THE IMPACT OF NEGATIVE INFLUENCES FACING CHILDREN WITH PHYSICAL DISABILITIES IN RURAL AREAS

by

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DECLARATION

I declare that **THE IMPACT OF NEGATIVE INFLUENCES FACING CHILDREN WITH PHYSICAL DISABILITIES IN RURAL AREAS** is my own work and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

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Brenda M Ben-David

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Date: 2011

ABSTRACT

The purpose of this study was to investigate the impact of negative influences facing children with physical disabilities living in rural areas.

Children with physical disabilities living in rural areas of South Africa have to deal with many negative influences in addition to their disability. The main theme is that all children in rural areas face negative influences, but these are far worse for the children with physical disabilities. Societal and educational exclusion and poverty continue to place these children at a disadvantage despite South Africa's policies that promote inclusion and equality. These rights are central to a meaningful democracy yet; research indicates that children with physical disabilities remain in a hopeless situation in the rural areas. To escape their plight inclusive education is pivotal. It is argued that the government's capacity to deal with all the negative influences is limited and this therefore necessitates community involvement.

Bronfenbrenner's Bio-ecological approach was used both to investigate the impact of the negative influences facing children with physical disabilities as well as providing a framework that tackles the barriers that prevent this marginalised group of children having an equal opportunity to education.

A qualitative and ethnographic study was undertaken to investigate these issues. This entailed the researcher living in four rural areas in KwaZulu-Natal, and collecting data through community participation, observations, questionnaires and interviews as well as photographs and drawings collected from the children. Data was analysed and poverty and exclusion clearly impacted not only on the children with physical disabilities, but their parents/caregivers.

It became clear to the researcher that unless this group of children received early intervention to prepare them for education they would not be able to be included in formal education from Grade 1 but would need to begin their schooling in a specialised and exclusive environment.

A framework for intervention based on Bronfenbrenner's model was formulated that involved community involvement on the micro and mesosystemic levels. This framework is unique in that it will provide intensive early intervention for children with physical disabilities with the explicit aim of preparing them for inclusion and at the same time giving their parents/caregivers an opportunity to escape their plight of poverty.

Every child in South Africa according to our Constitution and other policies is guaranteed equality. This equality needs to be provided to children with physical disabilities before they attend formal schooling and end up floundering never having had the opportunity to lift themselves out of the cycle of poverty that they face. Contemporary models for understanding these negative impacts and exclusion suggest that an important outcome of rehabilitation services is to optimise children with physical disabilities participation in the home, school and community life. Bronfenbrenner's Model is based on the premise that disability involves an interaction between features of the child and features of the environment that can be adapted to promote educational inclusion and thus reduce the cycle of poverty.

Key Terms

Children with physical disabilities, inclusion, negative influences, poverty, Bronfenbrenner's Bio-ecological Model.

DEDICATION

Dedicated to my late dad 'Butchie Boy', who taught me the meaning of compassion, for both people and animals, and my mom, Hannah, for her unconditional support and love

ACRONYMS

AAC   Augmentative and alternative communication

ACESS The Alliance for Children's Entitlement to Social Security

AIDS   Acquired immunodeficiency syndrome

ANC   African National Congress

ASAP   African Solutions for African People

BEE   Black economic empowerment

CBR   Community-based rehabilitation

CP   Cerebral palsy

CRC   Convention of the Rights of the Child (UN)

CRIN   Child Research Information Network

CWDs   Child with disabilities

CWPDs Children with physical disabilities

CYAD   Youth Affairs Organisation

DART   Disability Action Research Team

DICAG Disabled Children's Action Group

DKR   Disability knowledge and research

DPI   Disabled People International

DPSA   Disabled People South Africa

DTT   Disability Task Team

ECD   Early childhood development

EFA   Education for all

GDE   Gauteng Department of Education

HIV   Human immunodeficiency virus

IDASA Institute for Democracy in South Africa

INDS   Integrated National Disability Strategy

MDAA   Multi Disability Advocacy Association

NCESS   National Committee on Education Support Services

NCSNET National Commission on Special Needs in Education and Training.

NDPCP   National Division for Persons with Cerebral Palsy

NGO   Non-governmental organisation

NPA   National Plan of Action

OBE   Outcomes-based education

OECD   Organization for Economic Cooperation and Development

OXFAM Oxford Famine Relief

PCS   Picture Communication Symbols

PEPFAR   President's Emergency Plan for Aids Relief

PDO   People's with Disabilities Organisation

PPCT   Person–Process–Context–Time

RAPCAN Resources aimed at the Prevention of Child Abuse and Neglect

RDP   Reconstruction and Development Programme

SCS   Save the Children Sweden

UN   United Nations

UNESCO   United Nations Education, Scientific and Cultural Organisation

UNGEI   United Nations Girls Education Initiative

UNICEF   United Nations Children's Fund

WHO   World Health Organization

UNGASS   United Nations General Assembly Special Assembly on HIV/AIDS

DECLARATION

I duly declare that this -dissertation for the Doctors Degree of Inclusive Education at the UNIVERSITY OF SOUTH AFRICA has not been previously tendered by me for a degree at this institution or any other University. I further declare that this dissertation is my own work in design, structure and execution and that all materials and sources contained herein have been acknowledged.

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CHAPTER 1

CONCEPTUALISATION AND ORIENTATION TO THE STUDY

1.1   INTRODUCTION

Children with physical disabilities (CWPDs) have to deal with many negative influences in their lives in addition to their disability (Carson, 2009:8). Urie Bronfenbrenner advocates that "[n]o society can sustain itself unless its members have learnt the sensitivities, motivations and skills involved in assisting and caring for other human beings" (Bronfenbrenner, 1979:abstract). This assumption undergirds the choice of topic for the research reported on in this thesis; research into the impact of the negative influences facing CWPDs in rural areas. The main argument explored in this study is that these negative influences impact far more on the child living with a physical disability than typically developing children living in the same areas.

In the Human Development Report released by the United Nations as recently as 2010, South Africa's ranking had dropped. In the report's human development index that ranks the countries of the world according to national income, life expectancy and literacy, South Africa ranked 110 out of 169 countries, down six levels from its 2005 ranking (Whiting, 2011:1). In light of this, the urgency of this research study is clear: we need to improve our country's ranking on the human development index as soon as possible, as this will have the potential to reduce the impact of negative influences, especially for CWPDs. By including CWPDs in education they will have the opportunity to gain meaningful employment, improve their quality of life and add to the workforce. The real linchpin for human development is education for *all*. Education is the common denominator in bringing together all components of a country's development: national income, life expectancy and literacy. The education and inclusion of CWPDs leads to healthy societies and empowered citizens. Educated people show improved health and quality to life, and this should include CWPDs.

In all countries of the world, the daily reality of life for CWPDs and their families is frequently one of discrimination and exclusion. The discrimination they endure can be direct, indirect or a combination of the two. Direct discrimination takes place when a child with a disability is deliberately treated differently to a child without a disability. Indirect discrimination occurs when practices or policies that do not immediately appear to

discriminate against CWPDs actually have a discriminatory impact in practice, resulting in the denial of certain human rights (UNICEF, 2007:14).

As in other countries, the debate on both an inclusive society and, in particular, inclusive education in South Africa is inextricably linked to the process of democratisation and social restructuring. The establishment of an inclusive education system has profound implications for the provision and delivery of learning support in mainstream classrooms. One of the challenges lies in the input of mainstream personnel to accommodate the new system. This challenge explicably implies a paradigm shift away from the traditional narrow focus on specific categories of disability towards a human rights model advocating an alternative view of support for learners who experience barriers to learning (Dreyer, 2008:1). In the South African context, particularly in the rural areas, this paradigm shift is further complicated by multiple problems in the rural areas such as poverty, geographical isolation, negative attitudes, the lack of qualified staff and overcrowded classes. Primary education is mandatory in South Africa and, according to the South African Constitution; the country has an obligation to make education available and accessible for all.

Historically, the vast majority of people with disabilities in South Africa have been excluded from education, housing, transport, employment, information and community life. These injustices were reinforced by the inequalities of the apartheid system and, in the rural areas in particular, laws supported the cumulative disadvantages and social isolation of CWPDs. The ushering in of our new democracy in 1994 was billed as a miracle, and for the South Africans it brought with it hope, pride and expectations.

The democratic Constitution of South Africa (RSA, 1996) enshrines the principles of equality and inclusion for all children and gives all South African CWPDs equal access to all of their rights and responsibilities, thus promising all our children a better future (McClain, 2002:6). Today, the country has some of the most comprehensive legislation and policies in the world for promoting the rights of CWPDs. In our emerging democracy, South Africans needed to rethink the nature and experience of disability in our country. For this reason, social policies such as the Integrated National Disability Strategy, The Institute for Public Policy Research May 2010 and The White paper No.6 have been formulated that create a fair and equitable society. Accordingly, policies providing for equal social inclusion in South Africa are contained in the Bill of Rights, which forms part of the Constitution (1996). The Bill of Rights specifically prohibits direct and indirect discrimination, by the state or an individual,

against anyone on the basis of disability. Furthermore, the Alliance for Children's Entitlement to Social Security (ACESS, 2006), and the Convention on the Rights of the Child, which was the first legally binding international instrument to incorporate the full range of human rights, state that parties to the Convention are obliged to develop and undertake all actions and policies that are in the best interests of CWPDs, thus fulfilling their promises of equality.

These equality laws extend to educational inclusion, which is in keeping with the Millennium Development Goals (MDGs), in particular Target 3, which aims to ensure that by 2015, *all* children, *everywhere,* boys and girls alike, will be able to complete a full course of primary schooling. As a stakeholder, South Africa is committed to the MDGs. In light of this, key education policy documents such as the *White Paper on Education and Training* (Department of Education, 2005), *The Organisation, Governance and Funding of Schools* (Education White Paper 2) (Department of Education, 1996), the *Integrated National Disability Strategy White Paper* (Office of the Deputy President, 1996) and the South African Schools Act 84 of 1996, as well as the *Guidelines for Full-service/Inclusive Schools 2010* (Department of Basic Education, 2010) stress the principle of education as a basic human right (Muthukrishna, 2002:1).

Inclusive education, as an educational service offered to children with special needs, is an international phenomenon which is a permanent component of national policy. As mentioned above, this is in keeping with South Africa's commitment to the MDGs, in particular Goal 2, that is, to achieve universal primary school education. In fact, it is this goal that can act as a catalyst for all the other goals, as education increases income levels, empowers women and improves access to health care. Every vulnerable child needs a basic education to escape poverty, improve their health and change their lives (Whiting, 2010:2).

However, in South Africa today, despite our democratic Constitution and despite the fact that much has been achieved in making human rights central to our democracy and supporting the challenge and adoption of policy, policy implementation remains a challenge (Dube, 2005:3). In spite of the enthusiasm for making human rights central to our democracy through the implementation of a raft of policies, negative influences continue to hamper CWPDs in rural areas. The criticisms that can be levelled against these policies include the fact that legislation fails to protect the rights of children with disabilities and barriers still exist that prevent

children with disabilities from accessing equal opportunities, thus policies and practice do not meet.

Moreover, many aspects of the discriminatory legislation that existed pre-1994 still remain (Guthrie, 2001:9, Matsebe, 2006:1; Dube, 2005:3; McClain, 2002:22). As a result, a large section of the framework for inclusion in South Africa still fails to meet the international standards and principles with regard to the rights of children with disabilities (Integrated National Disability Strategy, 1997; McClain, 2002:18; Dube, 2005:4). The Americans with Disabilities Act (ADA) in the United States of America guarantees equal opportunities for individuals not only in terms of employment, but also for public accommodation, transportation, state and local government services, and telecommunications. In addition, punitive measures are available for every sector where there are violations and non-compliance with the ADA. This does not exist in South Africa.

Furthermore, in South Africa some of the new laws and amendments, such as the Building Standards Act 103 of 1997 indirectly lead to discrimination as the laws are inadequately defined to meet the specific requirements and ensure right of access to CWPDs (McClain, 2002:39). Moreover, there is no separate disability legislation in South Africa such as the ADA, which still remains the most comprehensive federal civil-rights statute protecting the rights of people with disabilities (Feldbaum, Lee & Michaud, 2010:1; Dube, 2005:2). The lack of separate disability legislation such as the ADA is deplorable, as despite all our legislation and policies the situation of CWPDs in rural areas remains unsatisfactory. In *The Development of Education: National Report of South Africa, 2008* it is reiterated that education policies are aimed at bringing various vulnerable groups that are in danger of marginalisation and stigmatisation into the mainstream. This includes those living in rural areas.

Despite the strong and explicit constitutional and legislative commitment, however, problems of both societal and educational exclusion have not yet been fully overcome. This is because social forces other than the law play a powerful role in influencing patterns of social behaviour and opportunity. The most significant of these are the inherited patterns of poverty, racism, sexism and negative attitudes to disability in South African society. These patterns are deeply entrenched and often more resistant to change than initially expected. Nonetheless, the South African government, including the Department of Education (DoE), is determined

to persevere in its efforts to build a just and inclusive society and ensure a fair and equal education for all.

Apartheid laws have been scrapped and, as discussed above, a raft of progressive, developmental legislation has been introduced. Many of the pre-1994 apartheid barriers have been broken down, but many barriers such as physical barriers, lack of opportunities for inclusion at many schools and negative attitudes remain, particularly for CWPDs living in the rural areas of South Africa. It is clear that the breaking down of many of these barriers requires more than just legislation; it requires attitudinal shifts. Current research indicates that at least 5% of the South African population consists of people with disabilities – this equates to two million people (Matsebe, 2006:1). In addition, the negative influences facing CWPDs have at least a 1, 7 times greater effect than on their non-disabled peers; this is also an international phenomenon (United Nations Children's Fund, 2005:5). Children who live with disabilities are among the most stigmatised and marginalised of all the world's children (UNICEF, 2005:4) and, thus, it can be said that despite our policies, inclusive acceptance into all communities has not yet been successful owing to the exclusionary practices that still exist (Alur, 2001:3; McClain, 2002:5; UNICEF, 2007:14).

Throughout South Africa many CWPDs are still seen by many as hopeless (Venter, 2007:2). Most negative attitudes are misconceptions that stem from a lack of understanding of disabilities and how they function (Gaad, 2002:314). This is largely due to widespread ignorance and prejudice in our society. It is reported by Save the Children that where there is cultural reverence for bloodlines, babies born with disabilities are hidden away as they are considered a sign of impurity (UNICEF, 2007:14). Therefore, cross-cultural studies of disabilities are important in understanding community attitudes towards CWPDs. If we understand the ways in which people with disabilities are denied their rights, then attitudes and practices can change, and barriers can fall (McClain, 2002:5). These attitudes are as a result of limited conceptual understanding, poor championing and a general lack of capacity in the rural areas (Dube, 2005:3).

This situation is exacerbated for CWPDs living in *rural areas* of South Africa where they face additional conditions that hamper their development owing to their geographical isolation. These conditions include limited opportunities for education (both specialised and inclusive), which further isolate and exclude them, and, sadly, this vulnerable group of children are often targeted by abusers who realise that access to the police is virtually

impossible in these areas. This is also because society tends to 'devalue' children with disabilities and tends to assume they do not feel pain or are not worth bothering about (Chenoweth, 2002:5). Communication problems that are in inherent in many CWPDs also make it difficult to report any abuse. In research carried out by the Nelson Mandela Children's Fund, it was found that CWPDs are at an increased risk of violence and are physically abused by both teachers and 'bullies' in South African rural schools (United Nations Girls Initiative, 2005:1).

Furthermore, the HIV/AIDS pandemic continues to wreak havoc in the lives of these children because so many of them are infected by the virus and/or have lost one or both their parents to this epidemic. This is particularly problematic in KwaZulu-Natal where the HIV prevalence is highest, that is, 15,8% of the general population (http:www.avert.org.aidssouthafrica.htm). Community isolation, a scarcity of resources and extreme poverty, as well as a lack of the things needed for a healthy, happy, safe life, contribute to their plight.

In addressing these problems, South Africa became a stakeholder in meeting the challenge of the MDGs, which, among other things, commit the international community to an expanded vision of equal development, one that vigorously promotes human development as the key to sustaining social progress particularly in the rural areas. South Africa recognised the importance of being part of this global partnership for development. In light of this commitment, the negative influences facing CWPDs in rural areas should be decreasing, but they are not (Dube, 2005:3). At this stage no meaningful implementation of policies as The INDS has taken place and the situation of CWPDs in these rural areas continues to remain unacceptable. CWPD are probably the most neglected group in the policy domain as well as in the private sphere and, although national policy (White Paper No.6 and The Bill of Rights makes reference to children with disabilities, little action is suggested to meet their needs, particularly in the rural areas (African Child Policy Forum, 2008:1). For too long children with disabilities have been forgotten and have fallen through the cracks in terms of services and support. It is time for change (Chenoweth, 2002:7)

In light of the above and taking cognisance of the words of Hubert Humphrey, who stated as far back as 1965 that "[t]he moral test of government is how it treats those who are in the dawn of life … the children; those who are in the shadows of life … the sick … the needy … and the disabled" (www.wikipedia Hubert Humphrey Quotes, United State Vice President

from 1965-1969), embarking on this research study is both necessary and essential. One of the greatest challenges in South Africa is that of rural education and poverty and the impact of other negative influences on CWPDs, which continues to exclude them from just treatment owing to their geographical isolation. This pernicious chasm of deprivation continues to segregate our society as the "Whites/Non-whites only signs did under apartheid" (Orford, 2004:8). Through the voices of the rural people and the children themselves, this study will not only investigate the nature of the impact of these negative influences, but also what can and should be done to conquer the hurdles on the long walk to freedom and equality in these areas. This study will richly document the life of CWPDs in these areas. The research is seen as coming at an opportune moment, as South Africa aims to attain certain MDGs by the year 2015.

This chapter will proceed with a brief discussion of the rationale and purpose of the study, the research questions, the theoretical framework, the definition of constructs used in the study and the plan of inquiry, including the methodology of the study, and will conclude with a discussion on the rigour and limitations of the research and an outline of the chapters of the thesis.

1.2   PROBLEM STATEMENT

Disability among children in the rural areas of South Africa is pervasive, but it is seldom recognised and often deliberately hidden (African Child Policy Forum, 2008:1). CWPDs face social, political and economic barriers that have an adverse effect on their development. The vast majority of these children receive no education, are absent from school data sets, and are invisible on the national policy agenda. This is backed up by Venter (2007:2), who states that according to his research these children receive no, inadequate or inappropriate intervention. These children's disabilities will therefore result in unnecessary lifelong handicaps such as poverty, financial dependence and social exclusion... Moreover, they are considered are often seen as curse to their family and are discriminated against and stigmatised at home, in schools, in institutions and in the community.

South Africans and South African organisations are committed to addressing injustices in remote and rural areas of South Africa where CWPDs not only have endured the worst excesses of apartheid but also too often continue to see the promises of democracy fade. The

story below illustrates the policy commitment of the South African government in this regard; that is, to prevent inequalities and suffering in communities.

