher insights into culture specific dimensions that could hardly be understood through employment of other research methods; it also allows the research to read the unspoken and unwritten information through observation of people as they express their feelings. The researcher is able to read the language of pain through reading facial expressions and other body language. The strength of qualitative research lies in the facilitation of studying a phenomenon in its natural setting and minimizing any attempt to displace it or to generalise findings. As observed by Patton (2002) qualitative approach is naturalistic in that the research is located in its own

setting. This is further affirmed by Gillham (2000) who observed that human behaviour, thoughts and feelings are partly determined by their context, and hence a motivation to study people in their own context. In studying within natural contexts, chances of distorting information are minimized and the researcher is able to present information as it is, without manipulating it to fit in some predetermined categories. Babbie and Mouton (2001) contend that qualitative approach is able to capture some issues that are not easily visible. As the researcher sits to listen to stories of informants, a better understanding of their situation is enabled (Denzin and Lincon, 2000:3).

This study adopted a triangulation of qualitative and quantitative methods in order to reinforce their effectiveness. The positive traits of both methods allowed the researcher to generate a wide variety of information which could be verified.

The quantitative method which is widely viewed as science's mainstay, allowed for generation of statistical data which could not be obtained through qualitative interviews and observation. Each method therefore worked to contribute towards the goal of the study which was to gain a better understanding on the issues that affect people with disability and their caregivers. The questions were directed at the adult caregivers since the people with disabilities in this case were children. Ethically it would have been problematic to try and gather information from children. The quantitative method used a questionnaire that was drafted by the researcher with pre-determined categories. The respondents were asked to choose the response that closely resembles what they know about the issue being asked. The quantitative inquiry was aimed at statistically generating information, for example, on how many people are in the household and how many of them were unemployed and how many times they had sought a particular service. A standardized questionnaire was therefore used to investigate varying perspectives and experiences of people. The predetermined responses allowed for the generation of relevant data only (Patton, 2002:14). The data collection instrument is controlled and results can be generalized. Krueger (1998: 5) however states that in quantitative enquiry, the results of the study come out the same every time the study is replicated. The qualitative approach on the other hand is able to generate different

results when the study is replicated as people's behavior is influenced by their environment.

By triangulating qualitative and quantitative research methods, this study was able to capitalise on the strength of each approach. The feelings of people being studied were captured, their behaviour and actions captured through observations whilst on the other hand statistical data to show how wide spread the problems facing people with disabilities are, were captured through quantitative statistics.

3.4 Case study

This study focuses on one community, Bophelong Township. The use of a case study was suitable for this research since there were a lot of dynamics that needed to be explored on the issue under study. Yin (2003:1) recommends a case study in situations where questions such as 'how' or 'why' are being posed and also when the focus of the study is on a contemporary phenomenon within some real-life context. A case study is therefore an empirical inquiry that investigates a contemporary phenomenon within its real-life context. It contributes to the web of knowledge about a group of people within a certain context. It attempts to examine individuals, groups and society with the chief purpose to describe (Babbie, 1998, Yin, 2003). Gobo (2008:12) summarises a case study as an expression denoting research on a system bounded in space and time. The research is conducted using diverse methodologies, methods and data sources, like participant observation, interviews, audiovisual materials, documents and many others.

In this study, which explores the challenges that are faced by caregivers in families that have children with disabilities, qualitative and quantitative research methods were triangulated in order to holistically answer the three research questions outlined in Chapter 1.

3.5 Data collection techniques

This section gives details of the techniques that were used under both qualitative and quantitative approaches. Under the qualitative method, the techniques used were the in-depth interviews, observations and focus group discussions. The quantitative approach used was a mini survey utilising structured questionnaire.

3.5.1 Observation

The fieldwork for this study lasted for two and a half months (October to mid-December 2012). The observations were done to reinforce data gathered through interviews. The observations allowed the researcher to read the behaviour and actions of people under study without even talking to them. This is because some unspoken sentiments can actually be acted both intentionally and unintentionally. In order to understand what was going on in the lives of families with children with disabilities, the researcher carefully observed them in their natural settings, with a view to gaining some insight into their living conditions, their interaction, their worries, and their daily struggles. As encouraged by Babbie (1998), one way to gain knowledge about a phenomenon under investigation is to utilise observation. Observational techniques bring the researcher closer to that which is being studied. Many scholars actually emphasise the significance of coming closer to the subject under investigation through engaging in observation (Hammersley and Atkinson 2007, Crang and Cook 2007, Davis, 2007, Gobo 2008). It is through observation that the researcher 'harvests' data from their natural setting. Meanings can then be generated from the observations made.

The researcher relied on non-intrusive, non-participant observations, as interviews were being conducted with selected respondents. Everything she observed mattered and meanings were later generated to further shed light on the issues under study. For instance, the researcher observed that the presence of a child with a disability changes and transforms the lives of most families. The researcher noticed the intensity of poverty characterising most families that participated in the study. These ranged from inadequate shelter, shortage of basic needs, scarcity of jobs and a general scramble for livelihood. It seemed that in most families with children with disability, poverty had a huge footprint and this clearly worsened their predicament. Indeed, poverty attracted other negative attributes into the lives of those that already had to deal with the difficulties that disabilities introduced in their lives. Most families that the researcher interacted with were out of employment and had limited educational background. Appropriate shelter was also a problem. In her observation, the researcher noticed that there was little care for families and children with disabilities. In her informal

conversations with other community members, it became apparent that there were aware of the plight suffered by families raising children with disabilities. There was not much help that could be offered by community members who were also battling with the effects of poverty and unemployment.

Through non-participant observation the researcher was able to capture a lot of information that could not be represented easily by spoken words. In most cases the unspoken actions represented valuable information; for that which people are not prepared to utter is easily represented through unspoken action and other body registers. It is generally difficult for people to articulate on situations that they consider to be too embarrassing, are stigmatised or in situations where they feel vulnerable. It is in such cases that observations become very pivotal and serve a very significant role in bridging such a gap. The researcher observed that most of the respondents were from female headed households, and that there was a clear absence of man presence in most families; this was further confirmed through interviews. It was also clear that due to lack of employment most households depended on grants and selling of sweets and vegetables and other informal activities. These did not generate much income for the families but it seemed like the only source of income that one could resort to under their current situation.

In all occasions that the researcher went out to conduct interviews, she made observations a big part of the research. Although she observed all relevant research ethics principles, she did not inform the respondents that they were being observed, as that would have upset the natural setting.

3.5.2 Individual in-depth Interviews

As stated above, individual in-depth interviews were used in conjunction with non-participant observations. Not everything can be understood and deconstructed through non participatory observations. Therefore interviews were used and these involved a conversation with key informants. These informants were identified through a

combination of snowballing and purposive sampling. The interviews were qualitative in nature. Babbie (1998:290) defines a qualitative interview as:

An interaction between an interviewer and a respondent in which the interviewer has a general plan of inquiry but not a specific set of questions that must be asked in particular words or particular order. It is essentially a conversation in which the interviewer establishes a general direction for the conversation and pursues specific topics raised by the respondent

Interviews are an essential part in qualitative research. They can be used as a tool to dig for further clues and directions. As noted by May (2001:120), interviews yield rich insights into people's biographies, experiences, opinions, values, aspirations, attitudes and feelings. The researcher therefore opted for the unstructured interview, so that respondents could speak more freely. Opening up the interview in an unstructured manner makes it possible to gather more information. Even other dimensions of the subject that are not necessarily evident could be revealed.

Although most of the informants in the study were generally busy, they were willing to take part in the study and help with information that could be useful. Through interviews, the researcher was able to crosscheck some of the information gathered through observations.

3.5.3 Focus group discussions

The Focus group discussions were held with 12 selected informants in Bophelong. The group comprised people that cared for children with disabilities. The researcher managed to get hold of these informants through snowballing. It was not easy to get these people to meet since most of them had little time to attend the meeting. The researcher was further assisted by the NGO that deals with people with disabilities in Bophelong: the NGO referred her to families that had children with disabilities. Getting the caregivers to meet was therefore not a very smooth process as some people that with whom one had made an appointment cancelled attendance at the last minute, citing tight schedule as the reason. Some selected respondents could not get helpers to look after the children whilst they attended the meeting, hence they also could not attend.

The focus group discussion explored various issues that caregivers faced, especially the challenges in raising children with disabilities under very difficult conditions where support mechanisms remained very minimal and problematic. The focus group discussion was held in one day and lasted for two hours.

3.5.4 Questionnaires

A total of 19 questionnaires were distributed to caregivers who were looking after children with disabilities. The questionnaires were administered in person by the researcher to the informants who would not have been in a position to independently complete a self-administered survey. The majority of them needed help in completing the questionnaires. The researcher had to translate the questions into Zulu and Xhosa whilst asking questions as some of the informants did not fully comprehend English. A few of the respondents spoke Sotho only and so had to be assisted by a fieldwork assistant that the researcher hired to help in the translation of the questionnaires.

3.6 Sampling

This study utilized both purposive and snowball sampling. This means that the informants interviewed were those with qualities on which the research was focused. Also families with children who had disabilities were able to refer the researcher to the other families with same conditions.

3.6.1 Purposive sampling

Gobo (2008:102) states that, purposive sampling consists in identifying sites with an extreme status of particular attributes, or sites which comprise a range of the status available such that all of the possible status is present. Hence the families that were interviewed were those that had children with disabilities. Adult caregivers were sampled.

3.6.2 Snowball sampling

According to Gobo (2008:104) snowball sampling involves the picking of individuals only, who display the necessary attributes, and then, through their recommendations, finding other individuals with the same characteristics. This type of sample is usually the one best suited to researching highly sensitive topics: socially stigmatised behaviour, for example, or behaviour of which the subjects are ashamed or which is illegal.

Because of the sensitive nature of the researcher topic, the researcher utilised snowballing to gain entry into the communities. Recommendations were made by other families that had children with disabilities; in this way only relevant informants were targeted.

3.7 Language

In Bophelong, the main languages spoken by people are Zulu, Xhosa, Sotho and Tswana. Many people also understand basic English. In the Province of Gauteng, there is a variety of languages that are spoken due to diversity of people that reside in that province. All eleven official languages of South Africa are spoken in different parts of the province. These languages are as follows; 'Afrikaans, English, isiNdebele, IsiXhosa, isiZulu, seSotho seTswana, Tshivenda, Xitsonga and indigenous creoles and pidgins'⁵. The diversity in languages spoken in the province makes it possible for some people to speak many languages. The most common language that is spoken in the province is Zulu: the majority of people understand this language.

Although the questionnaire and interview guide were designed in English, the researcher had to translate the questions into Zulu during the interview process. The informants sought explanations to some of the questions in this language. The researcher, who is proficient in Zulu and Xhosa, did not experience any problems in terms of language. Language proficiency played an important role in this study. Most scholars also agree that the researcher should possess language skills in order to succeed in the field. As observed by McNeill (1985:64), the value of language skills cannot be overestimated, and the only way a researcher can represent one's culture and a way of life is when they understand the language. Most of the respondents spoke Xhosa and Zulu and the researcher was able to relate with them because of her

⁵ For more information on languages spoken in South Africa refer to; <http://www.southafrica.info/about/people/language>.

familiarity with these languages. A few communicated in Sotho, but they could also speak in Zulu.