A young woman was taking a stroll by a river swollen by recent rains. As she was walking, her attention was drawn to an elderly man in the middle of the river who was in obvious difficulty. She jumped into the water without hesitation, swam out, grabbed him, and pulled him to the safety of the bank. As she was recovering, a girl floated past, flailing her arms and yelling for help. Again the young woman dived into the river and rescued the girl in the same brave way she had done with the old man. To the young woman's chagrin and to the amazement of a small crowd that was gathering on the banks of the river, a third person, a middle-aged woman, came floundering by in the water also in dire straits. For the third time, the young woman was the brave rescuer bringing in the grateful victim to safety.

Exhausted, she then started walking upstream. As she passed a group of bystanders, one of them asked her, "Aren't you going to wait to rescue others who may fall in the river and need you?' "No," replied the young woman, "I'm going further up the river to find out why these people are falling in and see if I can prevent this from happening?" (Duncan, Bowman, Naidoo, Pillay & Roos, 2007:11).

This parable illustrates the need to understand the context within which prevailing needs are articulated; a need which becomes more apparent as more individuals in difficulty come floating down the river. This requires the intervener (the researcher) to consider other options (research methods) for addressing the problem. Acknowledging the need to rescue individuals (CWPDs), she changes tactics and goes up the river to explore the broader context, changing to a preventative means of intervention that is, investigating the root causes of the negative influences facing CWPDs. This shift from a remedial to a prevention strategy will involve new interventions and strategies and clearly signifies a shift in the way in which the problem is conceptualised. Society/government must invest in preventative strategies, *but* in the interim the South African government needs to attempt to reduce the already existing negative influences that these children face. A contextual analysis of an investigation into the impact of negative influences facing CWPDs may lead to a different understanding of them, and perhaps a different, more informed and more effective intervention to reduce the impact of these negative influences. However, the researcher is not oblivious to the fact that the root causes of these negative influences are vast and cannot simply be erased, but acknowledges both the difficulties and challenges involved in undertaking such a study.

All children in rural areas suffer from poverty, but its effects are exacerbated for CWPDs. CWPDs need interventions such as feeding therapy and assistive devices that assist them in their day-to-day functioning. Without specialised drinking cups, they are unable to drink without difficulty and without specialised seating increased spasticity is a possibility. Many of these children have already weakened immune systems owing to their inability to move around and a lack of adequate nutrition weakens this already weakened immunity. Most children in rural areas have to walk long distances to school, but this is impossible for CWPDs, and the lack of tarred roads makes the use of wheelchairs impossible. Moreover, many CWPDs do not have wheelchairs. Whilst children in the rural areas have difficulty paying for taxis, most taxis will charge double for a wheelchair, making it impossible for many parents to afford this. In addition, parents/caregivers are unable to work as they have to look after CWPDs and income in one family is thus reduced.

Furthermore, CWPDs face social and school exclusion. Violence and abuse affects all children, but this study will show that CWPDs are more vulnerable. These negative influences will be further explored in chapter 5, which will discuss not only all the negative influences, but will also elucidate the way family and community members provide a degree of positive interaction.

The personal *raison d'être* for this study is my sensitivity to CWPDs in the rural areas of KwaZulu-Natal in South Africa who face unnecessary negative influences, their lack of support on all levels and my conviction about the value of inclusive education and the achievement of an inclusive and equal society as declared by the Constitution and the MDGs. Therefore, I have decided to focus this study on the needs of historically disadvantaged black rural areas of South Africa. Very little has been researched on the problem since the last Census was done in 2001 (Rudd, 2001:1). Actual figures on the prevalence of disability are hard to find for most developing countries and the availability of this data is critically important to bring about change in national commitment to CWPDs. Data is perhaps the best basis for establishing sound policies, strategic plans, and effective services and support. Knowledge is important for action, yet many authorities do not collect data on children with disabilities and there are also differences in how statistics are collected (Chenoweth, 2002:3). Therefore, documenting the reality in terms of the nature, extent and magnitude of the problem is an essential and integral aspect of any effort aimed at ensuring the equality of opportunity and treatment of CWPDs and ensuring their social inclusion.

According to the Children's Rights Centre (2010:2), an estimated 85 in every 1000 people in KwaZulu-Natal have a disability. Moreover, Venter (2007:1) uses the statistics gathered by the 2001 Census in rural areas and states that these figures more than likely represent an underestimation of the magnitude of the burden of disability. He found the prevalence of children with disabilities in KwaZulu-Natal to be 60 per 1000 children overall. It is thus important to undertake this research study as the findings can be used to benefit CWPDs and other stakeholders such as parents, caregivers, teachers, parents and peers.

1.3   RESEARCH QUESTIONS AND OBJECTIVES

The overall **objective** of this research is an improved understanding of the impact of the negative influences facing CWPDs in rural areas of South Africa. This study will concentrate on rural areas in KwaZulu-Natal, South Africa.

The main research question directs the focus of this study and is exploratory in nature:

- What is the impact of negative influences on the lives of CWPDs?

The main research question seeks to understand and explain the impact that these negative influences have on CWPDs.

To clarify the main research questions two sub-questions will be considered:

- What theoretical framework can assist the researcher to investigate these negative influences?
- What best can be done to reduce the impact that these negative influences have on the lives of CWPDs?

The primary aim is to verify *how* the negative influences that will be investigated and verified impact on the lives of CWPDs. Both the nature of these negative influences and the way they impact on the lives of children with disabilities will be investigated.

The secondary aim is to propose a framework and guidelines to reduce the impact that these negative influences have on this group of children. This framework and guidelines will be based on rich data collected not only from time spent living in these areas, but also from questionnaires, interviews, drawings and photographs. It is envisioned that these

recommendations and guidelines will ultimately result in the equality and inclusion of CWPDs in society and schools.

1.4 THEORETICAL FRAMEWORK

The theoretical framework of a study is a structure that can hold or support a theory of research work. It presents the theory which explains why the problem under study exists. Thus, a theoretical framework is merely a theory that serves as a basis for conducting research; this is in contrast to a theory which makes generalisations about observations and consists of an interrelated, coherent set of ideas and models (Khan, 2010).

Different people view the world from different perspectives. Consequently, they take up different positions in the world with regard to the subject of their research (Henning, 2004:14). A theoretical framework is a conceptual model of how one theorises or makes sense of the relationships among several factors that have been identified as important to the problem (Radhakrishna, Yoder & Ewing, 2002:692). Almost all research studies in the social sciences require the rationale of a basis for conducting research. This rationale is often called a theoretical framework. The theoretical framework in this research study is that of Urie Bronfenbrenner's bioecological model.

In the following section, the researcher explores the bioecological model as one theoretical framework in terms of which the negative influences that impact on the lives of CWPDs can be understood. Bronfenbrenner's theoretical framework looks at children's development in the context of the system of relationships that form their development. As we are examining the negative influences in the lives of CWPDs, changes or conflict in any one layer will ripple through the other layers. To understand the impact of negative influences then, we must look not only at the child and his/her immediate environment, but also at the interaction of the larger environment (Manteghi, n.d.:6).

An understanding of Bronfenbrenner's bioecological model not only helps to explain human behaviour in the wider environment, but also assists in planning interventions. In terms of the model, it is assumed that there are certain basic criteria that can be applied to all communities but there are also certain environmental factors which present unique opportunities and challenges for the support and promotion of equality and the reduction of negative influences in the rural areas. Opportunities in these areas are possible; however, intervention is needed to assist the communities in terms of what is available and what can be done.

The underlying epistemological assumption of this study is that CWPDs have very little support from their family members and the wider community. Consequently, it is very important to understand Bronfenbrenner's model as it takes cognisance of the entire community and beyond. It is thus vital to have an explanatory framework within which the promotion of social and educational inclusion is understood, and Bronfenbrenner's model explains inclusion in the community and wider social settings.

According to Engelbrecht (1999:3), such an approach enables us to transcend the simple reduction of the movement towards inclusive education as a debate around problems of professional practice, and enables us to focus on a comprehensive, global framework which makes current knowledge intelligible, simultaneously providing the foundation for future knowledge. Indeed, Bronfenbrenner himself states:

If the children of a nation are afforded an opportunity to develop their capacities to the fullest, if they are given the knowledge to understand the world and the wisdom to change it, then the prospects of the future are bright. In contrast, a society which neglects its children, however well it may function in other respects, risks eventual disorganisation and demise (Bronfenbrenner, 1979).

In light of the above statement it is evident we need to afford our CWPDs the opportunities to develop their capacities to the fullest and provide them with a bright future. Bronfenbrenner's bioecological model is essential for the researcher in understanding how to reduce the impact of negative influences in the lives of CWPDs and, moreover, in addressing social issues.

It is very difficult for any single group or organisation to alleviate the suffering that takes place. Having embarked on a wide and copious literature review, and after careful consideration, having read "Making human beings human: Bioecological perspectives on human development" (Bronfenbrenner, 2005), and "The ecology of human development" (Bronfenbrenner, 1979), Bronfenbrenner's theory of bioecological perspectives on human development, it became obvious that this model could be successfully applied to the CWPDs living in our poor rural areas and this model therefore forms a major part of the literature study. One reason for using this model is because it is impossible to improve a situation where there are so many 'players'. In poverty-stricken areas, the family alone is unable to improve its situation, but needs the assistance of the community, who in turn need the assistance of school governing bodies, clinics and other strong support systems. These

systems rely on government to ensure that policies, funds and other necessities are provided. Cognisance should therefore be taken of all the factors as they relate to the CWPDs.

Bronfenbrenner's model can be equated to the ecological environment which is conceived as a set of nested structures (Figure 1.1), each inside the next like a set of Russian dolls (Bronfenbrenner, 1979:3). At the innermost level is the **microsystem** (meaning the smallest) and this is the immediate setting containing the developing person, that is, for the purpose of this research, the child with the physical disability.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON HUMAN DEVELOPMENT

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child such as family & peers

This is the *Mesosystem*. It consists of linkages and interrelationships between two or more of the developing child's microsystems.

This is the *Exosystem*. Meaning outside, the child is not an active participant in this system eg. The school board.

This is the **Macrosystem**. It consists of the society and subculture to which the developing child belongs, with particular reference to belief systems and lifestyles

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

THE CWPD'S

Figure 1.1:   Bronfenbrenner's biological perspective on human development (Adapted from Bronfenbrenner, 1979).

This microsystem can comprise the family or the school, for example. The model acknowledges that a child affects, and is affected by, the setting in which he/she spends time. However, the next step requires looking beyond single settings to the relations between them. Bronfenbrenner argues that such interconnections can be as decisive for development as events take place within a given setting. A child's ability to thrive at school and in the

community is dependent on the relationships between the schools and other factors, such as neighbours and peers. The interrelations at this next level are known as the **mesosystem.**

The third level in the ecological environment is known as the **exosystem** and evokes a hypothesis that a child's development is profoundly affected by events occurring in settings in which CWPDs are not even present. For example, a child's experiences at home might be influenced by the mother's work, for which she may have to move to an urban area.

The final and outermost layer is the **macrosystem.** While not being a specific framework, this layer comprises cultural values, customs and laws. The effects of the larger principles defined by the macrosystem have a cascading influence throughout the interactions of other layers (Paquette & Ryan, 2001:2). Public policy is part of the macrosystem, determining the specific properties of the exo-, meso- and microsystems that occur at the level of everyday life and steer the course of behaviour and development (Bronfenbrenner, 1999:9).

Finally, the **chronosystem** involves temporal change in ecological systems, or within individuals, producing new conditions that affect development (Berns, 2010:26). This system encompasses the dimension of time as it relates to the child's environments. As children get older, they react differently to environmental changes and may be more able to determine how that change will influence them (Paquette & Ryan, 2001:2). The green represents the chronosystem which is the last system that Bronfenbrenner developed.

The bioecological system gives a clear understanding of children, families, schools and the community and enables us to understand the many settings and interactions that potentially influence the development of CWPDs in rural areas of South Africa; in this study predominantly in KwaZulu-Natal.

The researcher will attempt to analyse the socialisation influences of the family, non-parental childcare, the school, the peer group and the community on the child's development and synthesise the process of dynamic and reciprocal interactions of these agents and groups with the child and with each other, contributing to social outcomes – values, attitudes, motives and attributions, self-esteem, self-regulation/behaviour and morals (Berns, 2010:xvi).

It is an impossible task for the researcher to implement guidelines across all four levels, as the researcher has no control over government and it is unrealistic to attempt to challenge these four levels. Only by concentrating on the child (microsystem) and his/her immediate

relationships can we begin to travel the long road. Therefore, for the purposes of this research and creating workable theoretical guidelines, the researcher will concentrate on the **micro-** and **mesosystems** only**.** Having said this, the exosystem and macrosystem can never be excluded from the model and these will be looked at, although not in depth. Inclusion will feature strongly throughout all four levels, but guidelines for inclusion will be discussed at the micro- and mesosystemic levels only.

This model provides a valuable contribution to assisting CWPDs and understanding the interconnectedness of the challenges and barriers they experience in their daily lives. Bronfenbrenner's model will be used to explain the effects of poverty, violence and other negative influences in the rural areas. The rationale for using his theory was that it promoted a contextual analysis and synthesis and follows a systems approach.

The researcher acknowledges that many similar frameworks exist but has chosen to concentrate on this model. Other models of intervention based on theoretical frameworks are Maslow's hierarchy of needs and Vygotsky's theoretical framework, that is, his zone of proximal development (Manteghi, 2010:7). However, the theoretical framework of Bronfenbrenner and the strengths of this model have been and will continue to be discussed in depth throughout this study. Chapter 3 will discuss not only Bronfenbrenner's bioecological model, but also his development of the person–process–context–time (PPCT) aspects which he added to his model.

Accordingly, it is clear that Bronfenbrenner's model will be the frame of reference that underpins and guides this study.

1.5   RESEARCH PARADIGM, DESIGN AND METHODOLOGY

1.5.1   Research paradigm

A paradigm can be defined as a set of beliefs representing a worldview (Denzin & Lincoln, 1994:107). Further, according to Cresswell (2007:17), a paradigm or worldview is "a basic set of beliefs that guide action". A paradigm thus provides a conceptual framework for seeing and making sense of the social world. According to Burrell and Morgan (in Williams, 1998:2), "[t]o be located in a particular paradigm is to view the world in a particular way". It is therefore essential for the researcher to be aware of the influence of philosophy on strategies of research, because without knowledge of related philosophy, the researcher will

be apt to be confused when analysing the data in this study. A research paradigm can also be seen as a scientific frame of reference that the researcher adopts for the study). Within the research process the beliefs a researcher holds will be reflected in the way he or she researches the design, executes the study and presents the results.

According to Cresswell (2007), there are four worldviews that inform qualitative research and identify how these worldviews shape the practice of research. The four are post positivism, constructivism, advocacy/participatory and pragmatism (Cresswell, 2007:19). In this study the researcher will concentrate on the advocacy/participatory worldview. The basic tenet of this worldview is that research should contain an action agenda for reform that may change the lives of the participants, such as reducing the negative influences CWPDs face. The issues facing these marginalised groups are central to this study, and include exclusion and inequality, poverty and violence and other negative influences that will be discussed in chapter 5. As these issues are studied and exposed, the researcher will provide a voice for these participants and try to improve their lives. Kemmis and Wilkinson (in Cresswell, 2007:22) summarise the following key features of:

- The research is focused on bringing about changes in practice. Thus, at the end of advocacy/participatory studies, researchers advance an action agenda for change.
- Advocacy/participatory practice is focused on helping individuals free themselves from constraints found, for example in educational settings. Advocacy/participatory studies often begin with an issue or stance about the problems in society, such as the need for empowerment, equality and inclusion for CWPDs.
- It is emancipatory in that it helps unshackle people from the constraints of irrational and unjust structures that limit self-development and self-determination.
- The aim of advocacy/participatory studies is to create a political debate and discussion so that change can occur.
- Advocacy/participatory practice is practical and collaborative because it is inquiry completed with others. In this spirit, advocacy/participatory researchers engage the participants as active collaborators in their inquiries.
- In this way, the voice of the participants and, in this study the members of the community, became heard throughout the research process. These practices are seen in ethnographic approaches and in the advocacy tone of some forms of narrative research.

1.5.2   Research design

A research design determines the way the research should be conducted and the methods that will be used. For this reason a qualitative, descriptive, exploratory and contextual design will be utilised (Mouton, 2009:102) for this study. Qualitative research is a generic term for investigative methodologies described as ethnographic, naturalistic, anthropological, field, or participant observer research. It emphasises the importance of looking at variables in the natural setting in which they are found. Its focus is holistic – a total or complete picture is sought (Key, 1997:1). According to Stainback and Stainback (in Key, 1997:2), a holistic description of events, procedures and philosophies occurring in natural settings is often needed to make accurate situational decisions. This differs from quantitative research in which selected, predefined variables are studied. This research methodology will be discussed in greater depth in chapter 4.

A qualitative design is the most suitable for this study. This is because the researcher needs chiefly to obtain data from the community through interviews, children's drawings, photographs and questionnaires. As the researcher wants to make sense of feelings, social situations or phenomena as they occur in the real world, these have to be studied in their natural setting (Terre Blanche, Durrheim & Painter, 2008:287). In order to be able to research this study and be in the field, it is essential to undertake an ethnographic study.

Ethnography is a strategy of enquiry in terms of which the researcher studies an intact cultural group over a prolonged period of time by collecting primarily observational and interview data (Cresswell, 2009:13). Cresswell (1998) places ethnography at the "before" end of the continuum, as most ethnographers use one or two cultural theories to guide their study. Leedy (2001:152) agrees, stating that the researcher using this design should describe the nature of the study as it relates both to the research question and to one or more theoretical perspectives. Theoretical perspectives before data collection are aimed at creating a context, point of departure or frame of reference from which the data will be collected, rather than describing a particular theory or providing a theoretical base for this study (De Vos, Strydom, Fouche & Delport, 2005:264).

Ethnography is focused on behavioural regularities and interactions between individuals and within groups, attitudes and rituals. Therefore, this is a near perfect design eminently suited for this study, as can be seen by the criteria used in advocacy/participatory studies. The primary task of ethnographic research is to uncover and make clear the ways in which people

in particular settings(in this research study the community in rural areas) come to understand, account for and manage their situations (in rural areas), as well the problems and difficulties they encounter with having CWPDs. Gaining access through the gatekeeper(who introduces the researcher to the community and acts as a translator) and gaining the confidence of the informants is essential in an ethnographic study. Finally, a requirement of an ethnographic study is finding a group to which one is a 'stranger" (Cresswell, 2007:121).

One interpretative stance, which is used in this qualitative research, is disability theory which will be discussed in-depth under the Medical and Social Models of disability in Chapter Two. As this is crucial to the topic being researched; this will be applied in conjunction with Bronfenbrenner's model.

1.5.3   Research assumptions

All research is based on methodological assumptions that have their origins in the philosophical underpinnings of a research approach. One way of identifying this is to present the paradigmatic assumptions that drive the research and use examples to illustrate these assumptions. Merriam (1988:19–20) proposes six assumptions that apply in this approach. These assumptions enable the hermeneutics of the research design and provide a basis for the subjectivity of the work.

METHODOLOGICAL ASSUMPTIONS
UNDERLYING THE QUALITATIVE RESEARCH DESIGN

THE RESEARCHER
*is primarily concerned with process
*is interested in deriving meaning
*is the primary instrument for data

THE RESEARCH:
*involves fieldwork
*is descriptive
*is inductive
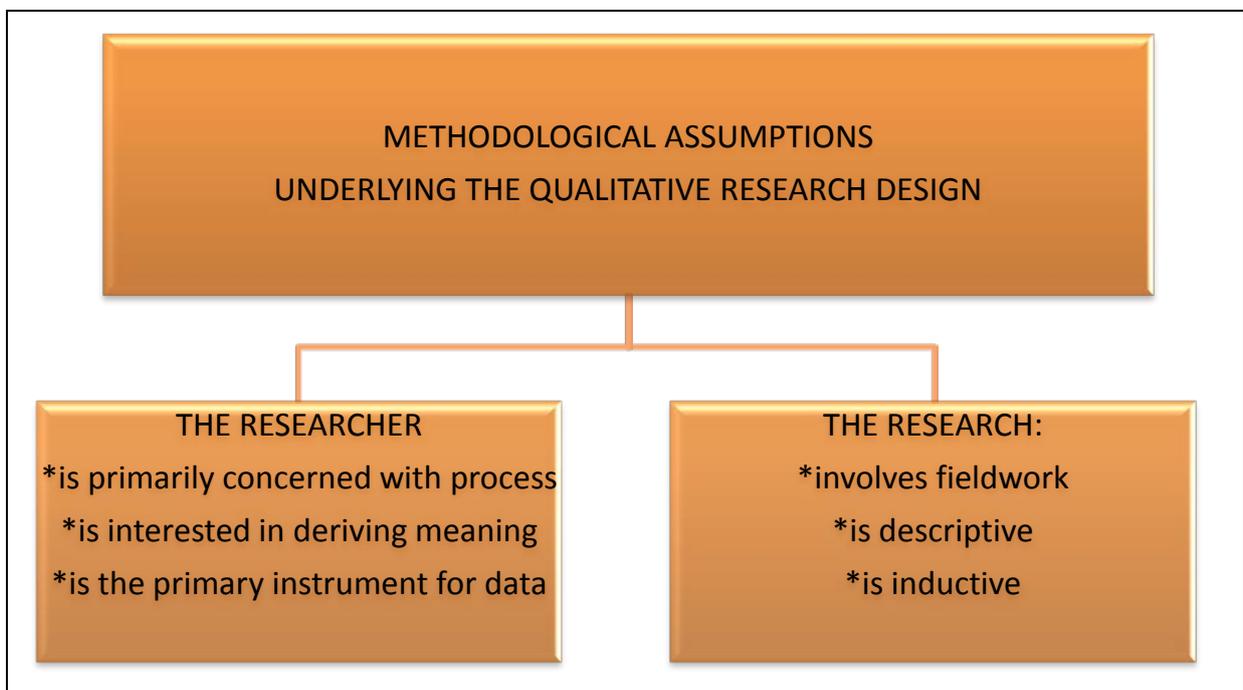
Figure 1.2:   Merriam's six methodological assumptions

The methodological assumptions of this type of research study are simple. The researcher will use inductive logic, study the topic within its context and use an emerging design.

1.5.4 Methods of data collection

Data collection offers one more instance for assessing research design within each approach to inquiry.

The diagram below indicates the data collection circle that the researcher will engage in the process of collecting the data (Creswell, 2007:118).

Figure 1.3:   The data collection circle

1.5.4.1   Literature review

An ongoing literature study formed part of the research methodology. This is beneficial as it contributes to a clearer understanding of the nature and meaning of the area being researched. It focused on the following areas:

- Cultural beliefs about CWPDs in South Africa
- Current studies of the negative influences CWPDs in rural areas of South Africa experience
- Bronfenbrenner's Bio-Ecological Social Model, which was researched in depth as it forms the basis of this research study

A literature review of models of disability in chapter 2 provides a thorough understanding of disability, as well as the preferred terminologies. Specific literature regarding the design and methodology used in this study allows the researcher to structure the research within an advocacy/participatory paradigm (Dreyer, 2008:12).

1.5.4.2 Observations

The focus of the researcher is on the everyday, natural experiences of the respondents. According to De Vos, Strydom, Fouche and Delport (2008:276), the researcher should strive at all times to gain feelings and impressions and to experience the circumstances of the real world of participants by living alongside them, and interpreting and sharing their activities.

The advantages of direct observation are that the community can be observed and studied firsthand. This is important because researchers then do not have to depend on the participants' possibly misleading reports (either in interviews or questionnaires) but use direct observation (Welman, Kruger & Mitchell, 2008:172). The researcher's observations will come initially from being an onlooker and, as time passes, to becoming a full participant immersed in the community. The observation will be overt. Observation is a powerful tool for the researcher in this study, as many themes could be uncovered.

1.5.4.3 Interviewing

Qualitative research when a complex understanding of the issue under study is needed. Accordingly, information that will contribute to our understanding can only be obtained by talking directly to people and going to their place of work and their homes.

Interviewing is the predominant mode of data or information collection in qualitative research. Seidman states that you interview because you are interested in other people's stories (in De Vos *et al*., 2008:287). An interview is not just an informal chat but comprises a controlled interaction with verbal exchange as the main method of asking questions. An interview has a direction and a shape; it serves a specific purpose and it involves both the interviewer and the respondent in a dynamic relationship (Brand, 2005:48).

The questions in these interviews will be of an extremely sensitive nature. Therefore, for this research although the interviews are structured they will be informal and relaxed. Although there will be predetermined questions the answers might or might not affect the next question, or give rise to a new question. The interviewees will be given the opportunity to "chat" freely about events, behaviour and beliefs in relation to the research. This type of

interview is called non-directive (Welman, 2008:166), and will be in line with the qualitative or explorative research being conducted.

Moreover, depending on the answers given by the interviewee a semi-structured interview may also take place. Semi-structured interviews are especially suitable where an issue is controversial or personal (De Vos *et al.*, 2008:269). As each question is likely to have different answers which can give rise to new questions, interview order will be likely to change or additional questions may be added or deleted. This type of interview has the advantage that it can be used for all age groups (Welman, Kruger & Mitchell 2008:167).

Different cultures, ethnic groups and languages are being used and therefore the interviewer needed to adapt the formulation and certain terminology to fit the background and understanding of the community being interviewed. The interviews will take place in the mother tongue, and will be recorded and then translated by the gatekeeper. The gatekeeper is familiar with the customs and culture of the geographical areas being researched and is a qualified rehabilitation worker who is fluent in both English and Zulu.

It is not only members of the community and parents that need to be interviewed, but also nurses at clinics, local government bodies and, more importantly, teachers at schools. This would be in line with Bronfenbrenner's model, starting with the microsystem and working out to the macrosystem. The interviewees will be specifically chosen as they have firsthand knowledge of the issue under study. These interviews will guide the researcher as to how, where and when the direct study is most needed. Notes will be taken and a recording will be used if the interviewees permit. Confidentiality for both adults and children will be guaranteed and no names will be used. The researcher needs to be aware that at some point the responses to the research questions will be 'saturated', that is, when no further new information no longer comes to light; therefore the number of interviews conducted will vary among the different categories of interviewee.

1.5.4.4   Questionnaires

A questionnaire can be defined as a group of written questions used to gather information from respondents (Terre Blanche *et al.*, 2006:484). The wording of questions is extremely important and can dramatically skew prevalence rates (Hopper, 2008:18). Questionnaires and in-person interviews have a great deal in common: both are a manner of eliciting information directly from the community in question and both are essential to the nature of this study.

Although questionnaires are a secondary source of data collection they are important for the following reasons: firstly, more information can be collected from a wider source of people thus achieving a greater volume of information, and secondly, they offer confidentiality in fear of a negative response from community members. All questionnaires will be read to any interviewees who are illiterate, and this procedure will be recorded.

The more structured the questionnaire, the more easily the results can be analysed later.

In this qualitative case study the researcher will combine observation with interviewing in order to obtain a more in-depth understanding of the negative influences. The use of more than one method is known as *triangulation.* As each data source has its strengths and weaknesses, by using triangulation the strengths of one procedure can compensate for the weaknesses of another approach (De Vos, Strydom, Fouche & Delport, 2005:314). This will be further discussed in chapter 4.

1.5.4.5   Drawings and photographs

Drawings will be collected from the children about their families and homes, and photographs will be taken of schools to establish the feasibility of inclusion in the rural areas. Aspects such as accessibility of schools in the form of roads and ramps will be used to illustrate possible difficulties. Photographs depict what words cannot. This too will be discussed in depth in chapter 4.

1.5.5   Population and sample

Sampling specifies how participants are to be selected in a study (Enoch, 2009:12). Purposeful sampling will be used as there are a limited number of communities in KwaZulu-Natal that can be visited. These communities will be targeted with the help of Kwazamokuhle School which is attended by CWPDs. The school will be aware of which families and communities can be interviewed, and will also know all the children well. The school will also assist to identify areas where CWPDs face the most negative influences and are in need of intervention. Permission has been obtained from the KwaZulu-Natal provincial education department. The community members selected for interviewing will be those who have a direct influence on the lives of CWPDs, such as parents/caregivers, teachers, health professionals, church ministers, *sangomas* and community leaders.

The interviews with the children will be informal and relaxed. We will explain the purpose of the interview to them and there will be an attempt to have an equal balance of gender, age and type of disability wherever possible. In order to ensure the validity and credibility of the research as far as possible, the school will be asked to identify parents/caregivers, as they are aware of parents who are credible. The school will be given the criteria first, that is, parents/caregivers of children who have a visible physical disability.

Data collection will be fully explored in chapter 4.

1.5.6   Data transformation (analysis)

In a qualitative research study such as this, there is no clear point at which data collection stops and analysis begins (Terre Blanche *et al*., 2008:321). As in the quantitative arena, the purpose of conducting a qualitative study is to produce findings; as Patton (in De Vos *et al*., 2008:234) states, qualitative analysis transforms data into findings. This involves reducing the volume of raw information, sifting significance from trivia, and then identifying significant patterns and constructing a framework for communicating the essence of what the data reveal. An essential part of this research is the transformation of the data. The initial task in analysing qualitative data is to find some concepts that help us to make sense of what is going on in the scenes documented by the data (Oka & Shaw, 2001:8). In this research the aims are to

- examine relationships (that lead to violence, abuse and neglect)
- forecast possible new strategies
- explain (findings verbally) (Data in the form of words, either written or spoken, will be a common feature.)

Coding the data

When using coding from the interviews, the researcher will regard a concept as important if it is confirmed by at least two interviewees, such as parents stating that a lack of transport might be a negative influence for their child. Depending on the nature of the outcome of the results data will be categorised into any emerging themes.

Using quotes

The researcher will use quotes from the interviews that will support the themes and ideas that the researcher has generated.

Because flexibility is one of the principles of qualitative research, the researcher was not confined to using only one strategy in the analysis, and therefore employed all the above strategies in the data analysis.

1.6   ETHICAL CONSIDERATIONS

Research ethics are principally concerned with the effects of research on people. Ethics is the study of moral standards and how they affect conduct and ethical behaviour is especially important in this research study. The principles underlying 'research ethics' are universal and concern issues such as honesty and respect for the rights of individuals (Welman, 2008:181).

Ethical guidelines also serve as standards, and a basis upon which each researcher ought to evaluate their own conduct. As such, this is an aspect which should be borne in mind continuously (De Vos *et al*., 2008:57). The African Child Policy Forum (ACPF), being a rights-based organisation, attaches great value to respecting the rights and upholding the dignity of children and their family members. The research approach, therefore, will abide by ACPF ethical policy and other international codes. The researcher remains accountable for the ethical quality of the inquiry and should take great care, when in doubt, to ask advice (Henning, 2004:74). Once the data collection methods have been finalised, the process of ethical clarification can begin.

There are four ethical considerations that must be considered when conducting this study. These issues will be discussed in depth in chapter 4:

1.6.1.1   Informed consent
Obtaining informed consent implies that all possible information on the goal of the investigation, the procedures which will be followed during the investigation, and the possible advantages, disadvantages and dangers to which the respondents may be exposed will be made known to the respondents (De Vos *et al*., 2008:59).

The researcher will obtain the necessary permission from the respondents after they have been thoroughly and truthfully informed about the purpose of the interview and the investigation. Furthermore, whatever relevant permission that is needed will be obtained, for example from the KwaZulu-Natal Department of Education, Kwazamokuhle School and clinics. Subsequently, the respondents will sign a consent form. With regard to the respondents, their consent will be taped as they will have the consent forms read to them in

their mother tongue in the event that some respondents might be illiterate (see Addendum 1). Kwazamokuhle School where the researcher will be based will give consent on behalf of the children, as the children reside at the school. The school has stipulated that their social worker be present at these interviews.

1.6.1.2   Right of privacy

The respondents will be assured of their right to privacy by signing a consent form in which we will guarantee it. For the purposes of this study, violation of privacy and the denial of the right to self-determination and confidentiality can be viewed as being synonymous. Singleton (in De Vos *et al*., 2008:61) explains that "the right to privacy is the individual's right to decide when, where, to whom, and to what extent their attitudes beliefs, and behaviour will be revealed".

1.6.1.3   Indemnification against harm

The responsibility for protecting respondents against harm reaches further than mere efforts to repair, or attempt to minimise, such harm afterwards (De Vos *et al*., 2008:58).

The respondents will be given the assurance that they will be indemnified against any physical and emotional harm as all consent forms and interviews will remain anonymous.

1.6.1.4   Involvement of the researcher

The researcher should guard against manipulating interviewees as objects or numbers rather than individual beings (Welman, 2008:201). Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation. In this research study both the researcher and her gatekeeper are experienced and competent to undertake the proposed investigation (De Vos *et al*., 2008:63).

1.7   VALIDITY AND RELIABILITY

Mouton (2006:109) argues that validity should be viewed as a synonym for the "best approximation to the truth". This makes validity and reliability in the field of social science research a very contentious issue (Dreyer, 2008:14). To counteract this contentious issue, Mouton (2009:108) suggests that the rationale for a research design is to plan and structure a research project in such a way that the eventual validity of the research findings is maximised by either minimising or, where possible, eliminating possible error. Cresswell (2009:190) states that *qualitative validity* means that the researcher checks for the accuracy of findings

by employing certain procedures, whilst qualitative reliability indicates that the researcher's approach is consistent across different researchers and different projects. Lincoln and Guba (in De Vos *et al*., 2008:346) propose four constructs, credibility, transferability, dependability and confirmability, which should reflect the assumptions of the qualitative inquiry. These are discussed below.

1.7.1 Credibility

Credibility is analogous to 'internal validity' in conventional criteria. In this research study, one of the criteria is that the researcher spends a 'prolonged engagement' and builds trust with the participants. This was done in Phase 1 of the research; when the researcher returned to the research site in phase 2 it was like returning 'home'. Secondly, the researcher's gatekeeper will be used continuously for peer debriefing. The gatekeeper is credible in that she is a qualified community-based rehabilitation worker who works in the community.

1.7.2 Transferability

Transferability in this research study will be used to ensure that what is collected in one context can be applied to another, for example, another rural area of South Africa. This is in line with 'thick descriptions', so that by describing what is applicable in one rural area is described in such depth that other users can apply the findings to their rural area.

1.7.2.1 Dependability and confirmability

In this study the audit trail includes materials such as the recordings, the interview transcripts, the list of interviewees, the lists of categories and the hypotheses the researcher used while analysing the data.

1.8 ROLE AND LIMITATIONS OF THE RESEARCHER

Owing to the nature of this research, there will be limitations that might affect how far the researcher is able to generalise conclusions, or how confident the researcher might be at the end of the research (Hofstee, 2006:87). These might be the percentage of the rural community in South Africa the researcher is able to reach in order to yield accurate data and assessing accurately how culture affects attitudes towards CWPDs in these remote areas. As a great deal of the research will be done through a translator, the researcher will be dependent on accurate translations by the interpreter who speaks African languages and English and the

honesty of the community being researched. Finally, however, it should be noted that studies conducted at different times and under different circumstances may provide different results.

Furthermore, ethnography is challenging to the researcher, as the time needed to collect the data is extensive, involving prolonged time spent in the rural areas. Sensitivity to the needs to the families of CWPDs is especially important, and the researcher needs to acknowledge her impact on the people and the place being studied (Cresswell, 2007:72).

1.9   DEFINITION AND CLARIFICATION OF CONCEPTS

Language reflects the values and attitudes of the social context in which it is used. These concepts will be discussed in depth in chapter 2.

1.9.1   Children with physical disabilities

Extremely inadequate and inappropriate definitions of disability used in the past have not only resulted in a limited understanding of disability, but have also contributed to the inequalities and discrimination faced by children with disabilities. This concept will be explored in depth in chapter 2.

1.9.2   Discrimination and oppression

Discrimination refers to the treatment of people who are different in an unfair, biased or prejudicial way. Oppression occurs when individuals are *systematically* subjected to political, economic, cultural or social degradation because they belong to a particular social group (Charlton, 2000:8).

1.9.3   Exclusion

Social exclusion is a relatively new concept. It is multidimensional in nature and is related to the relative position of an individual within the entirety of society (Citizen First, 2003:2). Social exclusion can also be defined in this study as being prevented by social systems from participating or benefitting, being shut out or left out because society is unable to accommodate different or special needs.

1.9.4   Social inclusion

Inclusion is regarded as a moral issue of human rights and values, and as such it is linked to the fundamental democratic reforms discussed above. Inclusion represents the wider social awakening to the needs of people who experience oppression (Dreyer, 2008:20).

Inclusive education does not only occur at schools. Inclusion occurs in all contexts. In this study the family, the community and other sectors need to be involved from the start. Social inclusion will be central to this study, hence the use of Bronfenbrenner's model.

1.9.5   Rural areas

There is no agreement about what constitutes rural and urban areas in South Africa (Emerging Voices, 2005: x). In this study, the researcher has defined a rural area as those areas in South Africa that are geographically isolated. For the purposes of this study the areas in the province of KwaZulu-Natal will be investigated. The findings should then be able to be applied to other rural areas of South Africa.

1.10   DIVISION OF CHAPTERS

Chapter 1 introduces the reader to the context of this thesis and provides basic information on the study within the framework of both societal and educational inclusion in South Africa. The research problem, the design and the methodology are also discussed.

Chapter 2 focuses on providing an understanding of disability, as well as an understanding of disability within the context of the rural areas of KwaZulu-Natal.

Chapter 3 provides the reader with an explanation of Bronfenbrenner's model and a discussion of his theory of person–process–context–time. His model is discussed together with the concept of inclusion, as Bronfenbrenner stressed the need for both community and social inclusion.

Chapter 4 explains the research design and the methodology used in this research.

Chapter 5 entails an interpretation of the findings and provides an in-depth discussion of the impact of the negative influences facing CWPDs. In addition, it provides a discussion of the results.

Chapter 6 presents the recommendations and guidelines for a reduction of these negative influences in the lives of CWPDs in the rural areas. Furthermore, the limitations of the study and the themes identified that justify further research are presented.

1.11   CONCLUSION

Research is "a systematic process of investigation, the general purpose of which is to contribute to the body of knowledge that shapes and guides academic and/or practice disciplines" (Higgs, Horsfall & Grace, 2009:5). In this chapter, the researcher contextualised the study within Bronfenbrenner's model. The philosophical paradigm underlying this research was briefly discussed and the design and methodology applied were outlined. A brief description was given of the anticipated ethical guidelines for this study, which was followed by a brief discussion on the validity and credibility of a qualitative study. The research design and methodology will be discussed in detail in chapter 4. In the last section of this chapter the key concepts used in this study were clarified, after which the chapter divisions are outlined.