3.8 Data analysis

The quantitative data (collected using structured questionnaire) were analysed and while qualitative data (from interviews and FGDs) analysis utilised descriptive narrative. As noted by Dey (1996:31), data analysis is a process of resolving data into their constituent components, to reveal their characteristic elements and structure. As pointed all along, data were gathered through both quantitative and qualitative approaches in order to capture various issues affecting caregivers of children with disabilities and the children with disabilities.

The qualitative data that was gathered through in-depth interviews, observations and focus group discussions was first entered onto the fieldwork diary and then analysed thematically. This involved describing various issues which were classified into different themes in order to gain a deeper understanding of issues affecting people with disabilities. During the analysis of qualitative data, it became clearer how different concepts interconnect and influence one another.

3.9 Ethical issues in the research

This research was fully compliant with the ethical procedures that must be followed by social science researchers. Ethical principles require that any research involving human subjects is framed and conducted in a way that respects the human rights of the individuals concerned. This research studied very vulnerable people (care givers of children with disabilities).It observed the vulnerable children too, although they were not the primary focus of the study. At all stages, the researcher showed a respectful and caring attitude towards the participants. In-depth interviews, particularly on sensitive topics, may bring up traumatic memories; hence, appropriate measures were put in place as part of the research design. It was paramount to identify any signs of stress in a research participant so that they could be asked if the interview should stop or be postponed.

To the best of her ability, the researcher conducted the study in a responsible way in the light of both moral and legal order of the South African society⁶. The researcher explained to the participants the purpose of the research and ensured that potential research participants were not only fully informed about the research but also understood its purpose and its implications, their freedom to choose to participate, and their freedom to withdraw from participation at any time. Informed consent forms were signed by all participants, following a detailed explanation about what the form and the signing entailed. While signed consent forms provide evidence that consent has been given, it was also crucial to review consent issues throughout the research process since signed consent forms are not an automatic evidence of fully informed consent. A wide range of ethical considerations was adhered to in this research. Churton (2000) advises that sociologists must ensure that the goal of their research does not impinge on the rights of others, and they that must safeguard the well being of research participants and obtain their informed consent.

It must be emphasised that in relation to issues of informed consent there was no simple solution; indeed, it was a challenging process. At all stages of the research process the researcher was mindful of various issues that could arise and ensured that consent was an ongoing process – even after consent forms had been signed prior to the commencement of interviews. For instance, the participants were reminded of their right to withdraw from the study at any time. Any form of coercion, manipulation or undue influence to participate in research is unethical and potentially harmful; hence, the researcher avoided pressurising participants and managed suggestibility and compliance in research participants.

It was also important to exercise particular care when researching in care settings since the care givers were used in the interviews. The researcher explained to the subjects the research objectives in a manner and language they understood and explained the context, purpose, nature, methods, procedures and sponsors of the research⁷. The

⁶ See <http://www.the-sra.org.uk/documents/pdfs/ethics03.pdf>.

⁷ www.aappolicy.aapublications.org

research was conducted in a competent manner to ensure that participants experienced no psychological or physical harm. It was carried out in full compliance with and awareness of local customs. Therefore, the researcher put considerable effort in trying to familiarise herself with the host culture, and respect and maintain dignity of all individuals involved in the research.

All informants were assured that this was an academic study, whose findings would yield valuable information for future poverty studies and the understanding of vulnerability and social disadvantage in the South African society and beyond. Data confidentiality and respondent anonymity were discussed and assured. In sum, the research was carried out with respect, dignity, autonomy equality and diversity of all those involved – key principles that underpin an ethically sound social scientific study.

CHAPTER FOUR

FINDINGS AND DISCUSSION - DYNAMICS OF ACCESS TO CARE DEPENDENCY GRANTS

4.1 Introduction

The findings of this study are analysed, presented and discussed in this chapter and in the Chapter 5 under two main themes. The theme of this chapter is dynamics of access to care dependency grants, while the next chapter focuses on challenges faced by families of children with disabilities. The theme of the present chapter derives from the first two research questions of this study, which were elucidated in Chapter 1:

- What factors affect access to care dependency grant?
- To what extent does care dependency grant assist children with disabilities in Bophelong Township?

The findings presented and discussed in Chapter 5 relate to the third research question:

- What are the challenges faced by families with children with disabilities.

As stated in Chapter 3, the study triangulated quantitative and qualitative research methods to gather empirical data. The quantitative data collected through a questionnaire survey were processed into descriptive statistical measures to provide snapshots on various issues. The in-depth qualitative interviews provided detailed narratives from selected respondents directly affected by issues of disability.

4.2 Employment status

In most families with children with disabilities, the majority of family members were not employed and depended on the grants provided by the government. Considering the amount of the disability grant which currently stands at R1200, the pressure on this limited income is immense. Most of the informants indicated that the failure to get employment made their lives very difficult. This meant that the caregiver grant support which was meant to improve the lives of people with disabilities was channelled to buy food, pay bills and cover other basic household needs. One informant actually mentioned that it was not intentional that they always diverted grant money for other

uses, but that they were left with no option in face of the current shrinking job market and scarcity of money:

You see, I have spent more than five years out of employment. I have tried looking for a job but I just cannot get one. I need to earn enough to be in a position to hire extra help for my child with disabilities, but that opportunity has not yet come. So this caregiver grant is the only income available to us. It covers other things as well.

Similar sentiments were expressed by the majority of informants who found it difficult to balance job hunting and caring for a child with such needs. The lives led by most of the informants reflected the challenges that they encountered daily. It was self-evident that they struggled to make ends meet and in most cases diverted grant money for other emergencies in the house. As a result, the intended beneficiary actually got little or none of their money and suffered a lot. Most of the respondents actually justified diverting the money to other uses often stating that people in the house could not starve whilst trying to be transparent with the money. It was clear that there was no follow-up on how money was used by beneficiary holders and in most cases, the children could not voice over how this resource was used. Table 1 below shows the employment distribution amongst the caregivers. Only 26.3% of informants were employed and 68.4% were unemployed. Even those that indicated that they were employed earned little income, and were in temporary placements with no benefits.

Table 1: Respondents' Employment Status**Fully employed**

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	5	26.3	26.3	26.3
No	13	68.4	68.4	94.7
Valid wrong response	1	5.3	5.3	100.0
Total	19	100.0	100.0	

There was high level of unemployment amongst families with children with disabilities. Although most people indicated that they were continuously looking for jobs, they simply could not get them for various reasons ranging from lack of education and skills and the prevailing economic system. The employment prospects in South Africa are currently not very promising. The economy has been going through the global economic trauma which has led to serious shedding of jobs. People with little or no education are frequently being axed out of the economy where they find it difficult to re-integrate either in the formal sector or in the informal sector. Most people stated that as they faced these struggles daily, their options were running out.

Although most caregivers had indicated that they were looking for better paying jobs as was the case with other family members, they actually possessed little education and skills to get better jobs. As such, most of the female respondents were actually looking for domestic jobs and other menial placements. Table 2 below illustrates that 15.8% of the informants did not have formal education, and 36.8% had only gone through primary education up to grade seven. Only 5.3% had gone beyond matric, thereby minimising the chances to be employed in well paying occupations.

Table 2: Respondents' educational qualifications

What is your highest qualification?

	Frequency	Percent	Valid Percent	Cumulative Percent
None	3	15.8	15.8	15.8
Grade 1-7	7	36.8	36.8	52.6
Grade 12	6	31.6	31.6	84.2
Valid Post Matric diploma	1	5.3	5.3	89.5
Other	2	10.5	10.5	100.0
Total	19	100.0	100.0	

The less educated often find it very difficult to actively participate and integrate in the economy. Most people that find themselves shielded out of the formal economy normally find solace in the informal and unregulated economy where business is difficult to generate due to a variety of reasons. Most respondents said that it was increasingly difficult to generate enough business start-up income, and that competition was also very high in the informal sector. Some actually said that it was almost impossible to do anything else except caring for their children with disabilities as it was often difficult to get support to raise such children. Another informant indicated that it was extremely demanding to care for a child with disabilities and most people were hesitant to care for such children. As such most households had to make do with very little income which made it very difficult to properly care for these children. One lady actually said that she was not looking for a job because of the severe disability suffered by her child. She indicated that it would not be easy to get domestic help to assist with the child; neither could the family afford to pay for such assistance. As such they had to survive on this small amount of money. In the event that she got a job elsewhere, she was concerned that it would not last as she might be sacked to asking for time off regularly. This was

because had child feel ill frequently. Although they survived on very little income each month, she felt that there was a greater need for her to raise her child. The monthly incomes of respondents were very limited. As reflected in Table 3, the majority survived on less than R1000 a month.

Table 3: Respondents' Monthly Income

What is your monthly salary?

Amount (R)	Frequency	Percent	Valid Percent	Cumulative Percent
0-1000	14	73.7	73.7	73.7
3000-5000	1	5.3	5.3	78.9
5000-10000	4	21.1	21.1	100.0
Total	19	100.0	100.0	

The majority of respondents (73.7%) indicated that they generated an income of below R1000 a month. This shows that it was difficult for households to survive on a monthly basis. Considering that a single family had an average of four to six family members most of whom were not employed made it hard to survive on such a small amount. As can be seen on Table 4 below, most households had many family members that were unemployed.

Table 4: Number of people in the household

How many people are in your household?

Size of Household	Frequency	Percent	Valid Percent	Cumulative Percent
2 people	2	10.5	10.5	10.5
3 people	4	21.1	21.1	31.6
Valid 4-6 people	12	63.2	63.2	94.7
more than 6 people	1	5.3	5.3	100.0
Total	19	100.0	100.0	

Because most households had bigger family members, this increased pressure on basic services such as electricity and water. In the absence of money from elsewhere, the caregiver grant money meant for the children with disabilities ended funding the extended needs of the family.

4.3 Distance to SASSA offices

Most of the informants (94.7%) indicated that the SASSA office where they could apply for grants was too far. This is reflected in Table 5 below. The respondents indicated that it required transportation to get there and that depleted their limited resources since they had to travel several times to get the grant processed. Other relevant offices such as Home Affairs and Social Development were also said to be too far making it difficult for people to apply for relevant grants. Some people in the area were not in a position to afford transport fees for an extended period of time whilst trying to apply for caregiver grants. The poor families were therefore left out of accessing grants. Some children still had no birth certificates and no visits had been made to social workers at Social Development due to lack of funds. In South Africa, official documentation in form of a birth certificate and an identity document is regarded as the first step towards getting

government assistance but some members of the community remained excluded due to their poverty status.

Table 5: Distance to SASSA Offices

How far is SASSA Office from your home?

Reported Distance in Km	Frequency	Percent	Valid Percent	Cumulative Percent
less 1 km	1	5.3	5.3	5.3
Valid more than 10km	18	94.7	94.7	100.0
Total	19	100.0	100.0	

Most respondents indicated that their lives would improve if the government put its offices within the vicinity of the township so that people do not travel long distances to get help and to apply for grants. The distance was seen as a limiting factor as some families struggled to raise small amounts for taxi fare as they had no other sources of income. The little that they raised was normally used for food.