Let me end this brief excursion into my research topic with a few personal observations. The degree of suffering and, ultimately, the negative influences that affect children with physical disabilities and their families and that were part of the legacy of apartheid are both overwhelming and inexpressible. Together, we (as a new country and new democracy) have travelled a long road to where we are today, but the scars are still present. It may be argued that, fifteen years into democracy, the era of apartheid should no longer be blamed for ills that continue to exist today, and we are still confronted by the exasperated injunctions of those who have forgotten the evils of South Africa's past and who insist that people should move forward with their lives and stop fixating on the past. Whilst the quest for the comforts of social amnesia is understandable this is, however, not a useful stance to take in any attempt to understand the reasons why CWPDs are impacted upon by so many negative influences (Duncan *et al*. 2007:19). This research will show that the ongoing effects of apartheid continue, relentlessly, to affect both the poor and other marginalised groups living in rural South Africa. As Nelson and Prilleltensky (in Duncan *et al.,* 2007:19) observe, if we are to be effective in addressing negative issues, it is essential that we deal with the 'causes of causes' of people's problems, such as the effects of past apartheid practices. No matter how it is argued, we must continue to rectify these injustices, and, thus, an intensive investigation into the reasons why this marginalised group of children continues to suffer will be conducted during the course of this research study. However, in so saying, it must also be remembered that our present government has not lived up to its promises − see chapter 5.

Chapter 2 will begin with an in-depth discussion that will explore the issues and theories of disability and will explore the context of disability in rural areas.

CHAPTER 2

DEFINING DISABILITIES, MODELS OF DISABILTY AND CHILDREN WITH PHYSICAL DISABILITIES IN RURAL AREAS

2.1   INTRODUCTION

In chapter 2 the concept of disability will be probed. In exploring the issues of disability within a particular geographical community, two questions need to be addressed. The first relates to the very *definition* of the term 'disability' and the debates around it. The second, which is crucial to this study, relates to the mitigating factors that lead to the plight of the child with physical disabilities in *rural* areas (which will be discussed in chapter. 3). These are closely related and this chapter will highlight that the very definitions and understanding of disability influence the conceptualisation of responses to it.

In 1995, South Africa adopted the Convention on the Rights of the Child. Article 23 (office of United Nations High Commissioner for Human Rights) of the convention states: "A mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self reliance and facilitate the child's active participation in the community." This entails full inclusion and, in order to be able to promote full inclusion and reduce the impact of negative influences that CWPDs face, it is necessary to understand the terminology of disability.

The prevalence of childhood disability varies according to the local definition of disability and the various environmental factors. According to the last census there are about 200 000 CWPDs, representing between 2 and 3% of the population. According to Venter (2007:2), this more likely represents an underestimation of the magnitude of the burden of disability. In the area of KwaZulu-Natal, where this research study took place, the prevalence of disability was found to be 60 per 1 000 children overall, 28 per 1 000 for motor disability. However, the field of disability still provides large areas to be explored, as the majority of these children were receiving no, inadequate or inappropriate intervention. Many of these children's disabilities will therefore result in an unnecessary lifelong handicap.

2.2   TOWARDS A COMMON LANGUAGE FOR DEFINING DISABILITY

Defining disability is a daunting challenge, as there is no neutral language to discuss disability. Part of the difficulty of defining disability has to do with the fact that disability is a complicated multidimensional concept.

A global definition of disability that fits all circumstances, though very desirable, is in reality nearly impossible. Fundamental to advancing the science of disablement is the ability to communicate with one another and to speak in a common language that is understood across related professional fields and disciplines. The use of different frameworks and definitions for the same disablement concepts has led to confusion in communication. This confusion of languages has created a veritable "Babylonian Tower of Babel" with its resulting weakening of the foundation for our research (Jette, 2009:1).

Negative and patronising language produces negative and patronising images. Language can be used to shape ideas, perceptions and attitudes. Words that are in popular use reflect the prevailing attitudes in society. Positive and respectful attitudes can be shaped through careful use of words that objectively explain and inform without judgemental implications (Heijen, 2005:4). For most CWPDs terms such as 'cripple', 'spastic' and 'mongol' have lost their original meaning and simply become terms of abuse (Barnes, Mercer & Shakespeare, 2008:6). Attempts have now been made to define disability with simple statements, theoretical models and classification schemes, and even through different forms of measurement (Albrecht, Seelman & Bury, 2001:97).

According to Gillespie-Sells and Campbell (in Burke, 2008:13), the medical model of disability views disability as a condition to be cured. This is hardly surprising; the mainstream of medical training is about preventative treatment or curing illness, so a pathological orientation is to be expected. However, if an individual is considered only in treatment terms the pathological overrides the individual's sense of wellbeing. In the context of definitions of disability, the needs of CWPDs should not be solely governed by medical descriptions. As children first, their needs will in many ways be in common with other children, and in other ways will be unique (Burke, 2008:19).

Disability rights activists consider that the social environment structurally creates the social disadvantages and discriminatory situations experienced by people with disabilities. Disability is socially constructed by environmental barriers, and causality is no longer placed

within the body and functional limitations but in the systemic inadequacy to adapt in the CWPDs in this research (Albrecht *et al*., 2001:179). It is vital for the black community in rural areas to understand the occurrence and causes of CWPDs, as this can be used to help to erase any of their illusions about disability. This will be discussed in the section below.

2.3   WHY DEFINE DISABILITY?

Using the right word matters; it is important to recognise the important role that language has had in reinforcing society's assumptions about groups of people (Carson, 2009:15).

Having a clear understanding of where thinking about where disability has come from is important in order to see that underlying negative attitudes and stereotypes have been reinforced by society over many centuries.

Every individual, regardless of sex, race or ability, deserves to be treated with dignity and respect. As part of the effort to end discrimination and segregation – in employment, education and our communities at large – it is important to eliminate prejudicial language (Texas Council for Developmental Disabilities, 2007:1). Terminology is important, because words reflect our attitudes and beliefs. Therefore, how disability is defined is of crucial importance to the child with the disability, and to others to promote the necessary understanding and respect (Carson, 2009:15). The presuppositions informing particular definitions can be offensive and provide the basis of stereotyping and stigmatisation. In the same way that women and some people from different cultural backgrounds have identified the power of language in the promotion of sexism and racism, people with disabilities have become more sensitive to the way words perpetuate discriminatory behaviour and language (Carson, 2009:15). The following section will provide deeper insight into the way the community explains disability in KwaZulu-Natal.

2.4   RESEARCH CONTEXT

KwaZulu-Natal is one of the nine provinces of South Africa and is situated in the south-east of the country. The issues that are of importance in this area are

- the high rate of HIV/AIDS infection
- the high rate of unemployment
- stigmatism and the culture of silence related to HIV/AIDS

- language and race barriers between people

- geographic isolation (see map below)

Philpott (in Hanass-Hancock, 2008), in her assessment of access to basic services in rural areas in KwaZulu-Natal, found that only 46% of the community had access to electricity, 64% to tap water, 29% to a pit latrine and 16% to a flush toilet. These conditions make life for CWPDs and their families who need to assist them very difficult and also limit the use of modern devices that could assist them. Furthermore, 78% of CWPDs had access to public transport, but 27% of them had problems accessing the road between their home and the public road. Philpott also noted that 76% had no knowledge about rehabilitation such as Early Intervention for example speech, occupational and physiotherapy and 60% had no knowledge of their human rights.

Figure 2.1:   Map of KwaZulu-Natal

The following section is an attempt to elucidate some of the associations attached to the cultural construction of disability among the community under study in KwaZulu-Natal.

It has been often argued that it is important, while studying how people in a particular society perceive and react to disability, to know something about both the cultural and the social

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attitudes of the society in which they live. 'Culture' is a term often used in explaining the different ways of handling disability and it is viewed by Helman (in Hanass-Hancock, 2008) as

> … a set of guidelines (both implicit and explicit) which individuals inherit as members of a particular society, and tells them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment.

Culture in this sense provides people with guidelines to understand the world they inhabit and how to live within it. In the context of disability, cultural imaginations about an abnormal condition help to understand the conditions and at the same time these notions can stereotype CWPDs. The individual experience of disability, however, differs a great deal and there is a difference in the perception of disability between the people with disabilities and those without.

Based on their subjective interpretation of illness and disability, Zulu-speaking people in KwaZulu-Natal differentiate between natural diseases and diseases associated with African people (Hanass-Hancock, 2008:12). It is therefore significant that, in South Africa, in the area of KwaZulu-Natal where this research took place, the Zulu language uses different words to denote those children who are born with disabilities, and those who acquire disabilities in life. Those born with a disability are referred to as *isidalwa*, 'one who is created'. This word evokes a sense of fatalism, where one had no control over God's creation, and it evokes sympathy. In contrast, those who acquire disabilities later in life are felt to have in some way deserved it, so they are subject to much less sympathetic attitudes (Philpott, 1996:21). Many derogatory terms are used to refer to them, such as *isilimi* ('one who is hit/punished') (Philpott, 1995:22). This is in keeping with Hanass-Hancock (2008), who argues that most people in KwaZulu-Natal roughly categorise the causes of disability into two groups, being either natural or spiritual. Natural causes are understood to be everything that happens without the influence of witchcraft, a superhuman being or spirit. Disability caused through spiritual influence is traditionally described as 'African diseases' and it is generally assumed that they cannot be healed with any 'Western type of medicine'. Interestingly, it is not the origin of the substance that makes it an African medicine, but rather the person who prescribes the so-called *umuthi*, and the fact that certain rituals have to be followed. Some of

these substances may even be imported from China but, if prescribed by a traditional healer, they will be considered an African medicine (Hanass-Hancock, 2008:12).

Members of the community choose healthcare depending on their individual interpretation of the disease or disability. Interpretation and treatment of disability are therefore highly dependent on people's choice of concept and access to knowledge. In Mkize's 2002 study (in Hanaas-Hancock, 2008:14), he found that if bewitchment was suspected there was a delay in seeking help from the public system. If a disability is believed to have been caused by loss of protection from the ancestors, then the family has the option to sacrifice to the ancestors. In these cases, people apply the 'traditional' concept and try to seek help from a traditional healer or *sangomas* of which three were interviewed in this study (see chapter 5). The notion about CWPDs being 'unclean' or 'stupid' and seen as 'cursed by God', and unsuitable for a partnership, influences the social life of the child. This exclusion will be discussed in the next chapter, chapter 3. Literature on the conceptualisation of disability in KwaZulu-Natal is very rare apart from Ngubane's major contribution (which was conducted as far back as 1977) and Baloyi (carried out in 1997) (Hanass-Hancock, 2008:17).

2.4.1   The notion of disability in KwaZulu-Natal

2.4.1.1   The notion of natural causes

In regarding nature as a factor in causing diseases and abnormalities, Zulu-speaking people see natural forces as operating on different levels. Ngubane (1977) describes two categories: the first deals with the symptoms and the body itself while the other looks at the environment. What is important for people in KwaZulu-Natal, however, is to treat the symptoms and to understand why a person is affected by a certain abnormality at a certain time.

Umkhulane – diseases of general character

Most diseases in this category are referred to as *Umkhulane*. This term means that an 'illness just happens', ranging from serious epidemics like pox to common colds. Diseases in this category are seldom associated with disability.

Ufuzo – family-related explanations

One of the most common interpretations of mental and physical disabilities is *Ufuzo*. A disability that is obvious from birth or has been acquired shortly afterwards is said to be inherited. In most cases, the father, or his family, will reject the child with the explanation that the child must be from another man, as they have no family members with disabilities.

As a result, the mother and child can be rejected and sent back to live with the mother's family. The notion of *Ufuzo* also causes many problems for CWPDs as they are often not believed to be capable of having children.

Imihkondo – environmental causes

Certain animals, especially wild animals, are believed to leave dangerous tracks, *Imihkondo*. They can be left on the floor or in the air. Often these tracks are associated with witchcraft and the belief that someone had purposefully planted a substance in a person's path so as to ill treat them. These tracks are usually invisible and one can contract a disease or disability by accidentally stepping over or inhaling them. If the *Imihkondo* is caused by witchcraft, a *Sangoma* can give the affected child something they can use to protect their home.

Moral and sexual causes

Adultery and moral misconduct is not only believed to cause disease and death, but also to cause permanent damage and disability to children. This is only believed possible if one has lost the protection of the ancestors, who probably do not approve with the morally loose behaviour of their descendents. This results in a loss of protection by the ancestors through misconduct.

2.4.2   Modern science and biomedical models

An increasing number of people are being exposed to biomedical models and explanations of disability. These are often based on knowledge acquired through formal education. It is therefore not surprising that this knowledge is taken into account when people explain the causes of disability. Words that have their origin in physiological studies like 'brain damage' are used to explain such causes. Parents/caregivers who use these kinds of explanations will consult a formally educated doctor if they conclude the problem belongs in this area of expertise. Usually these doctors use Western types of medicine. The child will then be seen as 'normal' and the disability as 'manageable'. It will not then be necessary to perform any rituals. In the African context identifying the natural causes of the 'problem' is crucial in interviews conducted by Clacherty, Matshai and Sait (2004) and Hanass-Hancock (2008), as well as my interviews which will be discussed in chapter 5; the problem of attitudes was a recurring theme. Negative attitudes can also be described as stigmas, which are in general understood as an attribute that triggers social discredit. The social implications of such negative attitudes are the denial of privacy, superficial acceptance and the status of being a

non-person. This results in incorrect and demeaning terminologies which CWPDs then have to deal with (Hanaas-Hancock, 2008:418).

If incorrect terminologies are used, the views of and attitudes towards children with disabilities will never change. Some negative terminology to be avoided includes the following:

- **Afflicted with** – this conveys a tragic or negative view of disability.
- **Suffering from** – this confuses disability with illness and also implies that a disability may be a personal burden. Increasingly, people with disabilities view their disability as merely a negative rather than a positive experience.
- **Crippled by** – rather use the phrase 'the person has ...'
- **The disabled** – rather use the term 'children with disabilities'. This is the latest accepted term according to the International Classification of Functioning (ICF)**,** and is used as the noun comes first; consequently, by using the noun first one is not announcing and labelling the child first, for example he is a *severely disabled child*. It further implies that the child has other characteristics as well.

Other terminology referring to CWPDs includes:

- **Wheelchair bound** – person who uses a wheelchair
- **Special** – everyone is special!

Typical definitions based on a restricted perception of disability are those historically offered by the World Health Organization (WHO, 2004:1):

- **Impairment** – any loss or abnormality of psychological, physiological or anatomical structure or function
- **Disability** – any restriction or lack, resulting from impairment, of ability to perform any activity in the manner or within the range considered normal for a human being. A disability can also be seen as the result of a medically definable condition that limits a person's movements, senses or activities.
- **Handicap** – a disadvantage for a given individual resulting from an impairment or disability that prevents the fulfilment of a role that is normal depending on the age, sex, social and cultural factors associated with that individual. A handicap is therefore a

barrier or circumstance that makes progress or success difficult, such as impassable stairs (http://fs.fed.us/eng/toolbox/acc/acc02.htm).

2.5 COMMUNITY BELIEFS WITH REGARD TO CAUSES OF DISABILITY LEADING TO NEGATIVE ATTITUDES

The aetiologies of disability in the black communities clearly differ from the causes of disabilities as stated by various Western researchers in the past, such as Louw, Meiji and Warner (in Baloyi, 1997:65). A clearer and better perception of the community's myths and beliefs could be directed at the perceived cause of disabilities.

- Uncooked liver – marriage between cousins should be purified by eating the liver of a slaughtered cow or goat prepared for the wedding feast.

- Pregnant women are not permitted to look at people with disabilities as it is believed that they will produce a similar child.

- Laughing at people with disabilities – the belief existed among the black communities that if one laughed at people with disabilities or ridiculed them, one would be the next victim of disability.

- Many black people today (this was confirmed in the researcher's study) still believe in the influence of witchcraft and believe that disabilities are associated with witchcraft.

- Taboos – many black people believe in taboos. If one fails to respect any taboo, the child will have a disability.

- Many boyfriends – according to African tradition if a girl has many boyfriends before she is married, and eventually marries her firstborn will be born with a disability.

- Divorced man – if a man has divorced his first wife and remarries, the new wife is not allowed to use the property of the first wife. If she fails to observe this restriction, there is a possibility of producing a child with a disability.

- Albinism – in the black community there is a belief that albinism is a result of adultery or punishment for the bad deeds of the parents.

- Sexual intercourse with parents – if a girl is molested by her father, there is a strong possibility that her child will have a disability.

- Blaming a mother for the birth of a child with a physical disability because she might have touched someone with a disability during pregnancy (MDDA, 2009:6).

2.6   EXTERNAL FACTORS THAT MAY BE RESPONSIBLE FOR DISABILITIES IN THE BLACK COMMUNITY

According to South Africa's Integrated National Disability Strategy (1997:9), many factors are responsible for the rising numbers of people with disabilities and their consequent isolation from the mainstream of society.

2.6.1   Violence and war

Disabilities are caused by violence, especially against woman and children, injuries as a result of landmines, and psychological trauma.

2.6.2   Poverty

Disabilities are caused or exacerbated by overcrowded and unhealthy living conditions. Disability feeds on poverty and poverty feeds on disability. This factor will be discussed in depth in this research study.

2.6.3   Lack of information

People do not have accurate information about disability, its causes, its prevention and its treatment. This is because of a high illiteracy rate and poor knowledge about basic social, health and education services. This is particularly prevalent in the rural areas.

2.6.4   Failure of medical services

The occurrence of disability is increased by the inadequacy of primary health care and genetic counselling services, weak organisational links between social services and the faulty treatment of the injured when accidents do occur. This research study will show how prevalent these causes are in the rural areas of KwaZulu-Natal.

2.6.5   Unhealthy lifestyle

Disability is caused by the misuse and/or abuse of medication as well as the abuse of drugs and other substances. It is also caused by deficiencies in essential foods and vitamins – a huge problem in the rural areas. Disability may also be caused by stress and other psychosocial problems in the changing society in the rural areas.

2.6.6   Environmental factors

Disabilities are caused by epidemics, accidents and natural disasters; pollution of the physical environment, and poisoning by toxic waste and other hazardous substances. Such conditions

are common in rural areas where the community is dependent on water from rivers and, to make matters worse, there is no sanitation in many areas.

2.6.7   Social environment

The fact that people and children with disabilities are marginalised and discriminated against creates an environment in which prevention and treatment are difficult.

2.7   THE INFLUENCE OF THE RURAL COMMUNITY'S TRADITIONS ON ATTITUDES AND FEELINGS TOWARDS CHILDREN WITH PHYSICAL DISABILITIES

Among the communities in rural areas "there is little if any room for the concept of chance in the worldview" (Philpott, 1995:20). Religion and culture thus provide the construct for the traditional approach to disability. These beliefs give the framework for ongoing research and a *cause* for understanding the reasons for the occurrence of disability in rural communities.