4.4 Access to and dependency on grants

As mentioned above, the majority of interviewees were out of employment and some solely depended on the care dependency grant to survive. The high number of family households out of employment made it particularly difficult for the grant to serve its purpose. As a result, the money in most cases covered other business besides that of the child with disability and families justified this often blaming it on poverty and the unavailability of job opportunities in the area. One of the respondents actually said that:

If it was not for this grant, our life would be very difficult. I fought hard to get this grant. I travelled for many kilometres for several days processing papers for this money. When the assessment was done and we qualified I was very delighted, although it is not enough at least we do not sleep on empty stomachs.

Most of the informants related how they had fought hard and endured the long process of getting the care dependency grant. They eagerly waited for the approval as this was the only source of income. They described how traumatic the situation was before the grant was approved as they did not have any alternative income or employment. Through observation, one realised that the situation in most families seemed to be dire, although they indicated that there had been a slight change with the approval and payout of grants. They however complained at the long assessment period endured before the grant was finally approved. Some actually said that some cases of children with minor disabilities were actually thrown out and disqualified from accessing the grants and the families of such children often struggled. Others complained that the amount that was paid out was now very insignificant considering that everything else kept going up. 'These prices are meant for people with money not us without money, we are struggling to afford the basics and this money is too little now' complained another informant. The payouts, although meant to cushion the disabled from absolute poverty, were being viewed as a sort of salary by some of the respondents. As such others were buying clothing and electrical gargets using this money. There was clearly a lot of pressure on this income making it appear to be very little and insignificant. It kept most households perpetually dependent on it, with stories of lack of employment becoming a common chorus amongst many of the interviewees.

4.5 The burden of women

Most of the interviewees were of the opinion that children with disabilities had generally become a burden to women. This was also reflected in the gender distribution of caregivers, the majority of whom were women. This was mainly because in most families with children with disabilities, there was an absence of a male figure and most women were either single or separated from their partners for various reasons. This meant that the women who already suffer from a lot of discrimination in society also had to carry the burden of children with disabilities, whose life demanded a lot. To make matters worse, most of these women were out of employment yet they still had to care for the other household family members as well. One informant actually said that her

situation was made even more difficult by the nature of disability suffered by her child who could barely do anything on his own without assistance:

I have to carry the child alone from point A to B without assistance. His father left us a long time ago, I don't even know where he is, and neither does he care about us as he is not involved in anything that goes on in this household.

The researcher observed during the fieldwork that there were many cases of children with disabilities being abandoned by their fathers were. Many people indicated that it was rare for women to abandon their disabled children in comparison to men. As is reflected on Table 6 below, the majority of caregivers were women. Women caregivers were 63.2% whilst male caregivers were 36.8%.

Table 6: Gender of Caregiver

What is your gender?

Gender	Frequency	Percent	Valid Percent	Cumulative Percent
Female	12	63.2	63.2	63.2
Valid Male	7	36.8	36.8	100.0
Total	19	100.0	100.0	

Only 21.1% of the caregivers were married. The majority (47.4%) were single whereas 15.8% were separated. The relationships where a child with disability was born into seemed not to last for long. Most respondents cited stress and pressure of such a situation as often responsible for break-ups. However, it was very difficult for a single parent to carry all the responsibilities in caring for the child with disabilities. As reflected in Table 7 below, the marital status of the caregivers was varied.

Table 7: Marital Status

Marital Status	Frequency	Percent	Valid Percent	Cumulative Percent
single	9	47.4	47.4	47.4
married	4	21.1	21.1	68.4
separated	3	15.8	15.8	84.2
Valid living together	2	10.5	10.5	94.7
divorced	1	5.3	5.3	100.0
Total	19	100.0	100.0	

The findings showed that although there was usually only one person responsible for taking care of the child with disability, there was often a conflict in most families when it came to decisions on how to spend the caregiver grant. The control of money was therefore a very sensitive issue.

4.6 Controlling the grant

Although the government often entrusted a particular individual to administer the caregiver grant and see to the needs of the child with disabilities, in most cases, there was a struggle in terms of controlling it. As a result the money ended up getting split to cover the interests of various people. Most people used the money to fulfil their own needs, whilst others wanted to be at par with their peers courtesy of this income. There were often diverse opinions in the family on how the care dependency grant should be used. Sometimes, even the parents often differed in prioritising different interests. Children were not consulted on how the money must be used. In many instances, nothing was saved out of this money. One respondent said that:

This money is too little, I even have to supplement it with what I borrow from my friends and some loan shacks. The problem is that I have to pay them back more with interest and I sometimes use part of this grant money to service the loan.

Because of the struggles in the control of the grant income, the child was the one left to suffer in most cases as the money had to take care of everyone. Others, because of selfishness actually put their own needs above those of their children, whilst in worst cases the money was spent on beer. As such some caregivers could not afford to cover the needs of children, thereby worsening their plight.

4.7 Challenges facing children with disabilities

It was established that children with disabilities face numerous challenges which in turn makes it difficult for the caregivers to give best care to these children. Some of these problems can be rectified yet others are more difficult to address. These problems depended on the nature of disability which in turn often dictated the route the life of the child was to take. For example, access to education depended on the severity of the disability.

4.7.1 Nature of disability

The interviewed caregivers had children that suffered from different forms of disability. The main disability was mental illness and physical deformity caused by Down Syndrome. There were a few children that had autism. Other children had been involved in accidents that left them crippled. Such cases were however very few. Other children suffered from HIV and were orphaned. The nature of the disability suffered by the child was cited as having a bearing on the overall well-being of the child. Respondents indicated that some disabilities were more challenging than the others. For example, most children suffered from mental illnesses, making it very difficult to raise such a child. In most cases the physical and emotional strain was transferred to the caregiver who was barely trained to manage such a condition. The child had to depend on medication which was to be taken at a particular time in a certain format. This meant that the caregiver could not be engaged in other activities such as employment as the child needed twenty four hours care and support. If the medication was not taken in a certain manner: that created serious problems later and the child's condition could even

relapse and become more severe. The failure of caregivers to be able to look for employment made the family income to become very unstable and insufficient and this led to over dependency on the grant.

Other informants complained that the government used a 'one size fits all' in distributing grants although the situation of other children was more severe than others, they still received the same financial support which was eroded as soon as it arrived depending on the condition of the child. At times some families had to get loans in order to get by. This created a cycle of poverty as the family was pushed into poverty from which it became very difficult to escape.

Although not all children suffered from mental illness and other psychiatric conditions which proved to be very common, some had severe body defects and were confined to wheel chairs. Such children could hardly do anything on their own and also needed constant supervision. They needed help with everything on a daily basis. The money paid out in form of caregiver grant could not cover the costs of additional help. In such an instance, the caregiver was locked out of any other form of employment. Other informants cited fatigue as contributing to a lot of stress among caregivers making it difficult to function properly. Because of the absence of psychological support, some caregivers were said to get into depression.

4.7.2 Difficult access to education by children with disabilities

Access to education remains a challenge for children with disabilities. As noted by Trami et al (2011: 1189) 'Children with disabilities are still combating blatant educational exclusion – they account for one third of all out-of-school children' in the world. This observation related to some of the findings reported earlier. Most of the respondents indicated that it was difficult to get the children with disabilities into the appropriate education system due to lack of such facilities in the area. As a result, parents with such children simply kept them at home and they missed out on education. As such, most people with disabilities remain illiterate because of lack of suitable facilities. Some of the appropriate facilities were said to be very far away and the caregivers could not afford to pay for transport costs. Some respondents indicated that they did not know where to get their children enrolled due to the severe type of disability. They indicated that there was

no information dissemination at Bophelong on where to enrol children with disabilities for education.

Some informants complained that the schools in the area also were not sensitive to children with special needs. The schools simply had no facilities to cater for the needs of such children. Besides, in most schools in the area, teachers were not trained to deal with children with disabilities and this often led to their rejection in the formal education system. Some children that did not have severe disabilities and managed to get enrolled through the formal education experienced problems later on. As the child's behaviour at school started to show unusual traits, this was not taken lightly by school authorities who summoned the parent several times for disciplinary hearings. This created problems especially if the caregiver had not initially disclosed the condition of the child. Some caregivers indicated that they were not prepared to take on the enormous pressure that came with trying to integrate their children in the education system and they decided to keep them out: at home.

The discrimination of children with disabilities was also cited as one of the reasons why some caregivers did not want to take on the trouble of sending their children to school. Children suffering from mental illness could not be easily understood by other children. Although medication was prescribed for such a condition that did not immediately translate to normality. Certain characteristics singled out such children who were stigmatised in most cases. A lot of stigma is attached to the condition of mental illness emanating from beliefs that people hold about the origins of such condition. The researcher learnt from respondents that normally when someone suffered from mental illness people related that to the wrong doing of the parents. Some actually feared associating with such as person as a way of avoiding contamination. At school, other children are said to bully children with disabilities that they see as very different from other normal people. A research done by Schneider et al (2011) noted that:

...disruptive behaviours, such as from a severely intellectually disabled adolescent or a mentally ill person, is difficult for others to understand and they shun both the person and his/her family.

As such the isolation that the child with disabilities might experience might actually influence them to drop out of school before going very far with education. The humiliation that is normally suffered by the family of a child with the disability at the hands of community members and society in general leads to many people preferring to hide their child at home and avoid exposing him/her to a judgemental world. In a number of the cases witnessed by this researcher, children with disabilities were of school-going age who were just kept at home without being exposed to any formal education. The illiteracy of the disabled consequently impacted negatively on the lives of children later on in life as they could not look after themselves and became financially dependent for the rest of their lives. As contended by O'Grady et al (2004:261), poor education can limit the extent of employment opportunities, and thereby restrict access to money and housing. Hence the education opportunities available to children with disabilities later determine the life style they would eventually lead.

4.7.3 Health access/medical costs

The health facilities that were not in the immediate vicinity of most households were cited as negatively affecting the wellbeing of the children, some of whom needed constant check up. As a result of the long distance to health facilities, some of these children missed out on vital appointments at the hospital and this in most cases, worsened their condition. The transport costs were identified as very high. For families already living on very little, they had to make a choice and in most cases, they chose not to take the child to the hospital. The lack of appropriate medication at some health centres was also cited as a problem. In most cases, the caregivers had to make several trips to health centres after failing to get appropriate medication. These challenges ended up discouraging most families from seeking vital medical attention.

Caregivers also indicated that some medication that was prescribed to the children followed a strict schedule, meaning it had to be taken at a specific time every day. This necessitated the continuous presence of the caregiver to administer the medication. The challenge was faced in a situation where there was no help from the extended family as this limited the time the caregiver could dedicate to other activities for example being engaged in another job. Most caregivers complained about the centralisation of medicines at health centres, arguing that the government must develop an alternative

system and deliver medication at the homes of children in need for it. Although this approach could introduce more complications, it seemed to be preferred by the already over-burdened caregivers.

4.7.4 Social pressure and exclusion

The socially constructed nature of disability was expatiated in chapter two. It was shown that to have a child with disabilities was to be exposed to pressures from society which in most cases resulted in social exclusion – both for the child and for the caregiver. As noted by Achuthan (2010:221):

Social exclusion occurs as a result of a series of problems which prevent people from being able to participate in activities which would be considered normal in their society.