Many authors have written about the ethno medicine and causality concepts within traditional belief systems (Philpott, 1995:20; Baloyi, 1997:66; Ashforth, 2005:292; Hanass-Hancock, 2008). The researcher investigated these beliefs and found that they have not changed since Philpott did her research in 1995. Masasa, Irwin-Carruthers and Faure (2005:41) had similar findings. The findings of the research in this regard will be discussed in depth in chapter 5. Suffice it to say here that, in many African cultures, disability is frequently seen as punishment or the result of ancestral anger or retribution by divine forces. These may be the result of

- neglect of simple customs or requests of the ancestors, indicating a lack of respect for their needs and wishes
- omission of a particular custom (such as the ceremony performed for the deceased head of a household to bring him back to the home of an ancestor)
- unethical behaviour of the family
- jealousy of neighbours who have resorted to the use of witchcraft (Philpott, 1995:20)

2.8   THE ROLE PLAYED BY WITCHCRAFT IN THE FORMING OF ATTITUDES AND FEELINGS TOWARDS THE DISABLED

It is important to discuss witchcraft together with disability, as witchcraft is still seen as a cause of disability. The researcher interviewed *Sangomas* (African Healers who play an

important part in South African history. Within the communities visited the term Sangoma is used to describe a holy man or woman a skilled diviner and healer within the tradition of the Zulu people- they are a crucial part of tribal life and customs) and has found in this study that the association of witchcraft and disability continue to play an important part in the causes of disability and the pursuant negative attitudes. This is not very different to the findings of Masasa *et al.* (1995, 2005:42), who obtained the following responses in one of their interviews:

> "Because my husband chose to marry me instead of their daughter, they decided to make me barren. I have only this one child who they also bewitched. He cannot talk or walk."

> "They put this medicine for me when I was pregnant. My body was full of that medicine and it passed to my child."

2.9   THE ROLE OF CULTURE AND ATTITUDES IN RURAL COMMUNITIES

The use of the concept of culture places disability in its proper context, especially in relation to attitudes and attitude change in the community (Kisanji, 1995:1). Sociological studies of culture have adopted a broad interpretation to include symbolic aspects of human society, such as beliefs, rituals, customs, values and norms, as well as work and patterns of leisure activities. These interpretations describe a diffuse view of culture as a shared 'way of life' – what we think and how we act (Barnes & Mercer, 2007:89). Community attitudes are an expression of people's culture. A study of some aspects of culture ought to reveal generally held beliefs about disability and CWPDs. These aspects may include customs, paintings, drawings, carvings and the folklore and language used in relation to disability and CWPDs (Kisanji, 1995:5).

As Bronfenbrenner is central to this research study it is vital that we examine his ecological theory pertaining to culture.

2.9.1   Bronfenbrenner and culture

The macrosystem includes plans for defining and organising the institutional life of the community, including the overarching patterns of culture, values, laws, customs, resources of culture and society.

The outermost level of Bronfenbrenner's model is the macrosystem. This is not a specific context, but instead refers to the values, laws and customs of a particular culture. The macrosystem encompasses the total culture in which the community lives. 'Total culture' in this regard refers to the behavioural patterns, traditions, beliefs and mores and all the other traits and pursuits that are endemic to a group of people and that are passed on from one generation to another.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON CULTURE

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child such as family & peers . It is essential for the child to be included in all family activities.

This is the *Mesosystem.* It consists of linkages and interrelationships between two or more of the developing child's microsystems. Exposure and integration of the CWPDs is crucial.

This is the *Exosystem.* Meaning outside, the child is not an active participant in this system eg. The school board, centres need to be provided for recreation such as parks.

This is the **Macrosystem.** It consists of legislation and laws .

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

THE CWPD'S

Figure 2.2:   Bronfenbrenner's perspective on culture (Adapted from Bronfenbrenner, 1994).

Positive attitudes begin at government level, where equality is legislated. This filters down to the exosystem where positive attitudes need to be carried out by school boards and for example the promotion of recreation centres for all. The mesosystemic and microsystemic levels are crucial as this is where CWPDs are directly involved.

The priority that the macrosystem gives to CWPDs living in rural areas will affect the support they receive at the lower levels of the environment, that is, the exo-, meso- and microsystemic levels. It is evident at this stage of the research study that the ecological systems theory is of applied significance, since it suggests that interventions at any level of

the environment can enhance development. For example, at the exosystemic level, if school boards have courses encouraging teachers and schools to hold positive attitudes towards the CWPDs and to promote inclusion and provide support and training where interaction takes place, this will filter through to the mesosystem and then to the microsystem. Here, in the microsystem, parents teach respect and acceptance for all. Bronfenbrenner emphasises here that a change at the macrosystemic level is particularly important because it affects all other environmental levels, revising established values and programmes in ways more favourable to positive attitude building and acceptance, and will ultimately have the most far-reaching impact on the child's wellbeing. Today in South Africa CWPDs have equal rights. Accordingly, the macrosystem behind the legislation that gives them such rights is rooted in the principles of equal opportunity (Ahuja, 2001: 2).

In terms of inclusion today, more research (Ashforth, 2005) is examining the use of culturally specific practices, such as the consultation of Sangomas (A traditional Zulu leader and respected elder), to rid the CWPDs of their disabilities. The contributions of Vygotsky in 1978 (Presseisen & Kozulin, 1992, 5-42). have played a major role in this trend. Vygotsky's perspective, termed 'sociocultural theory', focuses on the way in which culture – the values, beliefs, customs and skills of a social group – is transmitted. According to Vygotsky, social interaction (inclusion and exclusion) – in particular, cooperative dialogues between children and more knowledgeable members of society – is necessary to acquire the ways of thinking and behaving that make up a community's culture. Vygotsky's sociocultural theory takes a closer look at the social relationships that foster development; hence, an understanding of this development by professionals working towards inclusion will hopefully assist them with the difficult task of changing negative attitudes in the rural areas and promoting an understanding of the true causes of disability (Tissington, 2008:1).

Charlton (2000:25) agrees with this thinking and believes that culture is sustained through customs, rituals and mythology, each of which inform the beliefs and attitudes that contribute to disability. Culture exerts a profound influence on the way in which people think and what they think and how they act. This fits in with Bronfenbrenner's theory, as he maintains that the way that people think begins in the microsystem and ripples through to the meso- and exosystemic levels.

Furthermore, Riddell and Watson (2003:1) explore disability through the lens of culture. The socially dominant culture shapes the way in which disability will be viewed in the community

and, in turn, contributes to either positive or negative attitudes towards CWPDs. In a multicultural, multiracial and multilingual society such as South Africa, a lack of awareness of the diverse cultural beliefs and attitudes may hinder the social inclusion of CWPDs, leading to misunderstandings between community members and CWPDs and their lack of acceptance and inclusion. An understanding of the different cultures in South Africa can help to develop and promote societal and educational inclusion and reduce other negative influences that this group of children face. Disability Information Resources (1999:1) echoes the need for understanding disability, as this understanding in a socio-cultural context is critically important and deserves serious consideration. Knowledge of traditional beliefs and practices with regard to disability is of vital importance if we are to plan and implement inclusive programmes for CWPDs that will make a real difference in their lives and the lives in the rural communities in which they live.

According to Masasa *et al.* (2005:40), different belief systems give rise to different attitudes and practices relating to disability, which may have impact on important aspects such as rehabilitation.

2.9.2   Culture: a constant state of change in South Africa

Culture is not static – it is constantly changing and responding to shifting environments and circumstances. Within each culture there are many subcultures, which may mean that many beliefs, values, attitudes and behaviours are not shared by all people from the same culture (MDDA, 2009:1). This is especially true in South Africa where we share a multitude of cultures, languages and beliefs. Apart from a few very isolated communities in rural South Africa, all cultures are exposed to external influences. The rate at which cultures are exposed to external influences today is greater than ever before (MDDA, 2009:2). In addition to the external influences, within each culture there are internal tensions and pressures. Culture prescribes how we make sense of disability and respond to people with disabilities. In almost all societies certain types of disability are far more acceptable than others. This acceptability does not seem to be determined arbitrarily in cross-cultural contexts, but seems to be closely tied to how society explains the appearance of that specific kind of disability. In a multicultural, multiracial and multilingual society, a lack of awareness of the diverse cultural beliefs and attitudes may hinder the outcome of inclusion. The International Classification of Functioning (ICF) (Mont, 2006:10) stresses that 'participation' is the essential component of functioning in the home, school, recreational facilities and community.

Thus, participation in all aspects of life is influenced by positive attitudes. While some factors are physical, others reflect the knowledge, attitudes and beliefs of certain communities, in the case of this study, rural communities. Therefore, cultural practices are determinants of contextual factors (Masasa *et al*., 2005:40).

These beliefs can affect the terminology used in describing CWPDs:

Terminology of disabilities

Some terminology used with regard to the disabled is demeaning, for example, there is a certain elitist arrogance based on biological superiority in the concept 'able-bodied'. On the other hand, a term such as 'non-disabled' implies a continuum of all people and indicates that disability affects everyone (Carson, 2009:15).

Based on the fact that this kind of definition is so seriously at odds with the daily experiences of people with disabilities change became a necessity. It was clear to people with disabilities that, in the absence of any cure for their physical condition, the disability must be regarded as a *given:* a constant factor in the relationship between themselves and the society with which they attempt to interact (Carson, 2009:7).

Words when used carelessly hurt as much as any injury. It is imperative that educators and the community understand the correct words for CWPDs that do not ridicule or humiliate them. Using the correct terminology helps maintain their dignity.

Not using the correct terminology leads to stereotyping (Heijen, 2005:4). Stereotypes are often expressed in sentences beginning with 'All children with physical disabilities …' or 'All wheelchair users …' almost always followed by a broad sweeping statement. One of the problems with stereotypes is that they become the principle identifying characteristic for a child with a particular disability and distort further understandings of this disability. Stereotypes lead to prejudice and create barriers and a climate of insiders and outsiders, of 'us' and 'them'. Stereotypes can also lead to barriers that prevent CWPDs from accessing services or places, resulting in exclusion. Hence, the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modification necessary for full participation of CWPDs in all areas of life (Heijen, 2005:4). The use of neutral language is a helpful challenge in the practice of using discriminatory and offensive language sometimes found in questionnaires or other data collection instruments.

Like other minorities, the disabled community has developed preferred terminology – 'people-first' language (Ability Magazine, 2010). More than a fad or political correctness, people-first language is an objective way of acknowledging, communicating and reporting on disabilities, as it eliminates generalisations, assumptions and stereotypes by focusing on the person rather than the disability. As the term implies, people-first language refers to the individual first and the disability second. Equally important is to establish if it is even relevant and if the disability in fact needs to be mentioned when referring to individuals, in the same way racial identification is being eliminated from news stories in South Africa when it is not significant, hence the term CWPDs as used in this study. This is despite Heijen's belief (2005:4) that new terminology such as PWDs (persons with disabilities), CWDs (children with disabilities) and, in this study, CWPDs is to be seen as demeaning and that children should not be made into acronyms. However, terminology in this study is people first and the use of acronyms is for ease of reading, writing and research and is therefore not considered by the researcher to be demeaning.

Models of disability are used as tools for defining and understanding disability for the researcher in this study. These models will be discussed in the following section.

2.10   MODELS OF DISABILITY

Models are a useful framework in which to gain an understanding of disability issues, and also of the perspective held by those creating and applying models. Stated simply, a model is a framework for understanding information (Carson, 2009:5). Models of disability are essentially devised by people about other people. They provide an insight into the attitudes, conceptions and prejudices of CWPDs and how they impact on them. Accordingly, models reveal the ways in which our society provides or limits access to work, assistive devices, services, economic influence and political power for people and CWPDs.

The development of models makes provision for a continuum of changing social attitudes to disability and where they are at a given time. With an understanding of models in this study, it can be seen that a future objective should be to develop and operate a cluster of models that will not only assist in reducing the negative influences facing CWPDs, but will also empower them, giving them full and equal rights alongside their peers (Connections for Human Leadership, 2010:1). Essentially the models have no policy implications (Samaha, 2007:1).

There are several models (belief systems) of disability, of which three distinct models are the medical model, the social model and the biopsychosocial model. Models of disability are tools for defining disability and, ultimately, for providing a basis according to which government and society can devise strategies for meeting the needs of people with disabilities. These models are often treated with scepticism as it is thought they do not reflect a real world, are often incomplete and encourage narrow thinking, and seldom offer detailed guidance for action. However, they are a useful framework in terms of which to gain an understanding of disability issues, and also of the perspective held by those creating and applying the models. Models reveal the ways in which our society provides or limits access to work, goods, services, economic influence and political power for people with disabilities (Connection for Human Leadership, 2010:1).

For the purposes of this research study, disability will relate to a child's disadvantages in terms of the combination of personal traits and social settings (Samaha, 2007:1). The first model to be discussed will be the medical model.

2.10.1 THE MEDICAL MODEL OF DISABILITY

Looking at figure 2.3, it is clear that the problem lies with the child: this is the basis of the medical model. In terms of the medical model, disability is understood as an individual problem. If someone has an impairment – a visual, mobility or hearing impairment, for example – their inability to see, walk or hear is understood to be their disability (Carson, 2009:5).

In Western science and clinical medicine, the medical approach views disability as the diagnosis of some kind of illness or deficit, primarily motoric or cognitive in nature. This is, however, offensive to many people with disabilities because of the implication that the disability is an inherent trait within the individual and, in essence, pathologies the person with the disability. Disability rights activists maintain that functional limitations, such as the inability to walk, are characteristics of the person's existence but say nothing about his or her essential character (Carson, 2009;70. There are some people who simply do not want to be categorised in any manner as having a disability; in sensitivity to these issues the WHO (2002) defines health as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity". There is no prevalence data on the numbers of individuals who do not want to be counted as 'disabled' and the particular 'disability' groups

they would comprise if counted. Cultural barriers compound the current prevalence and definitional difficulties and demonstrate the need for a philosophy and climate of inclusion for various groups of people with disabilities and parents of children with disabilities in determining definitional standards to be used in gathering data (Marge, 2000:132).
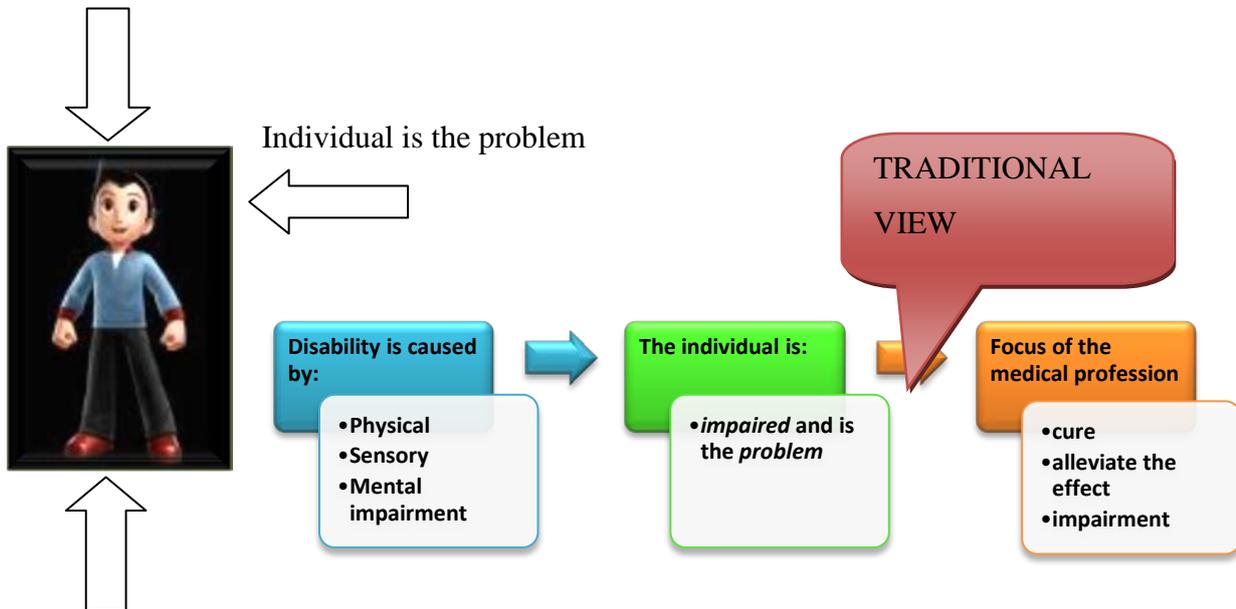
Figure 2.3:   The medical model of disability (adapted from the International Classification of Functioning (ICF) (WHO, 2002:9).

Disability in South Africa, particularly in the rural areas, is couched within a medical and welfare framework, with a strong emphasis on medical needs. This has resulted in neglect of the wider social needs, resulting in the exclusion of people and children with disabilities from mainstream society. In acknowledgement of this exclusion and the movement towards placing disability within a human rights framework, the government has developed the Office on the Status of Disabled Persons to monitor and coordinate access to fundamental rights for people with disabilities (Maart, Eide, Jelsma, Loeb & KaToni, 2007:359).

The medical model of disability also affects the way people with disabilities think about themselves. Many people with disabilities internalise the negative message that the problems of all people with disabilities stem from not having 'normal' bodies (Carson, 2009:8). CWPDs who grow up excluded are led to believe that their disabilities automatically prevent them from taking part in social activities (SAiF, 2009:8). This is especially prevalent in the rural areas. This internalised oppression can make CWPDs less likely to challenge their

exclusion from mainstream society. Subsequently, the social model was created by people with disabilities themselves primarily as a reaction to society's response to them, but also as a result of their experience of the health and welfare system which made them feel socially oppressed (Carson, 2009:9). The denial of opportunities, the restriction of choice and self-determination and lack of control over the support systems in their lives led them to question the assumptions underlying the traditional dominance of the medical model. The social model will be discussed in more detail in section 2.10.2.

2.10.1.1 Using the medical model and terminology

Although, the medical model no longer classifies disability by name, as the social model is now preferred, this is not always practical or feasible. In the researcher's experience, when drawing up class lists it is essential to know, for example, whether the teacher will have four quadriplegics (involvement of all four limbs) in a class or a diplegic (involvement of lower limbs). Such aspects include classroom space and arranging the layout to accommodate wheelchairs, as well as planning the need for specialised desks and chairs, as specialised seating is crucial to successful inclusion. Quadriplegics need assistance with feeding and prior knowledge of correct feeding methods is vital. Furthermore, teachers need to learn about and research the different disabilities that exist so as to be familiar with and knowledgeable about the specific disabilities of the children they are going to teach. For this research study the abbreviation CWPDs is used only for children with *visible* physical disabilities, as living in a rural area with a physical disability exacerbates their problems, and moreover, as a physical disability is immediately seen and people frequently view the disability before the child. Therefore, CWPDs have to face these negative attitudes.

The medical model has had and continues to have a profound influence on societal attitudes and public policy and, hence, cannot be discarded. In the field of disability, the medical model is useful in the management of severe symptoms using drugs. Work in the development of prosthetic limbs, for example, is to be lauded (http://severedisabilitykid.blogspot.com). Today, the medical model cannot be discarded because of the high degree to which medical solutions, such as surgeries, orthotics and clinical physical therapy, are emphasised, and the way they are intended chiefly as a way to 'normalise' a person with a disability's participation in society as much as possible. The medical model also has the advantage that it looks at disability or managing disability from a scientific perspective. It is important to bear in mind that a just society invests resources in

health care and related expenses to allow people with disabilities to function in society by being able to adapt the environment for them. This is the basis of the social model.