People with disabilities are constantly put on trial together with their families. This is mainly because disability is not seen as a normal condition. It is conceived as a 'difference' that detaches the person with disability from the mainstream society. It is viewed in a particular judgemental way and as such attracts stigmatisation of the 'different', and various negative labels are then attached on the person to further push them away Reid-Cunningham (2009:105) contends that 'disabled bodies have traditionally been labelled deviant because they stray from the norm and invoke stigma through this deviance' As alluded to by the Goffman (1963)

...labels which have the power to stigmatise are informed by discourses which discriminate against the labelled groups, explaining their inferiority in relation to essential biological characteristics, breeding or the consequences of their actions (Ward 2009:241) .

In many instances, families have to keep responding to societal pressure. One caregiver said that her child was treated badly by neighbours to the extent that they had to move away from the house they rented to another section of the township. People with disabilities are often judged for not being able to operate like a 'normal' human being and always needing assistance. As noted by Reid- Cunningham (2009:100), 'people with disabilities are often labelled "the Other," somehow separate from people who are not considered to have disabilities'. Society in most cases has no patience

towards the needs of those with disabilities. The processes of stigma are illustrated in Figure 3 below.

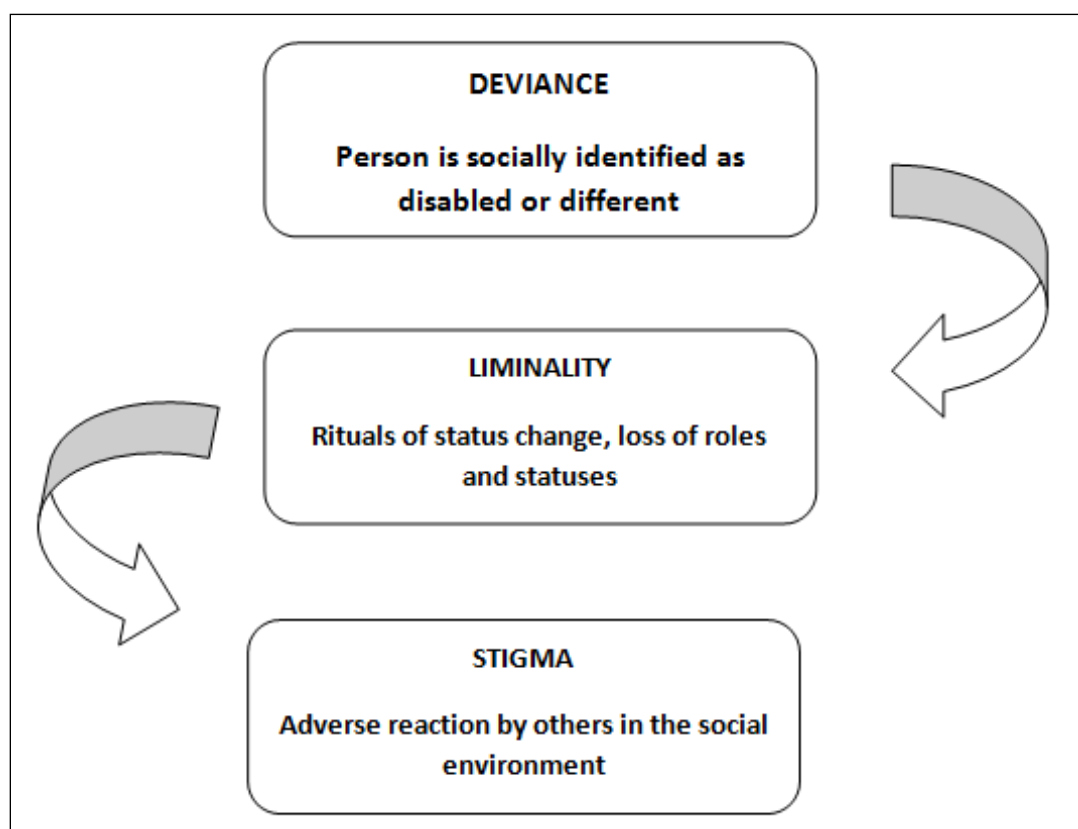


Figure 3: The process of stigmatisation

Source: Reid-Cunningham (2009: 105)

This causes a lot of pressure which is felt by both the child and the caregiver. According to Gray et al (2010: 479) 'stigma not only affects people with mental health problems but also their families and carers'. This pressure and social alienation often leads to stress of having to be constantly on trial for being different. Furthermore the excluded lose out on life chances in education and employment. As noted by Ward (2009:239):

Social exclusion ... involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.

Although people with disabilities experience a lot of discrimination, there are few programmes that have been created at national level to sensitise society about disability. Hence out of ignorance, some people at times act in an insensitive manner that transfers pain to the families with children with disabilities.

4.8 Conclusion

This chapter detailed the dynamics of access to care dependency grants at Bophelong Township. It was highlighted that most households with children with disabilities are unemployed; as a result there is a high dependency on the grant as a source of income supporting the whole family. It was also indicated that although some caregivers wanted to have a job in the formal sector this proved to be difficult because of low education levels and also lack of specialised skills. Furthermore it was indicated that there is often challenges in the control of the caregiver grant with many parties in the household attempting to influence its distribution. It was also noted that due to poverty and social stigma, most households failed to send their children to attain formal education.

CHAPTER FIVE

FINDINGS AND DISCUSSION - CHALLENGES FACED BY FAMILIES WITH CHILDREN WITH DISABILITIES

5.1 Introduction

People with disabilities are confronted with numerous life challenges that are not easily understood by people without disabilities. The biological condition of impairment puts pressure on a number of resources, especially financial resources. As discussed in Chapter Four, most families with children with disabilities are likely to be in poverty. The results of the survey conducted for this study amongst caregivers indicated that most households with disabled members are likely to be on the edge of poverty due to limited employment opportunities. Due to lack of employment and financial back-up for families with children that have disabilities, the caregiver grant has in most cases been converted to be the main source of income, with several family members deriving livelihood from it. This has had a detrimental effect on the well-being of the intended beneficiary. This chapter explores the impact of social assistance on households with children with disabilities. The issues that are discussed range from disability, vulnerability and citizenship, housing and disability, economic inclusion and exclusion, and disability and society.

5.2 Disability, vulnerability and citizenship

People with disability are viewed as vulnerable because of their biological condition of disability. The condition of disability results from birth defects and accidents. It was discussed in Chapter Four that a wide range of disabilities are experienced by children in Bophelong and the most popular form of disability being mental illness. Most caregivers expressed that they encountered a lot of difficulties in raising children with mental illnesses and the pressure emanated from the fact that their entire lives depended on chronic medication that had to be supervised all the time. In this way, the caregivers experienced physical and psychological drain as the energy needed to raise such a child was enormous. Some caregivers actually indicated that caring for their disabled children had become a full-time job leaving little space for them to explore

other careers. This full-time attention was necessitated by the intense vulnerability of their children who needed supervision all the time. One caregiver had this to say:

Ever since my child was born twelve years ago, my life changed tremendously. When I look at my child, I see him as very vulnerable. He suffers from cerebral palsy and can hardly do anything by himself. I find it difficult to even go to the shops and leave him alone. I fear that danger can befall him. If there is no one who can look after him whilst I go to the shops, then I am stuck here the whole day, I wouldn't even go out. I can't even look for a job, it's just not possible.

There were many caregivers who felt that their children were too vulnerable and could actually do little for themselves. Most caregivers feared the possibility of injuries that children suffering from mental illnesses were prone to. As a result they tended to be very protective. However, some interviewees actually said that situations where children with disabilities were neglected by their carers who occupied themselves with other businesses leaving the children alone without care. This was mainly caused by the need for caregivers to get extra income from selling various things. Some sold snacks and fruits from outside their gates while their child was left alone inside the house. They could not take their children along for a variety of reasons. Because the children suffered from a mental condition, it became difficult to have them whilst conducting business activities. It was cited that some caregivers abandoned the children during month-ends after receiving the grant. 'They just go on a spending spree' said one respondent. This ultimately puts the life of the child in danger. However, people still risk out, hoping that nothing bad will befall their children. For some, this develops into a habit. Some informants said that children with disabilities are left in the care of other children, and this is very dangerous as children do not have the capacity to be carers.

When children with disabilities are not offered continuous attention, this becomes a risk and makes them very vulnerable as they could be harmed. This also makes them to be prone to injuries. Sometimes these children endure neglect since they are left alone without adequate food thereby exposing them to malnutrition. The fact that there is hardly any monitoring of the homes of children with disabilities makes it very difficult for their caregivers to be fully accountable for what happens to the child.

Some caregivers indicated that society also had a role to play in the way their child's lives turned out. They generally felt that the treatment of children with disabilities in many communities influences the growth of the child. Most caregivers complained that their children were being discriminated against by both children and adults alike. One caregiver said that once people get to know that your child has a mental problem; they try to shield their children from developing any friendship ties with such a child in fear of 'contamination'. Besides, other parents in the community were accused of failing to teach their own 'normal' children about issues of disability. 'There is a lot of silence around these issues, people are not very comfortable to discuss disability issues, there is no room for such issues' said one caregiver. Some caregivers indicated that their children were often perceived as abnormal by other children and this often led to teasing of the child with disabilities but their parents did little to curb this. This attests to the ignorance that society still has towards issues of disability. Because of such treatment of children with disabilities, most caregivers prefer to keep their children at home, away from the sight of the judgemental society. Although this affects the growth of the child as they fail to socialise, most caregivers would rather suffer the consequences.

The failure of children with disabilities to integrate with the broader community affects their rights as citizens. Often, because the people with disabilities are seen as lacking, insufficient and abnormal, this erases their citizenship status. The stripping of their full citizenship status makes them to be vulnerable and further marginalised thereby limiting their life chances. As noted by Susen (2010: 262) citizenship is 'both a set of practices (cultural, symbolic and economic) and a bundle of rights and duties (civil, political and social) that define an individual's membership in a polity'. When that membership is severed based on various issues such as disability, one loses the status of citizenship and further experiences more discrimination. Faulk (2000) contends that citizenship status implies a sense of inclusion into the wider community. However when that inclusion is taken away, that culminates in vulnerability. It was revealed in this study that there is little value that is placed on people with disabilities as they are often viewed as incapable of doing anything of value to improve their lives. Some actually view them as people without a future. This was confirmed by a number of respondents that indicated

that people always pitied the presence of a child with disability. This seemed to emanate from the general assumption that people with disability can only have a life through medication, without which their lives would amount to nothing. This is one form of stereotyping that has often led to discrimination. Institutional discrimination is rooted in the assumptions of the traditional medical view of disability. This approach suggests that individuals with a disability, whatever the cause, are unable to ensure a reasonable quality of life by their own efforts (National Rehabilitation Board and Forum of People, 1995). As a result, people often see little value in a person with disabilities and what comes into their minds are machines and medicines that are pictured as central to the lives of people with disabilities.

Apart from the general discrimination that children with disabilities are exposed to, other structural pillars such as education also serve to impinge on citizenship rights of the children. It was mentioned in Chapter Four that the education system is ill equipped to handle issues of disability and this has led to most children with disabilities being denied their right to education. And because most children with disabilities fail to enrol in appropriate education institutions, this later affects their economic opportunities. The failure to have appropriate education increases the economic vulnerability of children later on in life leading to a perpetual cycle of grant dependency. Some children with disability that is not severe can be educated and be nurtured into economically productive members of society. But this requires an education system that is well equipped to accommodate those with disabilities.

What then can sustain the citizenship of children with disabilities? The change in public policies can have a positive impact on children with disability. The emphasis should be on the humanness of such children and hence it should be a responsibility of the broader society to facilitate their growth in an appropriate and supportive atmosphere. It is through a policy statement that society could be made aware of issues that affect children with disabilities and their families.

5.3 Economic exclusion, debt accumulation and disability

Most households with children with disabilities seem to be battling the drastic effects of poverty caused by the high rate of unemployment and less opportunities. Poverty and disability seem to be inextricably linked. People with disabilities are poorer, as a group, than the general population, and people living in poverty are more likely than others to be disabled (National Rehabilitation Board and Forum of People with Disabilities, 2005). This study established that the majority of people in households with children with disabilities were unemployed, while financial pressure was increasing. With reduced financial resources, it was becoming increasingly difficult for most families to make ends meet. The financial pressure to cover the needs of the children with disabilities kept increasing, yet the ways to overcome this challenge were not immediately available. The scarcity of financial means pushed most households to the margins where they toiled in poverty. As a result, the caregiver grant often became the main source of income. Hearle & Ruwanpura (2009:427) contend that the grant system was meant to harness various facets of life, with the underlying principle being that of bringing together health care, nutrition, shelter and social services when targeting the basic needs of the vulnerable. Although the grant has been valuable in arresting chronic poverty, most respondents actually indicated that it fell far short of their needs. Samson (2002:1) notes that, 'the severity of South Africa's poverty has persisted in spite of existing social security programmes and many people remain poor in spite of the benefits they receive'. In this study, it was revealed that caregivers highly depended on the caregiver grant to meet their financial obligations. Due to the high dependency on grant money as the main source of income for all family members, the child who was the intended beneficiary was in most cases not the primary focus. As such, the grant was widely distributed to cover many needs within the household.

The study revealed that in most cases, it is not out of choice that families with children with disabilities are unemployed; such opportunities are simply not available. Besides, many employers are not sensitive to families with children with disabilities in that they are subjected to the same treatment as other employees. The needs of such people are however different, and this affects the time available for them to focus on other forms of employment. And this often leads to misunderstanding and clashes at work with

employees being accused of being incompetent. One caregiver revealed to the researcher that she once had an office job that paid reasonably. However, as time went by, it became increasingly difficult to work within this office environment. The challenges she faced at home in terms of caring for her child at times kept her out of the office without properly notifying the management. They eventually gave her the ultimatum to resign as it was clear that she hardly copied. When she eventually gave in and became a full time caregiver, life took another turn and became increasingly difficult. The money was never enough whilst it was also very hard to get time to apply for other jobs. The experience that she had gone through at her last job also made her hesitate to engage in formal employment again. As such, money shortages had become very common in her household of six people that included other children of school going age. The shortage of money and the reliance on caregiver grant meant that the family had to forgo some of the essentials of life. As a cost saving measure, they cut down on their food consumption. They cut their meals to two, which means that they ate only breakfast and supper. They carefully budgeted to cover their basic needs. They also bought groceries and other items that were on sell at various shops. They also got into debt very often.

The researcher learnt from most family members interviewed that they were burdened with debt and it was becoming a problem to get out of it. This was because, each month, the households did not manage to make a surplus to cover for their needs and also to pay off their debts. Most of the informants reported that that they often started borrowing small amounts from family, friends and loan sharks. But as the habit became more pronounced, they borrowed larger sums of money from loan sharks. They indicated that it was very difficult to get a loan from the bank hence they preferred to borrow from unlicensed loan sharks. The deal between them and the loan shark was not balanced and favoured the later. As they borrowed this money, they were asked to leave their identity documents and bank cards. At times they had to leave their movable assets such as TV, radios and refrigerators as collateral. In the event of failing to pay back the loan, these assets were forfeited and sold to recover the money owed. More often than not, most people fail to pay back their loans and in the process lose their valuable assets. Although the assets were in most cases more than double the amount

of the loan taken out, when it became difficult to pay back the loan, the assets were auctioned at much lower rates. This however seemed not to discourage poor families from further getting into debt. They still continued to borrow because they could not afford to meet their financial needs each month. When asked whether they were not scared of losing their hard earned assets, some of the respondents said that they were prepared to face the consequences as they felt that there was no other alternative around this. Debt burden had therefore become part and parcel of many households in Bophelong. The financial pressure was one of the major worries in most households.

Some of the informants reportedly experienced financial pressure when the condition of their children deteriorated. Sometimes they had to rush the child to the doctor and that meant spending more money since they did not have medical aid cover or membership. They said that the medical aid schemes were out of reach for many people that were battling with the basic needs. Some actually referred to medical aid schemes as a luxury, something that was simply out of reach for the poor and a preserve for the rich. Medical aid schemes were too expensive for most families whose monthly income could not qualify them for membership. 'We don't even think of such things, we simply cannot afford' said one lady. The medical option for the poor remained state hospitals which were located far away and overcrowded. Most respondents stated that the government hospitals were not the best since they were faced with a plethora of problems, even though they remained the only option for the poor. People had to wake up very early to go and queue for medical assistance. One had to take the day off from other responsibilities and dedicate it to the numerous queues they had to join until they got to the doctor. From the doctor's consultation room, they still had to go and queue at the dispensary. To make matters worse, sometimes they were informed that the medication had run out and they were then asked to come some other day. This kind of inconvenience meant that they had to spend more money coming back to the hospital. All this pressure sometimes had negative outcomes within various households as it constrained the financial resources, leading to conflicts.

5.4 Family and disability

The presence of a child with disabilities has had varied impacts on different families. Informants were asked how their lives had been impacted by the fact of their having a child with disability. Most respondents indicated that they had been a tremendous change in their lives. The family had to decide on how best to accommodate the child. The major problem as stated before was the inability for most families to provide a suitable environment for the child. This was mainly attributed to poverty. Most families tended to look up to government programmes to assist them with their situation. The major help offered by the government was in form of grants and free hospital service. But this was not enough for most families. The resources offered by the government were said to be way below the demands of the situation that they were facing. The Non-governmental organisations and faith-based organisations were said to have assisted in many different ways, but the major responsibility still remained with the family.

Some of the respondents, especially the female caregivers, related how the birth of their child with disabilities had caused tensions within the family and relatives. One lady mentioned that it was after the birth of her child with disability that her husband changed totally, often refusing to accept the condition of the child. They were a lot of accusations as to what had brought about this disability and the friction often led to physical confrontation. This eventually resulted in the husband moving out and abandoning the family, leaving his wife behind to raise the child alone. There were many of such cases related to me. Although in some families, the extended family had been supportive to some extent, in most families, relatives tended to distance themselves. Some did not want to be associated with families that had children with disabilities in fear of tainting their images and being associated with the families of children with disabilities. This distancing by relatives confirms the fears that society has about issues of disability and abnormality (Scheper-Hughes 1992). Little information is available to explain the condition of disability in order to normalise it and make it more acceptable as a human condition. Disability is still viewed negatively and is associated with some bad spirit befalling those that have done wrong. Such myths have often been reinforced in the African culture where procreation is intimately linked with the spiritual realm (Bourdillon 1990; Van Gennep 1960). The birth of a disabled child is therefore viewed as some

form of punishment. According to Reid-Cunningham (2009:102), prior to the 1970s, disability was considered a “private problem of unfortunate families and their individual members in many parts of the world, however, this trend continues in contemporary South Africa. As such, people with disabilities have been stereotyped as incapable and needing to rely on medical assistance in order to survive. These sentiments have reinforced the discrimination of the disabled which is often justified on ‘incapability’ grounds. People with disabilities and their families often have to bear the brunt of being unfairly judged. At times they are stigmatised. This results in feeling of shame and embarrassment of having such a condition in the family. As noted by Gray (2010:478) ‘stigma not only affects people with mental health problems but also their families and carers’. This feeling of shame makes a person want to hide that which is viewed as abnormal. In situations where a family member suffers from mental illness, most people are not comfortable to admit that they are faced with such a challenge in fear of society’s reaction. Gray (2010:480) contends that mental illness is largely a taboo because it transgresses accepted social norms and can even be negatively associated with feelings of shame and taken as a sign of weakness.

The misunderstandings emanating from little knowledge on issues of disability continue to have a negative output. As such in most families, conflicts have emanated from the presence of a child with disabilities as such families are not counselled or trained to live with a child with a certain condition. Most families are left to figure out on their own how to raise such a child. In their words, it was ‘physically draining’ and ‘emotionally taxing’ to take care of such a child. To some people, this became too much of a burden to carry resulting in numerous conflicts and family breakdowns. Divorce, fights, stress and depressions were identified as resulting from failure to handle the situations that involved having to raise a child with disabilities. Some parents actually felt guilty and blamed themselves for the situation, yet others tended to point fingers at others, blaming them for the situation. This had a negative psychological impact on all family members. From the data, it became clear that disability was still treated as an external condition and is not accommodated in society. There is actually a lot of fear that is associated with the condition and spiritual remedy is seen as the solution to the condition of disability. Most people fear to take responsibility of the situation because of

little knowledge that they possess. In such a scenario, the condition of disability was kept enclosed and invisible, hidden away from the world.

In some families, the presence of a child with disabilities seemed to bring the family together. This is because there was a collective responsibility for the child. Each and every person felt the need to contribute one way or the other in the upkeep of the child. Family members took turns to assist the child either by bathing, feeding, cleaning and washing for the child. Although the researcher did not come across many such scenarios, this unity was observed in a few of the households. The conclusion drawn from this in terms of family and disability was that the condition of disability and its presence in the family alters family structure and function. The family structure remains very important in the life of a person with disability for the family fills the void in the life of such a person. They bridge the gaps in the life of such a person through the assistance that they offer.

5.5 Housing dilemmas

In this study it was revealed that the issue of housing is one of the major challenges facing families with members that are with disabilities. Most caregivers indicated that they did not own the houses that they occupied but that they rented them. Most of these houses were not well maintained and did not have enough space to facilitate a better life for the child. Some households actually rented a few rooms and shared the property with other families because they could not afford rent. This often led to overcrowding as rooms were shared by many people. The pressure of many people on a small house deteriorated the property. Congestion in facilities such as the toilets posed health risks. There was not even a single case in the study where there were facilities within the home that were custom-made to suit the needs of the child with disabilities. This was out of reach for most families whose income base was very low. A child that was crippled used the same facilities as those used by people without disabilities. There were a number of children that were on wheel chairs in houses whose entrances had a step but there was no ramp facility for wheel chairs.

Most houses were of average size and because of many people housed in these houses, there tended to be a lot of noise. This seemed to affect children that had mental

conditions. The researcher learnt that there was little that social workers could do to ameliorate the conditions under which some of these children lived: they could not take away the child to a foster care home simply because of the small size of property that the parents occupied. As long as there were no visible signs of neglect, that was not possible.

The households studied did not have enough space for child learning and playing. The concept of a 'home' was also not fully developed because of poverty. The caregivers could not afford to give the children the space that could fit the description of a home as the money needed to create such a space was not available. Some families rented only two rooms for a family of six people and the tiny space that they got was multipurpose and served many functions. As such, the children were cramped together with adults.