2.10.2 The social model of disability

In contrast to the medical model, the *social model* of disability argues that the 'problem' should not be located within the individual person, but rather in a 'disabling environment' which excludes and denigrates people with disabilities (Thompson, 2005:111; Carson, 2009:9; Swain, French, Barnes & Thomas, 2004).

Morris's diagram (Figure 2.4) below shows that it is not the disability itself which is disabling, but rather the social forces that exclude, marginalise and oppress disability. Morris sums it up in one sentence: "it is not the inability to walk which disables someone but the steps into the building" (Thompson, 2005:118).
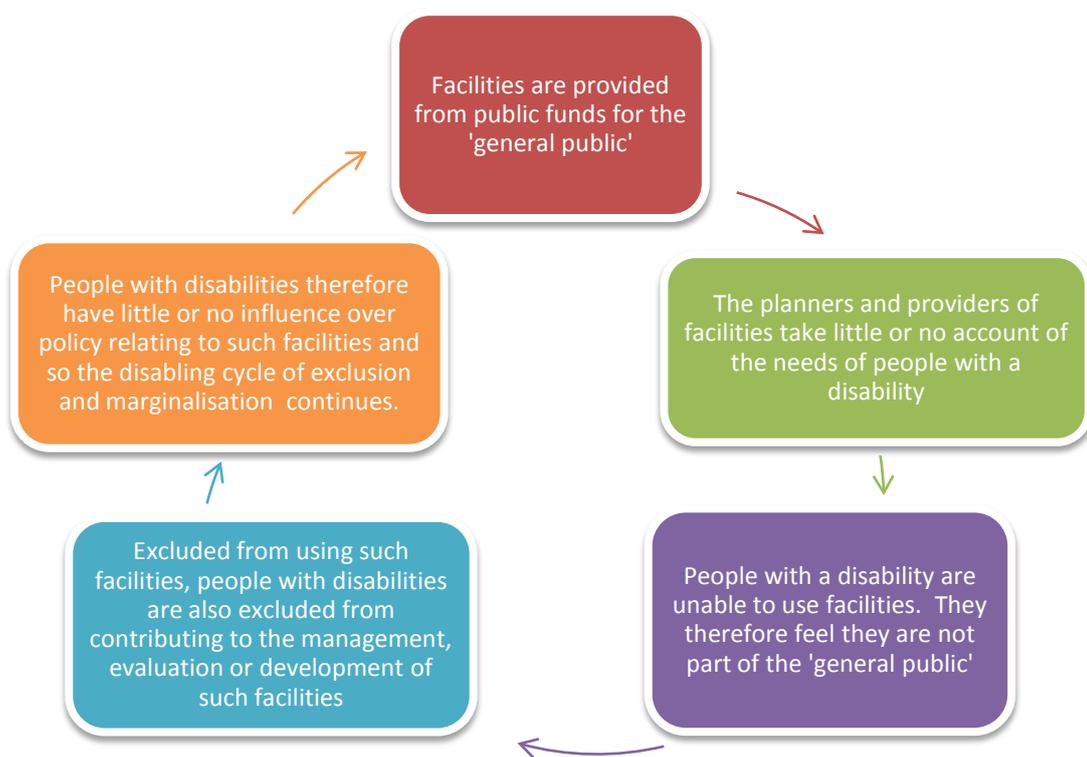
Figure 2.4:   Morris's 'vicious' cycle of exclusion based on the medical model

To overcome the vicious cycle of exclusion based on the medical model the social model has been developed as discussed below.
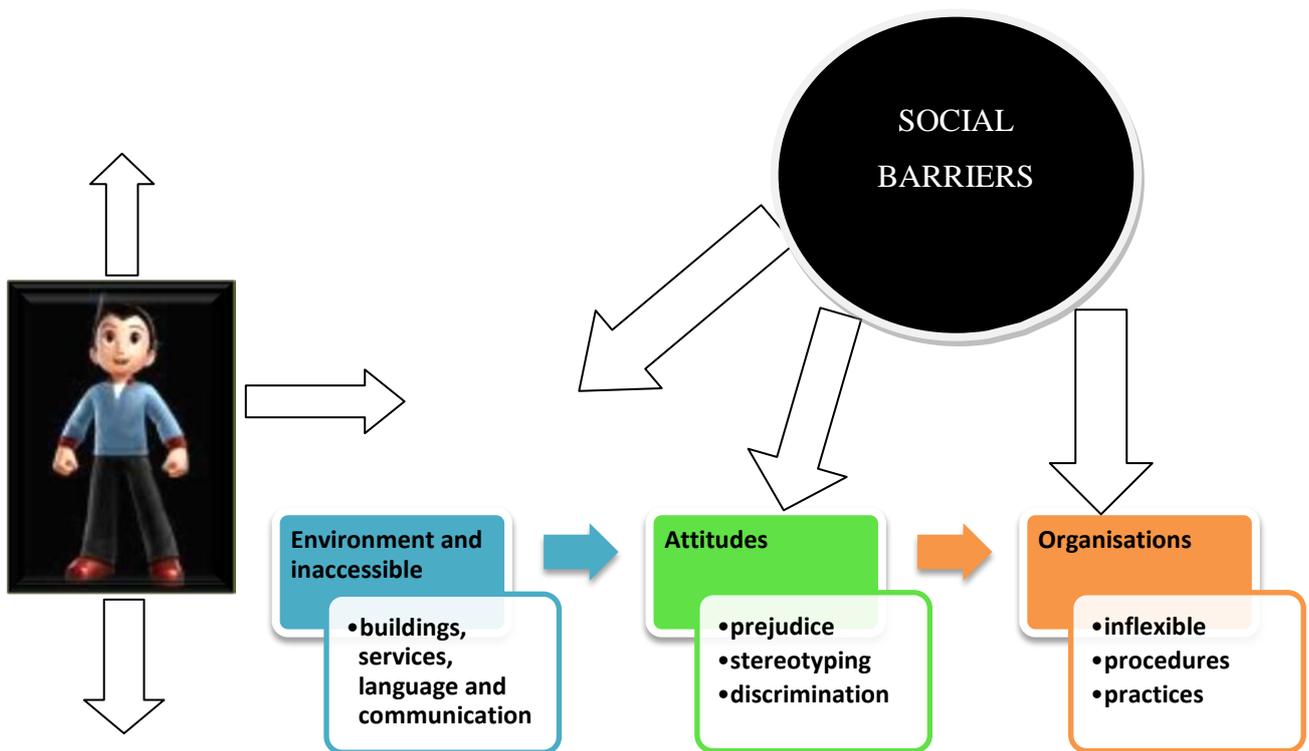
Figure 2.5:   The social model of disability adapted from the ICF (2002)

Figure 2.5 provides a clear illustration of the contrast between the social model and the medical model of disability. In this diagram it is clear that it is not the child that is seen as the problem, but rather society. This model has had a profound effect on academics, politics and the law since the 1970s (Samaha, 2007:1). Although the model had not been formally named in 1983, Mike Oliver adopted the phrase "the social model of disability" to reflect the growing demand by disabled people for a more holistic approach to the problems they encountered (Moodley, 2006:1).

If we look at the definition of disability given earlier in the chapter, and look at the social model of disability as follows, we will note that the difference is caused by society and not by the individual.

Disability is "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities" (Riddell & Watson, 2003:3).

Proponents of the social model of disability therefore argue that people with disabilities should concentrate on developing a shared culture of politics which focuses on the material causes of oppression (Riddell & Watson, 2003:5; Carson, 2009:9).
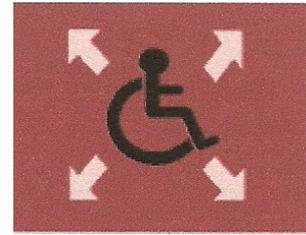
Thus, this model does not deny the problem of disability but locates it squarely within society; the problem is society's failure to provide appropriate services and adequately ensure that the needs of people with disabilities are fully taken into account in its social organisation. Hence, disability, according to the social model, is all the things that impose restrictions on children with disabilities, ranging from individual prejudice to institutional discrimination, from inaccessibility to public buildings to the unusable transport systems that are so prevalent in the rural areas.

2.10.2.1   A shift from the medical model to the social model

In the table below one can observe a shift from the medical to the social model in a number of characteristics. Elements of the new paradigm can be observed as empowering the person with a disability and shifting the emphasis to changing the environment, as opposed to changing the individual.

Table 2.1:   A comparison between the medical and social models of disability

MEDICAL MODEL	SOCIAL MODEL
Individual is faulty	Individual is valued
Diagnosis	Strengths and needs defined
Labelling	Identify barriers and develop solutions
Impairment is focus of attention	Outcomes-based programme designed
Assessment, monitoring, programmes of therapy imposed	Resources are made available; ordinary services
Segregation and alternative services	Diversity welcomed; child is included
Re-entry if normal enough OR permanent exclusion	Training for parents and professionals; relationships nurtured
Society remains unchanged	Society evolves

Source: adapted from the ICF (2005)

As with the medical model the social model has flaws. The ugly side of the social model is characterised by anti-cure, anti-treatment rhetoric, an over-the-top effort at altering disability related language and an 'either/or' mentality – either you support full inclusion or you believe in locking up people with disabilities. The social model frequently leads to the creation of

serious challenges for those seeking prevention/treatment/cure-related research and assistance. The extremists of this model, who insist on full inclusion, completely deny the fact that there are disabilities that are so severe that, without some sort of treatment or safe place, it is impossible to live 'in' society at all. Furthermore, it does not seem to acknowledge that appropriate treatment, cure or even special environments can be considered positive societal accommodations of disability.

The socio-medical model is another model that places responsibility on society to fully recognise and accept the many expressions of disability, to root out common stereotypes and to accommodate all disability in the most appropriate manner. Defining 'appropriate' depends on the type and severity of the disability and includes the possibility that some kinds of disability are best accommodated *outside the norms of common society.* A socio-medical model teaches that human value is intrinsic and not dependent upon the physical presentation of the individual. It allows that prevention and cure modalities, coupled with the concept of intrinsic value, are appropriate societal accommodations of disability. The socio-medical model of disability is 'the golden mean' for society (http://severedisabilitykid.blogspot.com).

In conclusion, the human rights approach to disability has led to a shift from a *child's limitations* arising from impairments, to *barriers within society,* that prevent the child from enjoying their rights as espoused in the South African Constitution. The literature on the models of disability is extensive. As discussed above, the two major models have been debated over and over. This has led to the development of the biopsychosocial model of disability which is discussed below.

2.11   THE BIOPSYCHOSOCIAL MODEL

On their own, neither the medical model nor the social model is adequate, although they are primarily valid. Disability is a complex phenomenon that is both a problem at the level of a person's body and an interaction between features of the person and features of the overall context in which the person lives; some aspects of disability are almost entirely internal to the person, while other aspects are almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention.

A better model of disability, in short, is one that synthesises what is true in both the medical and the social models, without making the mistake each makes in reducing the whole,

complex notion of disability to one of its aspects. On their own, the medical and social models are partially valid but not adequate, so a synthesis of both models is the most useful approach. The latest International Classification of Functioning (ICF) from the WHO is based on the *biopsychosocial model* which is an integration of the medical and social models and provides a coherent view of different perspectives of health – biological, individual and social (WHO, 2002).

The ICF adopts a biopsychosocial model of disability that incorporates what is true and useful in both models, and rejects what is counterproductive and distorted WHO, 2002). Disability is a complex phenomenon that includes both a dimension at the level of a person's body, and a dimension that is a complex and primarily social phenomenon. By the same token, environmental and social interventions are relevant for dealing with restrictions in a person's participation in educational, economic, social, cultural and political activities, that is, from the microsystemic level through to the macrosystemic level. It is for these reasons that this model is used in this research study, as it complements Bronfenbrenner's bioecological model, which is discussed in detail in chapter 3.

The biopsychosocial model embedded in the ICF broadens the perspective of disability and allows medical, individual, social and environmental influences in functioning and disability to be examined. Furthermore, advocates of both models can use the ICF as a platform for communication, and for choosing and comparing interventions.

Having examined the different models, the logic of following a middle path comes to mind. In Buddhism, the 'middle path' refers to neutral, upright and centred – extremes are to be avoided, whether good or bad. It means to investigate and penetrate the core of life and all things with an upright, unbiased ground. In terms of this study, we have to investigate the problem from various angles and viewpoints, analyse the findings, understand the truth thoroughly, and find a reasonable conclusion.

2.12   INTERNATIONAL CLASSIFICATION OF FUNCTIONING (ICF)

The International Classification of Functioning (ICF) is the WHO's framework for health and disability. It is the conceptual basis for the definition, measurement and policy formulations for health and disability. According to the ICF (2005), the term *functioning* refers to all bodily functions, activities and participation, while *disability* is an umbrella term for all impairments, activity limitations and participation restrictions. In terms of the ICF, disability

and functioning are viewed as outcomes of interactions between *health conditions* (diseases, disorders and injuries) and *contextual factors.* Among these contextual factors are external environmental factors (e.g. social attitudes, legal and social structures) and internal *personal factors,* which include gender, age and coping styles, social background and education, and other factors that influence the way disability is experienced by the individual. Thus, the ICF conceptual framework is based on the social model of disability. By contrast, previously disability began where health ended; once you were disabled you were in a separate category (WHO, 2002:3).

The ICF (WHO, 2002) therefore appears to be a simple health classification; however, it can be used for a number of purposes, the most important being a planning and policy tool for decision makers, which is especially important in documents that, for example, promote inclusive education. The ICF casts the notion of 'disability' in a new light.

Figure 2.6 below reflects three levels of human functioning classified by the ICF: functioning at the level of body or body part, the whole person in a social context. Disability therefore involves dysfunction at one or more of these same levels; impairments, activity limitations and participation restrictions. At the same time, the dimensions of disability are independent. As the diagram indicates, in the ICF, disability and functioning are viewed as outcomes of interactions between *health conditions* and *contextual factors.*

Among contextual factors are external *environmental factors;* for example, social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain and other contextual factors and internal *personal factors*, which include gender, age, social background and other factors that influence how disability is experienced by the individual.

In conclusion, the human rights approach to disability has led to a shift from a *child's limitations* arising from impairments, to *barriers within society* that prevent the child from enjoying his/her rights as espoused in the South African Constitution (McClain 2002:8) This is the essence of the social model of disability.
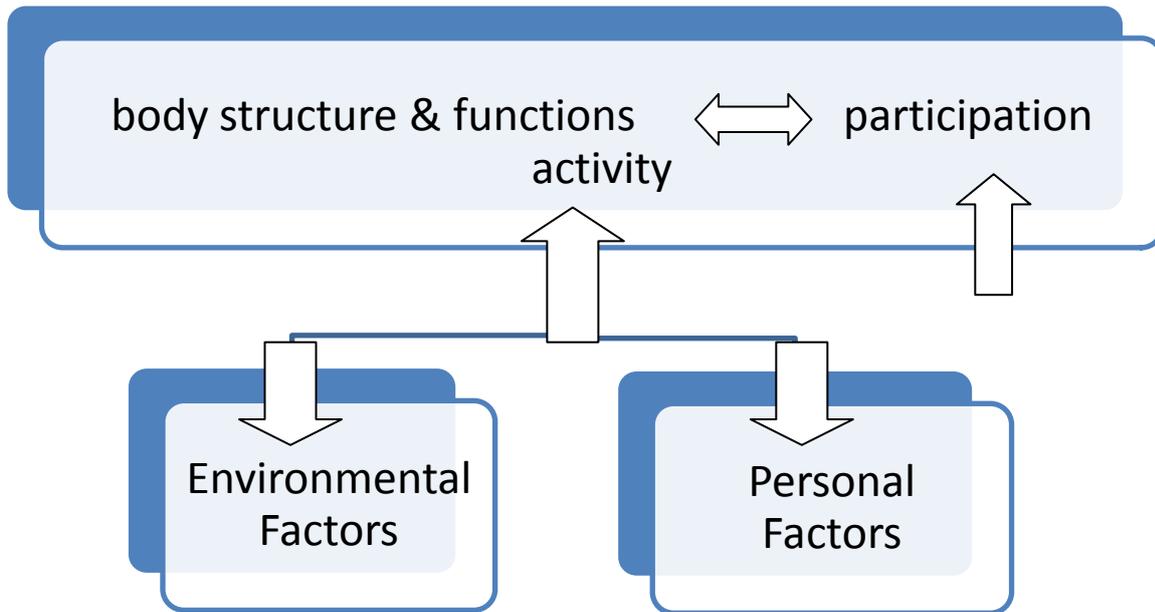
Figure 2.6: Diagram of the model of disability that is the basis for the ICF

In response to the above, the ICF was developed over a seven-year period when, in an international collaborative process, it was validated by means of field trials in over 70 countries before being officially endorsed by all the WHO member states in 2001 (WHO, 2005:13). This resulted in the creation of the International Classification of Functioning (ICF) in 2005, which is recognised internationally and by the WHO. Consequently, it was important to use it for this study. In addition, there are further beneficial uses of the ICF that are applicable to CWPDs in rural areas. These will be discussed in the following sections.

2.12.1 Policy development

In both the health sectors and the other sectors that need to take into account people's functional status, such as social security, employment, education and transportation, the ICF plays an important role. It goes without saying that policy development in these sectors requires valid and reliable population data on functional status. Legislative and regulatory definitions of disability need to be consistent and grounded in a single coherent model of the Disability Creation Process. This is an explicative model of the causes and consequences of disease, trauma and other disruptions to a person's integrity and development (Fougeyrollas, Cloutier, Bergeron, Cote & St Mitchell, 1998:1). Whether it is devising eligibility criteria for disability pensions, developing regulations and access for assistive technology, or mandating housing or transportation policy that accommodates individuals with mobility, sensory or

intellectual ability, the ICF can provide the framework for comprehensive and coherent disability-related social policy. In South Africa this includes policies that cater for CWPDs in particular, such as the *White Paper 6: Special Needs Education* (Department of Education, 2001) and *Guidelines for Full-Service/Inclusive Schools* issued in 2009, as well as South Africa's commitment to the MDGs. This is essential as if we intend to reduce the impact of the negative influences facing CWPDs in rural areas.

2.12.2 Economic analyses

Determining whether resources are effectively used in health care and other social services requires a consistent and standard classification of health and health-related outcomes that can be costed and compared internationally. To ensure that society can effectively prevent limitations on activities and restrictions on participation, it needs to cost the economic impact on functional limitations as compared to the modification of the built and social environment. The ICF makes both of these possible. This modification is clearly defined in the Promotion of Equality and Prevention of Unfair Discrimination Act No. 4 of 2000, which specifically requires the removal of obstacles that unfairly limit or restrict children from enjoying equal access. Furthermore, it prohibits the contravention of the South African Bureau of Standards (SABS) codes of practice or regulations that govern environmental access. In her parliamentary address on 16 April 2010, the Honourable Ms Noluthando Mayende-Sibiya, Minister for Woman, Children and Persons with Disabilities, affirmed South Africa's economic commitment to this vulnerable group and mentioned children in rural areas in particular. She further stated that South Africa is at present revising the National Policy of Disability and the National Plan of Action for Children. However, there was no indication of what financial aid would be available (South African Government Information, 2010).