In some households where the child that had disabilities needed a medicalised space, it became very difficult to offer such an environment as it was not possible to dedicate a room to one person. This often led to a lot of stress amongst other family members since the medicalised room had to be shared with other people. Sometimes medication and other equipment ended up getting lost or damaged because of the traffic to the room and limited space that could not cater for the needs of all people. Some informants stated that it was very difficult to manoeuvre around the specialised equipment for the child which at times took a lot of space in the house, further increasing the predicament of the family. Because the living space was not customised to fit the needs of the child, it became very difficult to access a lot of things around the house.

Most caregivers that did not own properties said that they had applied for free government houses but they had not yet been allocated since the housing list was very long. Until such a time when accommodation was made available by the government, they were going to remain lodgers, often moving from one place to another because of high rentals. This was very difficult for the children who were often exposed to new environments with new people. The buying option was out of reach for most families as they did not generate a substantial amount needed to buy a house. As indicated earlier, most families tended to rely on grants for income and this money could hardly

cover their basics. The lack of proper accommodation made most children to be vulnerable. They always had to mix with new tenants/lodgers moving into the property as others moved out.

5.6 Challenges faced by families (with children with disabilities) that have no access to care dependency grant.

Theoretically, the families with children with disabilities should be able to access care dependency grants but in reality this is a problematic terrain. The families silently suffer although the outer impression is that they are benefitting from government support and therefore their lives are normal. This shows that access to government welfare programmes remains precarious. In addition to the stress of the disability itself, financial strain due to medical bills or quality care becomes an additional dilemma especially to those who are not accessing the grant (Albrecht: 1995) This is contrary to the popular belief that the poor and the vulnerable are covered. One caregiver who is not accessing the grant revealed to the researcher that his child has a moderate disability and therefore was not eligible for the grant the caregiver did not have a support system and with no access to the grant life was unbearable. This clearly shows that the care dependency grant is limited in its scope and suffers from unclear eligibility criteria by targeting only children with severe disabilities in permanent home care. It excludes children who may have moderate disabilities but due to their socio economic situation become severe handicaps. (Olivier, 2004). According to Morris Because of the high degree of stigma associated with disability, parents and other family members may be reluctant to report that their child has a disability. Often these children have not even had their birth registered, with the result that they are not known to health, social services or schools. (Morris, 2001). The exclusion experienced by people with disabilities and their families is the result of a range of factors. In most cases families with children with disabilities have to spend their lives carrying a social stigma which consequently discriminates them from access to social welfare. This impacts negatively on the standard of their lives in general and therefore the complexities that stem out of such world view have long lasting consequences. According to Gray et al (2010:479) 'stigma not only affects people with mental health problems but also their families and

carers'. This pressure and social alienation often leads to stress of having to be constantly on trial for being different.

South Africa's constitution section 27 guarantees the right of all citizens to have access to social security, including, if they are unable to support themselves and their dependents. The Constitution is clear in this regard, that all the basic rights of children enshrined in the constitution apply equally to children with disabilities. It is a constitutional mandate to grant social welfare to the most vulnerable and poor in the society. Contrary to the belief that people with disabilities are covered, the realities of life are depicted in Bophelong Township. It serves as testimony that people with disabilities are forgotten in some instances. Their families and caregivers also go through trials and tribulations of prejudice, exclusion and discrimination. The psychological weight placed on family members sometimes translates to plethora of other challenges to the detriment of the disabled. As evidenced in chapter Four, there are many challenges that hinders access, for instance one caregiver was not aware of SASSA. This shows that there is still a long way to go to ensure that access to care dependency grant is not problematic. Most of the informants (94.7%) indicated that the SASSA office where they could apply for grants was too far. The respondents indicated that it required transportation to get there and that depleted their limited resources since they had to travel several times to get the grant processed. The poor families were therefore left out of accessing grants. With the majority of interviewees out of employment the burden is worsened with no access to the grant.

It was also reflected in the gender distribution that the majority were women; most interviews were of the opinion that children with disabilities had generally become a burden to women. This meant that the women who already suffer from a lot of discrimination in the society also had to carry the burden of children with disabilities. The additional dilemma becomes that of lacking enough money to take care of the child with the disability. With no access to care dependency grants most families struggle to get the children with disabilities into the appropriate education system. As a result, parents with such children simply kept them at home and they missed out on education. The illiteracy of people with disabilities consequently impacted negatively on their lives

as they could not look after themselves and become financially dependent for the rest of their lives. With no access to the grant, life becomes extremely unbearable

Although not all children suffered from mental illness and other psychiatric conditions which proved to be very common, some had severe body defects and were confined to wheel chairs. Such children could hardly do anything on their own and also needed constant supervision. They needed help with everything on a daily basis. Without access to care dependency grant it becomes impossible to cover the costs of additional help. Other informants cited fatigue as contributing to a lot of stress among caregivers making it difficult to function properly. With most households with children with disabilities unemployed; there is a high dependency on the grant as a source of income supporting the whole family. As a result, it becomes increasingly difficult for those who are not accessing the grant to cater for the needs of a child with a disability. The child suffers a lot with no access to basic needs due to financial constraints. This clearly shows that access to care dependency grant by families of children with disabilities is problematic. There are serious gaps in terms of access to welfare by those with disabilities in comparison to those with none. As a result it is the families and caregivers that suffers the consequences The families faces challenges daily, it was evident that they struggled to make ends meet.

5.7 Conclusion

The condition of disability within a family alters many things and most people battle a lot of negative experiences emanating from stereotypes created by society. In Bophelong, most children that suffered from mental illness went through a lot of challenges and at times their life became a living nightmare and a daily battle-field. As noted by Gray (2010:483) the impact of mental illness is felt across a broad spectrum of family life: employment; income; education and training; leisure; children; family health; and relationships with extended family, friends and neighbours. It was also noted that the condition of poverty which is very prevalent in most families with children with disabilities affected the well-being of the child and the family as a whole. The high dependence on the grant as a source of income means that the child does not become

the primary focus of the grant assistance as it gets converted into an income that has to cater for other needs as well. The economic battles that most households go through were discussed and this has often led to families falling into debt traps in which the escape becomes almost impossible. As a result, a debt cycle is generated. The pressure resulting from the condition of disability has at times destabilised families often causing conflicts and family disintegration. This is mainly because families in this situation are not counselled, neither are they trained on how to best take care of their child with disabilities. The weight of caring is then transferred to the caregiver. Housing was also identified as a major challenge to most households with children with disabilities. Because most caregivers are renters, it becomes difficult for them to modify their houses to accommodate the special needs of the child. Most households interviewed indicated that the option of buying houses was out of reach for them due to lack of income.

CHAPTER SIX

SUMMARY, RECOMMENDATIONS AND CONCLUSION

6.1 Summary

Taken together, the findings presented and discussed in the previous two chapters reveal that caregivers in Bophelong continue to experience considerable challenges as they negotiate the daily demands of caring for children with disabilities. Although the government has in place a social welfare safety net to cater for the financial needs of people with disabilities, the model has not been very comprehensive as it tends to leave out children leaving with minor disabilities. Most families with children living with disabilities indicated that this exclusion of some of the children needing assistance worsens their situation in the long run. It was also noted that most caregivers are out of employment and depend solely on the care dependency grant. The amount that is dispersed by the government was also seen as too limited and not enough to cover the needs of the children with disabilities. It was also indicated that there is heavy reliance on the care dependency grant by the whole family which sometimes causes problems as to how the money must be spent leading to competing needs and interests on the money that is intended to cater for the needs of the child with disabilities. One of the major challenges facing children with disabilities was also identified as limited infrastructure especially in terms of schooling facilities. Furthermore, lack of awareness on issues of disability was also identified as one of the causes of continuous discrimination and stigmatisation that people with disabilities have to experience.

6.2. Recommendations

On the basis of the findings and the literature reviewed in this study, the following recommendations become important:

- a) Disability awareness must be increased in communities using different platforms in order to arrest the discrimination of people with disabilities.

- b) The people with disabilities must be consulted on the programmes that can improve their lives. This would ensure better targeting and also avoid a top down approach to strategies meant to assist people with disabilities.
- c) People with disabilities should not be treated as merely recipients of government assistance but as active stakeholders in issues that affect their lives.
- d) The people with disabilities must also be seen and treated as full citizens by being afforded their full rights as citizens of the country.
- e) The people with disabilities must not be seen as passive recipients of assistance but programmes that can lead to skills transfer must be designed for them.
- f) Disability friendly infrastructure must be created; this includes schools that are able to cater for various forms of disabilities.
- g) The school curriculum should integrate more broadly the issues of disability. This would also ensure that there is broadened awareness about disability.
- h) The people that are responsible for taking care of children with disabilities must be consulted when designing programmes for the disabled. This would involve broad consultations with them in order to come up with an inclusive approach that would positively influence the lives of people with disabilities.
- i) The financial support offered to people with disabilities by the government must be increased and also varied according to the extent of the disability.
- j) Affirmative action must be applied in education and the job sector in order to facilitate a more upward mobility by people with disabilities.
- k) The social workers should be more active in the lives of children with disabilities and facilitate assistance from different stakeholders for an improved well-being of the children.
- l) There should be sensitivity to conditions of disability in the formulation of programmes to promote equality.

6.3 Conclusion

This study has shown that the children with disabilities and their caregivers face many challenges that emanate from a number of angles. Although the social welfare model in South Africa has gone a long way towards catering for the needs of many of the country's poor and vulnerable, the care dependency grant has not provided some of the critical answers to the challenges that people with disabilities face. The biggest challenge is that the current care dependency grant is insufficient to ensure a better life for children with disabilities. The uniform treatment of more serious and the less serious disabilities have meant that children needing more financial support are equalised with those needing less care. For children with severe disabilities the challenges in their lives continue to mount with no immediate solution on site. The financial resources are in most cases insufficient, mainly because of competing interests on the money. In most families with children with disabilities, it was revealed that poverty is very pronounced because most people are not employed. This makes them depend entirely on any available income.

It was also revealed in this study that children with disabilities are excluded in several ways. Society continues to cast a negative eye on the condition of disability often linking it with the evil or bad spirits that are a result of the family's wrong doing. As such some people actually shun those with disabilities and encourage their children to do the same. Some parents of children that do not have any disabilities actually watch as their children torment those with disabilities. This kind of treatment makes children with disabilities feel as outcasts and not as full members of their communities.

Interview and observational data show that children with disabilities find it difficult to integrate into the mainstream schools in Bophelong. There are no appropriate learning facilities to absorb children with varying degrees of disabilities, and this has made some parents opt to keep their children at home under their care. Such a scenario disadvantages the future chances of such children in terms of employment opportunities and independent living. Some parents even indicated that they did not trust the safety of their children with disabilities within school grounds; hence they opted always to keep

an eye on them. This is because there is limited awareness about issues of disability within the education system, to make matters worse; some teachers are not even trained to handle such children often resulting in the frustration of both the teacher and the child.

The findings no doubt have implications for theory. As stated in Chapter Two, the study aligns more with the social model and the human rights model. The findings discussed in this volume have clearly touched on both models. The Social model explains the discrimination against people with disabilities as emanating from their categorization in the society as the “other”. Society consciously establishes such categories in order to offer an explanation and differentiation between the normal and the abnormal. This conscious discrimination is a way in which society shirks responsibility for providing care for the vulnerable and pushes them to become the state’s responsibility (Barnes 2005: 365). The accounts of caregivers in this study reveal that children with disabilities suffer exclusion in several ways. Society continues to cast a negative eye on the condition of disability, often linking it with “the devil” or “bad spirits” that are as a result of family “iniquities”. As such some people actually shun those with disabilities and encourage their children to do the same. Some caregivers indicated that society also had a role to play in the way their child’s lives turned out. They generally felt that the treatment of children with disabilities in many communities influences the growth of the child. Most caregivers complained that their children were being discriminated against by both children and adults alike. All of this reinforces the social model theory that explains disability as emanating from society itself. The view of people with disabilities as abnormal serves to legitimize the inherent and structural discrimination suffered by people with disabilities. The discrimination in turn kills their confidence and self esteem; therefore it makes it impossible for the caregivers and families of children with disabilities to blend in society.

The social model was used as an analytical tool for the empirical enquiry. It investigated the social construction of disability in everyday discourse. It was also used to analyze different forms of exclusion.

The human rights model, on the other hand, strengthened the argument of this dissertation by advocating that the care dependency grant is not only about a few thousand Rands that the state gives to the lucky few but is a human rights issue as the access to care money improves the well being of the disabled and saves lives in some instances. From the findings of the study it was highlighted that most households with children with disabilities are unemployed; as a result there is high dependency on the grant as a source of income. This shows that the grant comes in handy, which underscores access to it as a human right. Access to the grant improves the well being of children with disabilities and saves lives in some instances. The failure to access such assistance results in social exclusion. (Anderson 1999: 52). In other words the human rights model makes it clear that access to the care dependency grant is, in fact, a human right as reinforced by section 27 of the Constitution. Social Security is meant to arrest the drastic effects of poverty by rescuing the vulnerable from very low standards of living. The failure to access such assistance results in social exclusion, which in turn, can lead to very poor standards of living due to lack of income. (Olivier 2004:74) The human rights model was therefore construed in this study, it was depicted that lack of access results in violation of human rights as this impacts negatively on families with children that have disabilities. The study therefore attempted to relate social exclusion to the consequences that it generates.

It was also revealed that the care of children with disabilities has mainly been done by women and this has basically transferred the burden of care to one gender. Women hardly have time to engage in any other productive things because of lack of time. As mentioned earlier on in chapter four, some women have even given up looking for formal employment in fear of having problems at both work and home. Many superiors at work are likely not to understand constant absenteeism caused by the demands of care, yet even at home, it is very difficult to get a reliable person to take care of the child with special needs especially if the case is severe. This scenario ends up forcing women to remain at home and not generating any money leading to the feminisation of poverty in many such families.

The challenges faced by children with disabilities and their caregivers need to be put back on the agenda with the active involvement of the people affected by this condition. In that way, a way forward to all the challenges can be appraised by the people that are experiencing the everyday challenges of living in an environment where disability is often stigmatised and given limited attention. It is only when people with disabilities are fully acknowledged and embraced as equal citizens that their lives would improve. The social security channels for people with disabilities need to be re-looked and deficiencies in the system improved. Children that are severely disabled must be catered for in that measure and not be treated on the same basis as the less disabled since they need more care and resources in order to improve their lives. It would be very useful to re-examine the dynamics that affect people with disabilities and appraise strategies that would improve their lives.

REFERENCES

- Albrecht, D.G, 1995. Raising a child who has a physical disability. New York: John Wiley and Sons, inc
- Achuthan, K Titheridge, H Mackett,R L. 2010. Mapping Accessibility differences for the whole journey and for socially excluded groups of people. *Journal of Maps*. 6 (1), 220-229
- African National Congress. 1994. The Reconstruction and Development Programme: A Policy Framework. Johannesburg, South Africa: Umanyano Publications.
- Anderson, E. 1999. What Is the Point of Equality? *Ethics* ,109, 287-337.
- Babbie, E. 1998. *The Principles of Social Research*, Eighth Edition, Belmont: Wadsworth Publishing company.
- Babbie, E. And Mouton J. 2001. *The Practice of Social Research*. Belmont, CA; Wadsworth.
- Barchiesi, F.2007. Wage Labor and Social Citizenship in the Making of Post-Apartheid South Africa, *Journal of Asian and African Studies*, 42(1): 39–72, <http://jas.sagepub.com/content/42/1/39> [Accessed 21/11/2012]
- Barnes C and Mercer G. 2005. Disability, work, and welfare : challenging the social exclusion of disabled people, 19(3): 527–545
- Bond, P. 2002. *Unsustainable South Africa: Environment, Development and Social Protest*, University of Natal Press, Pietermaritzburg.
- Bourdillon, M. 1990. *Religion and Society: A Text for Africa*. Harare: Mambo Press.

- Brown, M and Neku R.J. 2005. *International Social Work* 48(3): 301–312
<http://isw.sagepub.com/content/48/3/301>
- Charlton, J I. 2000. *Nothing about us without us: disability, oppression and empowerment*, California, University of California Press.
- Comaroff, J. and Comaroff, J.L. 2001. Millennial capitalism: First thoughts on a second coming, in Comaroff, J. and Comaroff, J.L. (Eds.). *Millennial Capitalism and the Culture of Neoliberalism*, Duke University Press, USA, 1-56.
- Churton, M. 2000. *Theory and Method*, London: Routledge
- Crang M and Cook I. 2007. *Doing Ethnographies*, London: Sage Publications.
- Davis, M.B. 2007. *Doing a Successful Research Project: Using Qualitative or Quantitative Methods*. New York: Palgrave Macmillan.
- Denzin, N and Lincoln, Y. 2000. *Handbook of Qualitative Research* (2nd Edition). California: Sage Publication, Inc.
- Dewes, A and Bray, R. 2007. 'A Rights based approach to Monitoring and the well-being of children in South Africa in Dawes A, Bray R & Van Der Merwe (editors), *Monitoring Child Well-Being: A South Africa Rights Based Approach*, Cape Town, Human Sciences Research Council.
- Emfuleni Municipality IDP 2007/2012, www.emfuleni.gov.za/docs/idp/idp0712.pdf.
[Accessed 22/11/2012].
- Faulks, K. 2000. *Citizenship*. London: Routledge.
- Gillham B, 2000, *Case study Research Methods*, London: Continuum.
- Gillham B, 2000, *The Research Interview*, London, Continuum.

- Gobo G. 2008. *Doing Ethnography*, Los Angeles: Sage.
- Gooding, K and Marriott A. 2007. *Social Assistance and Disability in Developing countries*,
http://www.google.co.za/#hl=en&tbo=d&output=search&client=psy-ab&q=kate+Gooding%2C+access+theory&oq=kate+Gooding%2C+access+theory&gs_l=serp.3...328.39468.2.40452.17.7.0.0.0.0.2531.5766.2-1j1j7-2j0j1.5.0.les%3B..0.0...1c.1.bcSwyB_LzLg&pbx=1&bav=on.2,or.r_gc.r_pw.r_qf.&fp=59682ea96c2c96a9&bpcl=38897761&biw=1024&bih=549 [Accessed 22/11/2012].
- Gray, M. 1998 'Welfare Policy for Reconstruction and Development in South Africa', *International Social Work* 41(1): 23–35.
- Gray B, Robinson, C. Seddon, D and Roberts, A. 2010. Patterns of exclusion of carers for people with mental health problems — the perspectives of professionals. *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community*. 24 (4), 475-492.
- Goffman, E. 1963. *Stigma: Notes on the management of spoiled identity*. New York: Jason Aronson.
- Hammersley, M and Atkinson, P. 1995. *Ethnography: Principles in Practice*, Second Edition. London: Routledge.
- Johannsmeier C. 2007. *The Social and Economic Effects of the Disability Grant*
- Harrison, P. Todes, A. and Watson, V. (2008). *Planning and Transformation: Learning from the Post-Apartheid Experience*, Routledge, London and New York.
- Harvey, D. 2005. *A Brief History of Neoliberalism*, Oxford University Press, Oxford

- Hatton, C., Emerson, E, Robertson, J. and Henderson, D. 1995. The quality and costs of residential services for adults with multiple disabilities: A comparative evaluation. *Research in Developmental Disabilities*, 16(6), 439-460.
- Hearle, C. And Ruwanpura, K N. 2009. Contentious Care: Foster Care Grants and the Caregiver–Orphan Relationship in KwaZulu-Natal Province, South Africa. *Oxford Development Studies*. 37:4, 423-437
- Herring, J. 2005. Farewell Welfare?, *Journal of Social Welfare and Family Law*, 27(20), 159-171
- Johannsmeier, C. 2007. The Social and Economic Effects of the Disability Grant for People with Disabilities and their Households – A Qualitative Study in KwaZulu Natal Province, Research Report No. 74, Durban, University of Kwazulu-Natal.
- Krueger, R A & Casey A M. 2000. *Focus Groups: A Practical Guide for Applied Research*, 3rd Edition, California: Sage.
- Krueger, R A. 1998. *Analysing & Reporting Focus Group Results*, London, Sage Publications.
- LAWSA. 2002. *Labor Law and Social Security*. Durban: Butterworths:
- Lester, A. Nel, E. and Binns, T. 2000. *South Africa. Past, Present and Future*, Pearson Educated Limited, Harlow.
- Ley, D. 1988. 'Interpretive Social Research in the inner city'. In Eyles, J. (eds) *Research*

in Human Geography, Oxford: Blackwell.

Maharaj, B. 2005. Geography, human rights and development: Reflections from South Africa, (editorial), *Geoforum*, 36, 133-135.

Mail and Guardian. 2009.June 18. Social grants in South Africa.

Massey, D. 2005. *For Space*, Sage Publications Ltd, London

Mackelprang, R W. 2010. Disability Controversies: Past, Present, and Future, *Journal of Social Work in Disability & Rehabilitation*, 9:87–98

Morris, J. 2001. Social exclusion and young disabled people with high levels of support needs, *Critical Social Policy*, 21(2): 161–183
<http://csp.sagepub.com/content/21/2/161.refs.html> [Accessed 12/11/2012]

McKinnon, R. 2004. "Promoting Social Security Worldwide: The Role of the ISSA", *International Social Security Review*, 57 (3), 3-21.

Mc Neill, P. 1985. *Research Methods*. London: Routledge.

Miles, M (2003) International strategies for disability-related work in developing countries: historical and critical reflections. *Zeitschrift Behinderung und Dritte Welt* 14 (3) 96-106.
www.uni-kassel.de/fb4/zeitschriften/beh3w/ausgaben/2003/ZBDW3-2003

Morris, J. 2001. Social exclusion and young people with disabilities with high levels of support needs, *Critical Social Policy* , 21(2): 161-183 (Accessed on 2nd October 2012 from <http://csp.sagepub.com/content/21/2/161>

National Rehabilitation Board and Forum of People with Disabilities Poverty Briefing
no. 4 Disability, Exclusion and Poverty, 1995. Combat Poverty Agency: Dublin

O'grady , A., Pleasence, P., Balmer, N.J., Buck, A., & H. Genn.2004.

Disability, Social exclusion and the Consequential Experience of Justiciable
Problems. *Disability & Society*.19:3, 259-272

Olivier M.P. 2004. Introduction to Social Security. Lexis, Nexis Butterworths.