2.12.3 Research purposes

Generally, the ICF (Mont, 2006:10) assists in scientific research by providing a framework or structure for interdisciplinary research in disability and for making research comparable. More recently, international concerns about health care outcomes have shifted to the assessment of functioning at the level of the whole human being in day-to-day life. The need here is for universally applicable classification and assessment tools, both for activity levels and overall levels of participation, in the basic areas and roles of social life, which is what the ICF provides and makes possible.

2.12.4 Environmental factors

One of the major innovations in the ICF is the presence of an environmental factor classification that makes it possible to identify environmental barriers and the ability to perform actions and tasks in daily living. With this classification scheme, which can be used either on an individual or group basis, it may be possible to create instruments that assess environments in terms of their level of facilitation or barrier-creation for different kinds and levels of disability (ICF, 2002:8). Using this classification scheme for either individual or population-wide data collection, it may be possible to create instruments that assess environments in terms of their level of facilitation or barrier-creation for different kinds of disability. With this information in hand, it would then be more practical to develop and implement guidelines for universal design and environmental regulations that extend the functioning levels of people with disabilities across the range of life activities. This study is very pertinent to intervention studies, as by investigating and understanding the impact of the negative influences that CWPDs face in the rural areas, guidelines could be put in place to reduce such negative influences.

The ICF offers an international, scientific tool for making the paradigm shift from a purely medical model to an integrated biopsychosocial model of human functioning and disability (ICF, 2010:2).

2.13 CLASSIFICATION AND DISCUSSION OF CHILDREN WITH PHYSICAL DISABILITIES

This study will concentrate on children with *visible* physical disabilities, as this is the area of interest to the researcher.

The term *physical disability is* broad and covers a range of disabilities and health issues, including congenital and acquired disabilities. According to the Individual's with Disabilities Education Act (IDEA), a United States federal law governing the way states and public agencies provide early intervention, special education, and related services to children with disabilities, a person with an orthopaedic impairment, brain injury, or other health impairment who, by reason of that disability needs special education and related services is considered to have a physical disability (http//wikidot.com/physical disabilities).

2.13.1 Types of physical disability

Physical disabilities and health conditions are classified either as congenital or acquired. Children with *congenital* conditions are either born with physical difficulties or develop them soon after birth. *Acquired* disabilities are those that result from injury or disease while the child is developing normally. The age at which a condition develops often determines its impact on the child, particularly in the rural areas where there is little if any early intervention and support (Morris, 2009:8-14).

Relatively uninformed rural communities have even less insight into strategies that should be available to help their children with special needs, and would be less inclined to lobby for or even demand services and relevant interventions for their children. It is widely accepted that early experience influences all areas of development. There may be critical periods for the achievement of certain skills and an inability to achieve these may lead to permanent deficits. Failure to provide early stimulation may not only lead to a discontinuation of normal development but may also in fact cause the situation to be exacerbated. Furthermore, failure to remediate one disability may multiply its effects in other developmental areas, and may produce secondary emotional handicaps. In addition, in the rural areas the parents need a great deal of support, encouragement and knowledge to manage their CWPDs. The prognosis for the child is often directly linked to the parents' support, commitment and enthusiasm (Venter, 2007:2). Sadly, in the rural areas of KwaZulu-Natal, the CWPDs have another negative factor and that is that very few CWPDs have both parents living owing to HIV/AIDs, and in many cases one parent has migrated to urban areas in search of work.

Disability can take place during the following stages:

Prenatal stage (before birth)
Many mothers in the rural areas live in extreme poverty which is characterised by poor nutrition and lack of access to adequate health care. Moreover, women in these areas often suffer from micronutrient deficiencies (Yeo, 2005:19). The current thinking is that at least 70 to 80% of cases of cerebral palsy (CP) begin before birth (emedicinehealth, 2005:1). In this regard, folic acid, a type of vitamin B, if used before and during pregnancy, prevents most neural tube defects (Medline Plus, 2011:1); however, supplying it to mothers in rural areas is virtually impossible. Furthermore, many mothers consume alcohol while pregnant, consequently producing children who suffer from Foetal Alcohol Syndrome (FAS).

Neonatal stage (immediately after birth)

Owing to a lack of access to hospitals and clinics in the rural areas of KwaZulu-Natal, many mothers have their babies at home where hygiene is not always adequate. Furthermore, should there be complications at birth there is no immediate help available. Premature babies thus do not always have the opportunity of being placed in an incubator, frequently resulting in brain damage. In addition, Rh factor incompatibility (which can be detected and treated in who receive proper prenatal medical care) causes many disabilities and fatalities.

Postnatal stage (any time after birth)

High rates of poverty make acquiring a disability more likely, as poverty is characterised by poor nutrition and lack of access to health care. Once again, micronutrient deficiencies mean that "children are left physically stunted or deformed condemning them to a marginal existence, or whether this is actually socially constructed, an interrelationship between poverty and disability is plain" (Yeo, 2005:19). Moreover, in the rural areas of KwaZulu-Natal typical conditions include a lack of sanitation and unhygienic, crowded living conditions, as well as insufficient or unhealthy food which, in turn, results in malnutrition, poor health and physical weakness. Near drownings, vehicle accidents and cerebral malaria can also result in disability.

It is important to note the association between social status and disability prevalence rates. Studies have confirmed that an odds ratio of 2.36 exists in this respect, that is, *that the families in the lower socioeconomic groups are almost two and a half times more likely to have a child with a disability.* Children with moderate to severe disabilities and chronic illness, including HIV/AIDS, form a particularly vulnerable group within our society. These children have the constitutional right to benefit from social security and social assistance (Guthrie, 2001:4).

2.14   CEREBRAL PALSY, ETIOLOGY AND CLASSIFICATION AND OTHER PHYSICAL DISABILITIES

As this research study does not concentrate on the medical model of disability, only a brief overview of disability types will be given here. This overview is intended to provide the reader with an understanding of the different types of visible physical disability researched in this study.

2.14.1 Cerebral palsy

The birth of a child with cerebral palsy often places the family in a dilemma. Awareness of society's ambivalence adds to the stress the family feels within themselves. CP is not a single disease, it is not inherited and it is non-progressive, although the clinical picture changes with time. Cerebral Palsy is a term used to describe a broad spectrum of motor disability CWPDs also experience the following: they develop seizures, ambulation can be clumsy, they may have severe speech disorders, learning problems are common, and there may be severe feeding and swallowing difficulties with excessive drooling. This excessive drooling is frustrating, as their clothing needs to be changed frequently or they need to wear a bib, which is humiliating for an older child. Children who drool also experience a great deal of teasing (Larkin, 2010:1).

From the above classification, the researcher will be referring to children who have a visible physical disability that requires special needs, assistive devices and intervention. It is also clear that the researcher has not discussed each disability in detail, as the emphasis is not on the disability itself. The WHO's ICF reflects modern-day thinking about disability and embodies a paradigm shift in the way that disability is now understood. Disability is the complete lived experience of non-fatal health outcomes, not merely body-level decrements in functioning. In summary, in this research study *disability* is an umbrella term for impairments, activity limitations and participation restrictions (ICF, 2005).

2.15   CONCLUSION

Disability theory tends to evolve around the dichotomy of medical and social concepts of disability (Maart *et al*., 2007:357). The importance of the correct wording when referring to CWPDs is essential as it attempts to reduce the negative attitudes that CWPDs face. Negative attitudes lead to exclusion, with the greatest barriers to inclusion being caused by society, and not by any particular medical impairments as discussed. Negative attitudes towards differences result in discrimination and can lead to a serious barrier to learning and can also take the form of social exclusion, social discrimination, lack of awareness and traditional prejudices. Moreover, there are many communities that believe that educating children with disabilities is pointless, and hence the urgency and the need for other research studies to change existing negative attitudes.

Depending on the person's point of view, a disability will be conceptualised as being a 'special task' or a 'curse'. The notion of a punishing God seems to be widespread and CWPDs and their parents often experience stigmatisation as a result. This, in turn, can influence a family in such a way that they will then try to hide the CWPDs. Hiding children is common in the rural areas of KwaZulu-Natal, as the chances are higher that the CWPDs will be undetected by other community members. However, as a result of a widespread community-based rehabilitation (CBR) system, available primary health care (95% coverage in KwaZulu-Natal) and government health workers, these cases are becoming rarer in the new South Africa. Nevertheless, there are still not enough community workers to eliminate this problem completely. Even if the CWPDs are identified, it does not mean that they will automatically be able to participate in the community, because the disability will still be seen shameful. As parents in rural areas do not necessarily have someone to watch their children while they see to other things, they lock their children inside their huts (this problem will be dealt with in chapter 5). A lack of general facilities makes it difficult for CWPDs to access community life in general and is a major barrier to social inclusion (which will be discussed in chapter 3).

As discussed above the use of the correct terminology is essential in reducing labelling, name calling and teasing, lack of acceptance and exclusion.

Poverty can be a cause of disability. This was very evident in the rural areas visited. This will now be explored in-depth.

2.15.1 Poverty as a cause of disability

The Convention on the Rights of the Child held in 2009 (CRC) has stated and, indeed, stressed that poverty is both a cause and a consequence of disability and that CWPDs and their families have a right to both an acceptable standard of living, which includes adequate food, clothing and housing, and to the continuous improvement of their living conditions. The World Bank also cites that a significant proportion of impairments and the consequent disabilities faced by children throughout the world arise from preventable factors. Nowhere is this more evident than in South Africa. Of the estimated 600 million persons with disabilities worldwide, approximately 80% live in Developing Countries while 82% live below the poverty line. The World Bank estimates that persons with disabilities comprise about 20% of the poorest of the poor. The relationship between poverty and disability has been described in relevant literature in terms of a vicious circle − with poverty leading to disability and

disability, in turn, leading to, and exacerbating poverty (http://www.inclusive-development.org accessed 2011/05/05). This finding is confirmed by the WHO which estimates that 50% of impairments leading to disabilities are both preventable and directly related to poverty. In 2006, 100 million people in the world had developed a disability as a result of malnutrition with malnutrition and poverty being inextricably intertwined (DFID: Disability, poverty and development, 2000).

The primary causes of disability amongst children in South Africa, as in other countries, have their roots in poverty. Poverty-related factors lead to many preventable disabilities and these disabilities, in turn, perpetuate poverty. Illness, pre-and peri-natal problems such as genetic disorders and birth trauma, injuries and violence are all major contributory factors. IN addition, children in rural areas are more likely to suffer from disabilities than children living in urban areas. CWPDs share the same general profile of the non-disabled poor. However, CWPDs belong to one of the most vulnerable groups of children and living in rural areas increases their vulnerability (CRC, 2006: Article 2). In addition, the birth of a disabled child, or the occurrence of disability in a family, often places heavy demands on family morale, thrusting the family deeper into poverty. There has been an increase in the number of families living at the poverty level as a result of disability (INDS: 2).

This section seeks to provide the reader with an understanding of poverty and its negative influences as a complex and multidimensional phenomenon with specific historical and political origins which, still today, continue to impact on the lives of CWPDs living in the rural areas.

While some of South Africa's children live in prosperity and even in opulence, for many millions of others, their daily lives are a constant struggle simply to survive. The ability of South African CWPDs in rural areas born into poverty or disadvantaged is compromised from the beginning of their lives, and continues to be undermined at every stage thereafter. Sub-optimal educational opportunities in the rural areas entrench the poverty cycle, while those who survive into adulthood often find themselves in a world which excludes them from almost any possibility of gainful and protective employment and inclusion into the society in which they live . Within this group of South Africa's rural poor, CWPDS are doubly disadvantaged compared to their typically developing peers. Combined with poverty, these factors keep CWPDs trapped mice in deprivation with one factor reinforcing the other.

> Poverty is a strong determinant of the other. [It] contributes to physical weakness through the lack of food, small bodies, malnutrition leading to low immune response to infections, and inability to reach or pay for health services; to isolation because of the inability to pay for the cost of schooling, to buy a radio or a bicycle, to afford to travel to look for work, or to live near the village centre or a main road; vulnerability through lack of assets to pay large expenses or to meet contingencies; and to powerlessness because of lack of wealth goes with low status: the poor have no voice (Chambers, 1983:111).

However, these negative factors are all recognised, particularly in the rural context of South Africa, where all the negative influences that CWPDs have to face have poverty as their root cause.

In the light of the severity of the poverty facing CWPDs, this research study focuses on examining the negative impacts that poverty has on the lives of CWPDs living in the rural areas. These negative impacts of poverty on the lives of CWPDs will be discussed in depth in chapter 5.

Poverty wears a multitude of faces and has numerous dimensions. It threatens all aspects of childhood by depriving CWPDs of those capabilities which are necessary in order to survive, to develop and to thrive. It entrenches or widens the social, economic and gender disparities that prevent children from enjoying equal opportunities and it undermines protective family and community environments, leaving CWPDs vulnerable to exploitation, abuse, stigmatisation and discrimination. Poverty in childhood is a root cause of poverty in adulthood (UNICEF, 2005 b:15).

The theme of poverty became apparent through observations, through living in a community in the rural areas and through the other data collection methods used in this research study. Although poverty affects all children the researcher envisages that her findings will shed light on the way in which CWPDs have to deal, not only with the negative influences which arise from living in the rural areas, but also with the way in which the impact of these negative influences are exacerbated for them.

However, before addressing any of the above, it is necessary, first, to discuss, in brief, the country that resulted from four decades of apartheid legislation and the draconian laws that resulted in a forced 'separate development' (Mbuli, 2008:50).

2.15.2 History of the rural areas in South Africa

For the majority of South Africans, 27 April 1994 signified an unprecedented political transformation in South Africa for it was on this day that the country finally emerged triumphant from more than a century of *de facto* and *de jure* apartheid oppression with 27 April 1994 heralding the advent of a new democratic, political dispensation (Mbuli, 2008:1).

It is well known that South Africa's apartheid past had imparted a strong and stubborn racial character to the country's poverty level and to the distribution of income and wealth within the country. Indeed, the conditions prevailing in the rural areas could be attributed to the apartheid era. During this era, the state engineered and encouraged a deviant system of structural poverty that was based largely on race. Specifically, the government programmes perpetuated a rigid racial hierarchy, with the majority of public resources being allocated to the whites, and with 'Africans' receiving the least (Government and Information System, 2003). For example, social services, such as education, health and welfare and housing were subsidised for whites while white people also enjoyed far greater access than blacks to government public assistance programmes, such as old age pensions and disability and child support grants. After 1948, when the National Party Government came to power, other labels were also used to refer to the term 'rural'. Dr HF Verwoerd's first word for the term 'rural' was 'Bantustan'. However, this term was later changed to that of 'homeland' as it was felt that the international world would find it easier to accept the notion of black people living in their own land. These areas were later termed 'national states' (http: encarta.msn.com).

McKendrick in (Duncan *et al.,* 2007:152) illustrates how, towards the end of the apartheid era, the state's welfare expenditure was consistently skewed in favour of the white population. For example, he shows how, in 1984/5, the government allocated approximately R1, 6 billion to welfare services but that 'enfranchised whites, coloured people and Indians fared better proportionately than did 'unenfranchised Africans'. In this equation, Africans received 20, 9% of the total amount allocated for welfare services, while coloureds received 26, 3%, Indians 7, 1% and whites 45, 8% of the total amount. It must be noted that, during this period, 'Africans' constituted 65% of the overall population of South Africa, while whites constituted 19,5% only, followed by coloureds with 12,9% and Indians with 3,4%. These figures clearly portray an anomalous situation in terms of which the smallest proportion of the population received the bulk of the grants.

Furthermore, the apartheid system also passed a plethora of laws that regulated and legitimised its policies which were aimed at entrenching racialised patterns of inequality and poverty. Certain pieces of legislation, such as the Native Land Act of 1913 and the Group Areas Act of 1950 (which closed all avenues for black entrepreneurship) severely compromised the wellbeing of black communities in South Africa. Ultimately, the trajectory of poverty in South Africa is inextricably entwined and coterminous with the history of discriminatory practices in the country –practices which, themselves, should be located within the global context (Duncan *et al.*, 2007:152).

In 2004, South Africa celebrated a decade of democracy and the demise of apartheid. Nevertheless, Mbuli (2008:2) notes that the general consensus among development practioners and institutions is that poverty is still widespread in South Africa today. Armstrong, Lekezwa and Siebrits (2009:1) agree with this assertion and note that, in 2005/6 − more than a decade after democratisation − the incidence of poverty among black and coloured individuals remains significantly higher than among whites.

It may, thus, be argued that, aside from a few legislative changes which are, nevertheless, fraught with problems as regards implementation, the situation of CWPDs has remained unchanged since the advent of democracy in South Africa. Despite the above protective measures, in the form of policies and legislation that had been introduced at the time of writing this article, CWPDs continue to remain a poverty stricken sector of the population living in the rural areas of South Africa (Guthrie & Sait, 2001:9) with KwaZulu-Natal remaining the province with the highest level of poverty (Armstrong & Lekezwa, 2007:1).

However, poverty is not simply a lack of resources. Some CWPDs are unable to access existing resources both because of their marginalised position, and because poverty and disability are inextricably linked. This lack of access to these resources has resulted in large scale exclusion from both the community and from educational facilities.

The issue of poverty will now be explored in depth.

2.15.3 Poverty

> To be poor is to be hungry, lack shelter and clothing, to be sick and not cared
> for, to be illiterate and not be schooled. But for poor people, poverty is more
> than this. They are often particularly vulnerable to adverse events outside their

control. They are often treated badly by the institutions of state and society and excluded from voice and power in those institutions (World Bank, 2000.)

Poverty is like heat; you cannot see it; you can only feel it; so to know poverty you have to go through it (Swanepoel & De Beer, 2009:2).

Poverty is a controversial concept and with good reason with arguments about the way, in which poverty should be conceptualised, defined and measured going beyond semantics and academic-hair splitting (Landsdowne, 2007:5). The reason for this state of affairs is that poverty may mean a number of different things. One important 'thread' in the poverty discourse is the notion of material lack − especially the lack of those resources which are necessary for survival (Landsdowne, 2007:10).

Duncan *et al.* (2007:150) define poverty as "the inability of individuals, households or communities to command sufficient resources to satisfy a socially acceptable minimum standard of living". In addition, poverty may be construed in either a narrow or a broad sense. In the narrow sense poverty means lack of income. In the broader sense, which is the sense in which the researcher will be addressing the issue in this research study, poverty may be seen as multidimensional, encompassing other issues such as housing, health and healthcare, education, and access to those services which are necessary for the CWPDs. Nevertheless, Clark and Qizilbash (2005) present a different concept of poor. Their study is based on a profile of poverty using the socially perceived necessities approach. This will be explored and discussed in chapter 5 as part of the findings of this study.

To be a child with a disability in South Africa is to travel a fragile path to adulthood. The country is home to nearly 19 million children, many of whom are extremely vulnerable. Two-thirds of all children live in poverty with many of them in homes with unemployed, single, chronically sick or elderly parents and caregivers. Poverty colludes with KwaZulu-Natal's severe AIDS epidemic, high unemployment and poor service delivery to create extreme hardship in the area, particularly for CWPDs. Moreover, poverty is inextricably linked with disability, exclusion and HIV/AIDS. It is, thus, a vicious circle. The poorest people will also, generally, have less access to health, education and other services than their wealthier counterparts. In addition, the poorest are also typically marginalised from society and have little representation or voice in public and political debates (participating at exosystemic and macrosystemic levels), thus making it even harder for them to escape their poverty. This is

especially true in the rural areas in which communities are geographically isolated (http://www.globalissues.org March, 2010).