Patel, L. 2008. Getting it Right and Wrong: An Overview of a Decade of

Post-Apartheid Social Welfare, *Practice: Social Work in Action*, 20:(2) , 71-81

Patton, MQ. 2002. Qualitative evaluation and research methods, Thousand Oaks,
California

Reid-Cunningham, J. Allison, R. 2009. Anthropological Theories of Disability, *Journal of
Human Behavior in the Social Environment*, 19, 99–111

Samson, M , Babson, O , Haarmann, C. Haarmann, D, Khathi, G. Mac Quene K. Van
Niekerk, I. 2002. Research Review on Social Security Reform and the Basic Income
Grant for South Africa. International Labour Organisation (ILO) : Economic Policy
Research Institute (EPRI)

SAPA,[http://www.news24.com/SouthAfrica/News/Disabled-living-in-poverty-study-
20100514](http://www.news24.com/SouthAfrica/News/Disabled-living-in-poverty-study-20100514) [Accessed 20 June 2012]

Saith, R. 2001. Social Exclusion: the Concept and Application to Developing Countries,
Working Paper Number 72, 1-17

Schwandt, T. A. 2001. Qualitative Inquiry: A Dictionary of Terms, 2nd edition. Thousand

Oaks, CA: Sage.

Schneider, M., Waliuya ,W., Barrett S., Musanje J.,

Swartz, L. 2011. 'Because I am disabled I should get a grant': Including disability in social protection programmes. International Conference. "Social Protection for Social Justice". Institute of Development Studies.

Scheper-Hughes, N. 1992. Death without weeping: The violence of Everyday life in Brazil. Berkeley: University of California Press.

Slabbert T.J.C. 2004. Emfuleni Population and Labour Force,

upetd.up.ac.za/thesis/available/etd-08192004.../04chapter4.pdf

Streak .J. 2002 Child Poverty Monitor, IDASA

South African Constitution of 1996

South Africa Government Services, Care dependency Grant,

http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/caredependencygrant/en_ZA

Susen, S . 2010. The transformation of citizenship in complex societies. Journal of Classical Sociology. 10, 259-285.

Thomas ,P Gradwell ,L. Markham, N, 1997, Defining Impairment within

the Social Model of Disability, <http://www.leeds.ac.uk/disability-studies/archiveuk/thomas%20pam/Defining%20Impairment%20within%20the%20Social%20Model%20of%20Disability.pdf> [Accessed 21/11/2012]

Trani, J F, Kett, M, Bakhshi, P and Bailey, N .2011. Disability,

vulnerability and citizenship: to what extent is education a protective mechanism for children with disabilities in countries affected by conflict?, *International Journal of Inclusive Education*. 15 (10), 1187-1203

Yin, RK. 2003. *Case Study Research: Design and methods*, Third Edition, London, Sage Publications.

Van Gennep, A. 1960. *Rites of Passage*. Chicago: University of Chicago Press.

Ward, N. 2009. Social Exclusion, Social Identity and Social Work: Analysing Social Exclusion from a Material Discursive Perspective. *Social Work Education. The International Journal*. 28:3, 237-252

Williams J.J. 2000. South Africa. Urban transformation, *Cities*, 17 (1-3), 167-183.

Appendices

Appendix 1: Caregiver Questionnaire

Care Dependency grants in a South African township: an assessment of access, challenges, and contradictions in Bophelong, Gauteng.

		Questionnaire Number							
Date _____									
Home Language_____									
Address_____									
Age									
Under 18	18-25	26-30	31-35	36-40	41-45	46-50	51-60	61 and Above	Enter code
1	2	3	4	5	6	7	8	9	
Gender									Enter code
1. Female 2. Male									
Race									Enter code
1. Black 2. Coloured 3. White 4. Indian 5. Other									
Marital Status									Enter code
1. Single 2. Married 3. Separated 4. Living together									

5.Divorced	
Background Information	Enter code
<p>a. What is your status in the household?</p> <ol style="list-style-type: none"> 1.Head of household 2.Wife or partner of head of household 3. Family member (sister, brother) 4.Relative to head of household 5. Other 	
<p>b. How many people are currently living in the household including yourself?</p> <ol style="list-style-type: none"> 1. 2 people 2. 2-3 people 3.4-6 people 3. More than 6 people 	
<p>c. What is the highest level of education you have completed?</p> <ol style="list-style-type: none"> 1. No formal Education 2. Grade 1-7 3. Grade 12 4. Post Matric certificate 5. Post Matric Diploma 6. Technikon Degree 7. University Degree 9. Other 	
<p>d. Are you full time employed?</p> <ol style="list-style-type: none"> 1. Yes 2. No 	
<p>e. What is your source of income?</p> <ol style="list-style-type: none"> 1. part time work 2. Full time work 3. Grants 4. Donations 5. Other 	
<p>f. How many people in the household are employed?</p> <ol style="list-style-type: none"> 1. 1 person 2. 2 people 3. 3 people 4. More than 4 people 	
<p>g. What is your monthly salary?</p> <ol style="list-style-type: none"> 1.0-1000 2.1000-3000 3. 3000-5000 4.5000-10000 5. More than R10000 	

<p>h. What is your personal annual salary?</p> <ol style="list-style-type: none"> 1. R500-1000 2. R1000-5000 3. R 5000-10000 4. R1000-30000 5. R30000-50000 6. R50000-100000 7. More than R100000 	
<p>i. How many people are attending school in this household?</p> <ol style="list-style-type: none"> 1. none 2. 2-3 3. 4-6 	
<p>j. How many children in this household are have a disability?</p> <ol style="list-style-type: none"> 1. 1 Child 2. 2 Children 3. 3 Children 4. Above 3 children 	
<p>k. How old are children that have a disability?</p> <ol style="list-style-type: none"> 1. 0-1 year 2. 2-4 years 3. 5-7 years 4. 8-10 years 5. 11-16 years 6. Above 16 years 	
<p>l. What is the gender of children with disability?</p> <ol style="list-style-type: none"> 1. Female 2. Male 	
<p>m. Do children with disability have birth certificates?</p> <ol style="list-style-type: none"> 1. Yes 2. No 	
<p>n. If no what is the reason for not having a birth certificate?</p> <ol style="list-style-type: none"> 1. Denied by Home Affairs 2. Parents of child missing 3. Home Affairs far away 4. Not sure 5. Other 	
<p>o. Have you had difficulties in registering the child with disability at home affairs?</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. I have not tried 	

<p>p. How are you related to the child with disability?</p> <ol style="list-style-type: none"> 1. Mother 2. Father 3. Sister/Brother 4. Grand Parent 5. Relative 6. Adopted 7. Other 	
<p>q. How long have you stayed with the child with a disability?</p> <ol style="list-style-type: none"> 1.0-1year 2. 2-4 years 3. 5-10 years 4. 11-16 years 	
<p>r. Do you have knowledge about Department of Social Development?</p> <ol style="list-style-type: none"> 1.Yes 2.No 	
<p>s. Have you been assisted by Social workers from Social Development?</p> <ol style="list-style-type: none"> 1. Yes 2.No 	
<p>t. Do you have knowledge about SASSA (South Africa Social Security Agency)?</p> <ol style="list-style-type: none"> 1. Yes 2. No 	
<p>u. Do you know about the grant you are entitled to as a caregiver of a child with disability?</p> <ol style="list-style-type: none"> 1. Yes 2. No 	
<p>v. Have you applied for a caregiver grant before?</p> <ol style="list-style-type: none"> 1. Yes 2. No 	
<p>w. Was your application for a grant successful?</p> <ol style="list-style-type: none"> 1. Yes 2. No 	
<p>x. If not, why was it rejected?</p> <ol style="list-style-type: none"> 1. Missing documents 2. Don't Know 3. Other reasons 	
<p>y. How far are the SASSA offices from your home?</p> <ol style="list-style-type: none"> 1. Less than 1 kilometre 2. 2-3 kilometres 3. 5-10 kilometres 4. more than 10 kilometres 	
<p>z. Have you sought hospital assistance for your child?</p>	

1. Yes 2.No	
----------------	--

Appendix 2: Caregiver Interview guideline

Qualitative Questions

1. How has lack of care grant impacted on the family?
2. Do you have community social workers?
3. How do people in your community view people with disability?
4. What challenges do families with children with disabilities face?
5. How is the government assisting families with children with disabilities?
6. In what ways has the Non-governmental and Faith based organisations assisted people with disabilities in your community?
7. Do people in your community have knowledge about care grants?
8. What can be done to improve the lives of children with disabilities?

Appendix 3: Stakeholder Interview guideline

In-depth interview guide sassa/social development

An assessment of access to care dependency grants in a South African Township: The case of Bophelong, Gauteng.

Date of Interview.....

Name of Interviewee.....

Place of Interview:.....

QUESTIONS
1. Briefly explain what work your office does?
2. Do you have social workers in Bophelong township? And what is their role?
3. What is the level of community knowledge about Care dependency grants?
4. What awareness campaigns about services do you offer?
5. How many people in Bophelong are receiving care dependency grants?
6. How often do you engage with the community on issues of social grants?
7. Do most applicants regard the payments as adequate?
8. What is the gender of most children applying for Care Dependency grant and what do you attribute this to?
9. What is the gender of most caregivers that apply for care dependency grants
10. What is the average number of people that apply for Care Dependency grants annually?
11. How many applications for Care Dependency grants are rejected each month?
12. What is the major reason for rejecting applications?
13. Do you accept re-applications?
14. In what way is the care dependency grant helpful to families?
15. Are people applying for Care Dependency Grants employed in most cases?
16. What is the general economic situation of the applicants?

17. How far is your office from Bophelong Township?
18. What kind of impairment are most children of the applicants living with?
19. What are the causes of most of the impairments?
20. What challenges do you encounter when working with Bophelong community?
21. How could the challenges be overcome?
22. Is there anything else that you wish to add?

Appendix 4: Letter of Introduction

113 Parkwood Flats
Vemeer street
Cw1 Vanderbiltpark

12 November 2012

To whom it may concern

Letter of self introduction

My name is Patricia Dimhairo. I am a Master of Social science student at the University of Fort Hare, South Africa.

I am currently doing fieldwork for my dissertation on Care Dependency Grants. I will be spending time in the Bophelong Township in Gauteng to gather the data. This will data collection exercise might take a few months.

If for any reason, there is need for clarity of my activities in this community, this letter must serve as an explanation that I am a researcher for purely academic reasons and I have no intention whatsoever to be associated with any activity not linked to this research. I am guided by the ethical guidelines in data collection and will not be associated with any activity that might cause public disorder.

Thank you.

Patricia Dimhairo

Appendix 5: DATA COLLECTION, REQUEST FOR ASSISTANCE FORM



05 December 2013

To Whom It May Concern

Dear Sir / Madam

DATA COLLECTION – REQUEST FOR ASSISTANCE

This letter serves to confirm that..... Is a registered Masters student in the Department of Sociology and Industrial Sociology for Masters of Social Science in Rural Development at the University of Fort Hare, East London campus.

She is currently collecting empirical data to enable her complete a research project, which is a major requirement for the degree.

We would greatly appreciate whatever assistance you can offer to enable her to successfully fulfil this important aspect of the degree requirements.

Please be assured that the data collected are strictly meant for academic purposes.

Many thanks.

Yours sincerely

DR. PHILANI MOYO

Head of Department