FEW OPPORTUNITIES TO MOVE OUT OF THE CYCLE OF POVERTY

POVERTY

POOR ACCESS TO SERVICES

POOR HEALTH AND NUTRITIONAL SERVICES

POOR EDUCATIONAL OUTCOMES
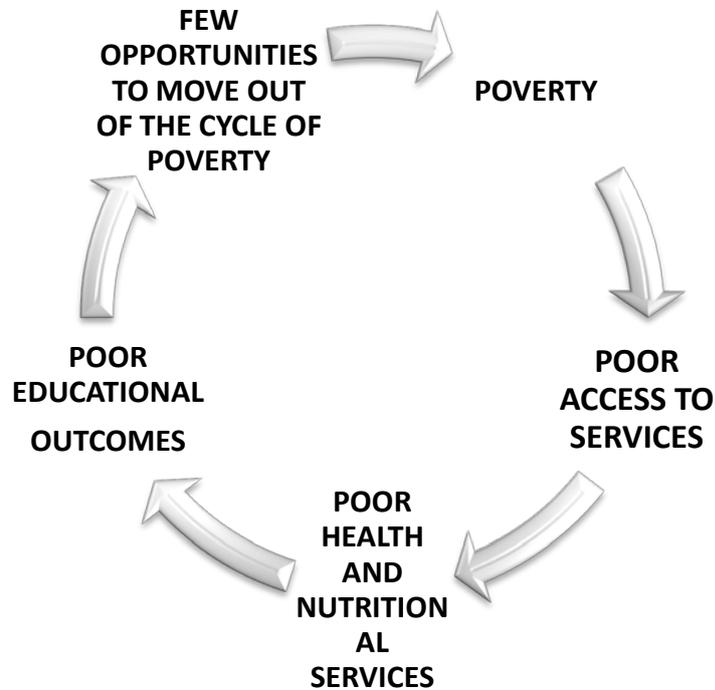
Figure 2.7:   A cycle of poverty (adapted from Lake et al. 2010:83)

"Whatever the content and criteria of social membership, socially excluded groups and individuals lack capacity or access to social opportunity" (Silver, 2007). This study utilises a definition of exclusion that includes mention of access to resources, such as transport, as access to this type of resource would enable CWPDs to participate in society as full citizens and, thus, not have to face both societal and educational exclusion. Such discrimination, for example in the form of lack of access to resources and transport, constitutes a form of exclusion and may be regarded as one of the causes of poverty. Within this context of exclusion, it is essential that education be inclusion as part of the struggle against poverty and social marginalisation, especially in relation to the exclusion of CWPDs as a result of their poor economic background (UNESCO: Inclusive Education: The Way of the Future, 2008:21).

There is a growing need for CWPDs to be included in all of life activities. Despite policies, agreements and guidelines being published and promises being made, nevertheless CWPDs remain excluded from both education and society and this very exclusion increases the risk of

their being unable to lift themselves out of the vicious cycle of poverty. Accordingly, it is essential that greater efforts be made to create the necessary political will and to instil real commitment both to investigate and to put into practice the most effective recommendations and a framework designed to reduce the impact of these negative influences that will be discussed in depth in chapter 5. The Millennium Developmental Goals (MDGs) constitute one such strategy. Adopted by world leaders in 2000 and earmarked for realisation by 2015, the MDGs provide concrete, numerical benchmarks for tackling extreme poverty in its many dimensions.

2.15.4   Bronfenbrenner's biological perspective on poverty

According to Bronfenbrenner, poverty in a child's life is the result of specific social and economic circumstances, which are always interrelated and complex. The ecological approach to understanding the complexity and totality of children's lives can be represented by figure 2.2 below. It is accordingly evident that the lack of all the resources required by CWPDs impacts of their wellbeing even if they are not directly involved. The figure below also illustrates the way in which one domain interacts with the other to compound the poverty experienced by CWPDs.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON POVERTY

This is the **Microsystem** and refers to the activities and relationships with significant others experienced by the developing child such as family & peers .Poor social support and high household density, single female parents, unployment, parents with substance abuse affect the child.

This is the **Mesosystem.** It consists of linkages and interrelationships between two or more of the developing child's microsystems. Neighbourhood unsafe. Lack of community resources.

This is the **Exosystem.** Meaning outside, the child is not an active participant in this system. Parent's social support network and overall neighbourhood context, lower quality community environment.

This is the **Macrosystem.** It consists of legislation and laws .Lack of housing, nutritious food, access to employment and health care.

This is the **Chronosystem** and incorporates the time dimension. Temporal changes in ecological systems or within individuals, producing new conditions that affect development. Historical events and changes such as lefe transitions within the developing child.

THE CWPD'S

Figure 2.8:   Bronfenbrenner's bioecological perspective on poverty (Bronfenbrenner, 1994).

The nested structures of the ecological environment proposed by Bronfenbrenner's process-person-context-time model provide a useful framework for examining the effects of poverty experienced by CWPDs in the rural areas.

2.15.5 The Millennium Goals, poverty and disability

Poverty is a worldwide problem and South Africa, as a member of the United Nations, has pledged that, as a country, it would try to attain the eight goals as encompassed by the MDGs by the year 2015. Twala notes that, on the African continent, South Africa is one of the few countries that have the necessary resources to meet the MDGs within the time allocated. Nevertheless, she argues that current trends do not point to the achievement of the goals by 2015. She goes on to say that, in South Africa, the issue is not a lack of resources but rather a lack of institutional support and planning (in Duma, 2007:1).

The eight MDGs include:

- Goal 1: Eradicate extreme poverty and hunger
- Goal 2: Achieve universal primary education
- Goal 3: Promote gender equality and empower woman
- Goal 4: Reduce child mortality
- Goal 5: Improve maternal health
- Goal 6:Combat HIV/AIDS, malaria and other diseases
- Goal 7: Ensure environmental sustainability
- Goal 8: Develop a Global Partnership for Development

Persons with disabilities comprise as much as one-fifth of all people living in poverty worldwide. Accordingly, if we ignore persons with disability in poverty reduction programmes, we ignore 20% of the world's poorest most excluded people (World Bank, 2006).

The Millennium Goals (MDGs) are the most broadly supported, comprehensive and specific development goals upon which the world has ever agreed. These 8 time-bound goals provide numerical benchmarks for tackling extreme poverty in its many dimensions and include goals and targets in respect of income, poverty, hunger, maternal and child mortality, disease, inadequate shelter, gender inequality, environmental degradation and a Global Partnership for development. In keeping with the MDGs, the South African Constitution guarantees

everyone the "right to have access to health care services". In addition, every child has the right to "basic health care services". However, Kibel, Lake, Pendlebury and Smith (2010:58) comment that "although every child has the right to basic health care services, these services have not yet been clarified by the courts or parliament".

The first goal − "Eradicate extreme poverty and hunger" – is particularly relevant to this research study. In 2000, 38% of the population in South Africa was below the national poverty data line. However, in 2008, this figure had gone down to 22%, indicating that South Africa was attempting to fulfil its pledge in terms of the MDGs. Nevertheless, these statistics give no indication as to whether this decrease is in urban or rural areas. However, according to Machethe (2004:1), poverty is more pervasive in rural areas, particularly in the former homelands, with the majority (65%) of the poor being found in rural areas and 78% of the chronically poor also in rural areas. KwaZulu-Natal has the highest poverty rate, followed by the Eastern Cape and then Limpopo. It is, thus, not surprising that 60, 1% of poor individuals live in these three provinces (Armstrong *et al.*, 2009:1).

Although disability is not mentioned specifically in the MDGs, CWPDs are implicitly included. Most development agencies acknowledge that it would not be possible to attain these goals without addressing the needs and rights of CWPDs. However, Thomas (2005:7) mentions that the relationship and relevance of disability to the MDGs are neither well articulated nor are they acknowledged.

The mortality rate for children with disabilities may be as high as 80%, even in countries in which the under-five mortality rate is below 20%. However, every child should have an equal right to life and it is essential that all efforts to reduce child mortality also pay particular attention to the most disadvantaged children (Department for International development (DFID: 2000). MDG 4 commits countries to reduce the under-five mortality rate − a key indicator of child health − by two-thirds between 1990 and 2015. Nevertheless, child mortality trends in South Africa have shown no sign of improvement within the last 15 years and this is a cause of grave concern (Kibel *et al.*, 2010:29).

In short, despite the fact that both the international community and South Africa have made a commitment to attain the MDGs, this will not be possible if the perspectives of CWPDs are not included in these MDGs. Disability both leads to poverty and also exacerbates poverty at the individual, family, community and global levels.

2.15.6 Poverty, disability, health and the resultant exclusion of CWPDs in the rural areas

"Because poverty and disability are inextricably linked, poverty can never be eradicated until people with disabilities enjoy equal rights with non-disabled people" (Yeo, 2001:5).

Moores and Yeo (in Yeo, 2005:19) provide diagrams to illustrate the vicious circle between poverty and disability. The similarities between the characteristics of poverty and those of disability are self-evident and a vicious circle highlights the causal relationship between poverty and disability.

As noted in the *White Paper on an Integrated National Disability Strategy* (INDS) (2008:1), South Africa is no exception in this regard. While a number of surveys have attempted to address the issue of disability in South Africa, there is, nevertheless, little agreement between their findings, even in terms of the national prevalence rates as illustrated in diagram 1 and tables 1 and 2 below in figure 2.9 below.

In addition, poverty alleviation measures are unlikely to help poor communities that are isolated from opportunities and services. Consequently, in order for poverty programmes to be fully effective, it is essential that they take disability into account. The World Bank has noted that, if the rights and needs of people with disabilities go unheeded, it is highly unlikely that the Millennium goals will ever be attained.

CWPDs experience discrimination either from birth, or from the moment when they become disabled. The birth of a child with a disability is often considered a tragedy with such a child needing more care than children without disabilities. In addition, many may not be considered to have potential and many people believe that supporting them is a waste of resources, as it is unlikely that they will be able to contribute in any way to the family in the future. In communities that are already living in chronic poverty, CWPDs may be excluded from society and even from educational opportunities. If there are limited resources it may be regarded as economically irresponsible to apportion an equal share of these limited resources to a child with a disability who is perceived to be unlikely to be able to provide for the family in the future. "Early lack of investment in children with disabilities is not just a reflection of ignorance. In situations of poverty this is a desperate but rational decision" (Yeo, 2001:9).

Table 1: Disability/Chronic Poverty Cycle
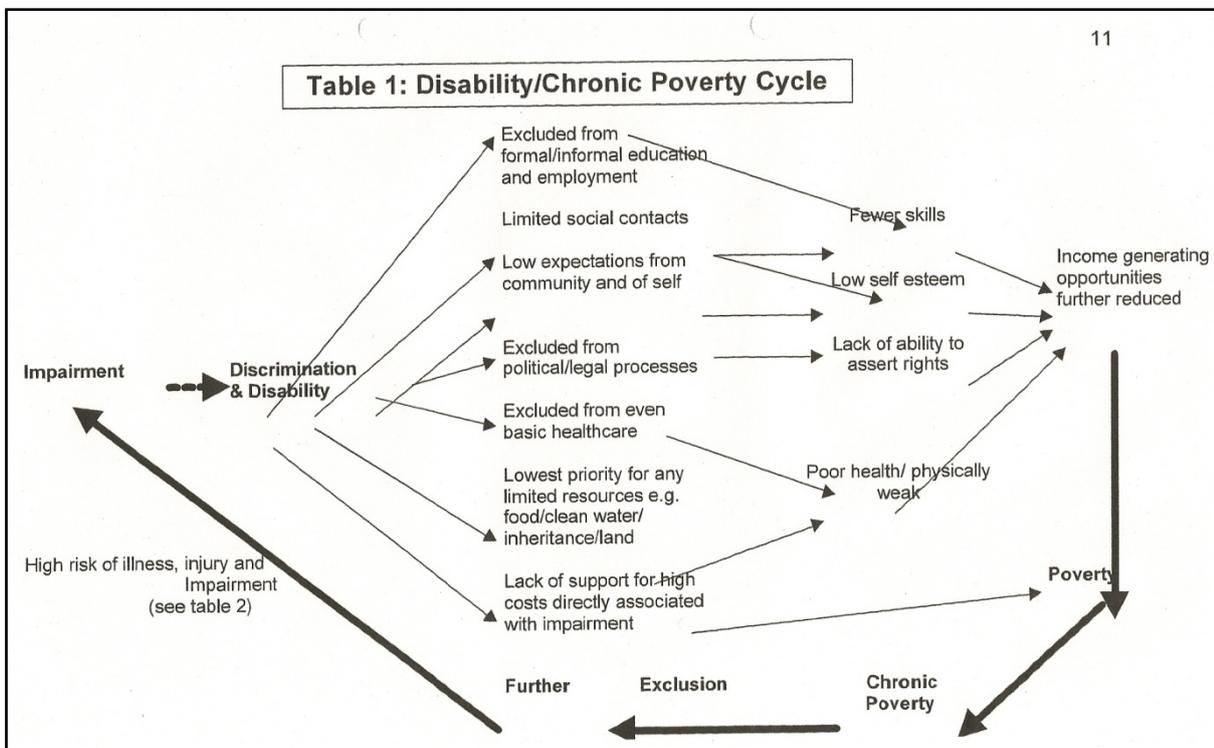
Table 2: Chronic Poverty/Disability Cycle
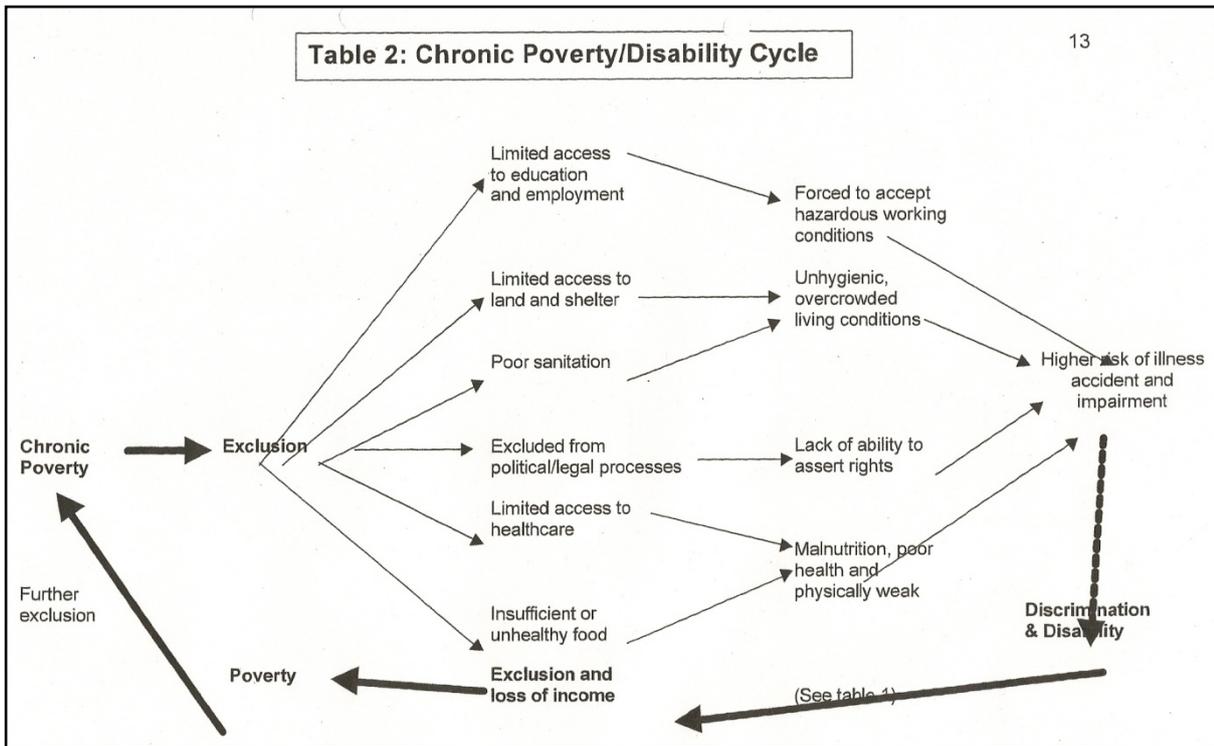
Figure 2.9:   R. Yeo's (2001) Poverty cycles.

The Tables above clearly illustrate the impact of poverty on CWPDs, such as exclusion to education and the consequences thereof.

CWPDs are often the last to access food and other basic resources. As in the case of assistive devices, such as wheelchairs, walkers and adapted cups for drinking, the complex interrelationships between disability, poverty and race in South Africa appear to be intertwined with issues of locality, and in particular, location in urban and rural settings. This

is particularly relevant to South Africa where, under the apartheid system, the former (largely rural) homeland areas were severely underfunded and deprived of both social and economic services. As pointed out in the INDS, the location of people in disadvantaged areas such as the former homelands has 'had a particularly severe impact on CWPDs who found themselves in an inhospitable environment, facing poor living conditions and unable to access the help they needed'.

CWPDs are less likely than other children to be sent to school (even if physically possible), for fear that they will either not cope, the disclosure of their disability may stigmatise the family and affect the marriage prospects of siblings, or they are not regarded as a worthwhile investment and others should receive priority. The International Disability and Development Consortium estimates that 98% of children with disabilities in developing countries are excluded from any formal education − yet another clear statistic of discrimination against and exclusion of CWPDS (Yeo, 2001:9). In addition, those CWPDs who do receive an education are often accorded inferior treatment, they have low expectations of themselves and the expectations of others as regards them are also often low and they do not receive the support they need in order to participate equally. CWPDs often have fewer demands placed on them, and, therefore, may learn less than non-disabled siblings, even in an informal setting. According to Watermeyer, Swartz, Lorenzo, Schneider and Priestly (2008:211), boys with disabilities attend school more frequently than girls with disabilities − yet another form of exclusion.

It is essential that these findings be seen against the background that special schools 'have traditionally captured most of the budget for their special needs' and that there is limited provision only for catering for the special educational needs of children with disabilities in mainstream schools. The CASE data (information collected relevant to the study undertaken) (IDEA- Individuals with Disability Act 1990) showed that children attending special schools were more likely to have access to and be using assistive devices than those in mainstream schools. In general, both Indians and white people with disabilities were more likely to be using assistive devices than black and coloured people. Furthermore, and, important for this research study, is the finding that the majority of assistive device users live in *urban* areas.

Moreover, the following as reported in the Millennium Development Goals Country Report 2010 (Republic of South Africa) is alarming:

- Three out of every five children younger than 17 are living in poor households with a total income of less than R1 200, mostly in *rural areas*. Every fifth child in South Africa suffers from hunger and malnutrition.
- Four out of 10 children have to travel more than 30 minutes to the nearest available clinic.
- One in 20 infants die before their first birthday.
- Half of South African children younger than 17 do not have access to reliable, clean water either in their houses or in their yards (www.globalissues.org./poverty: 2010).
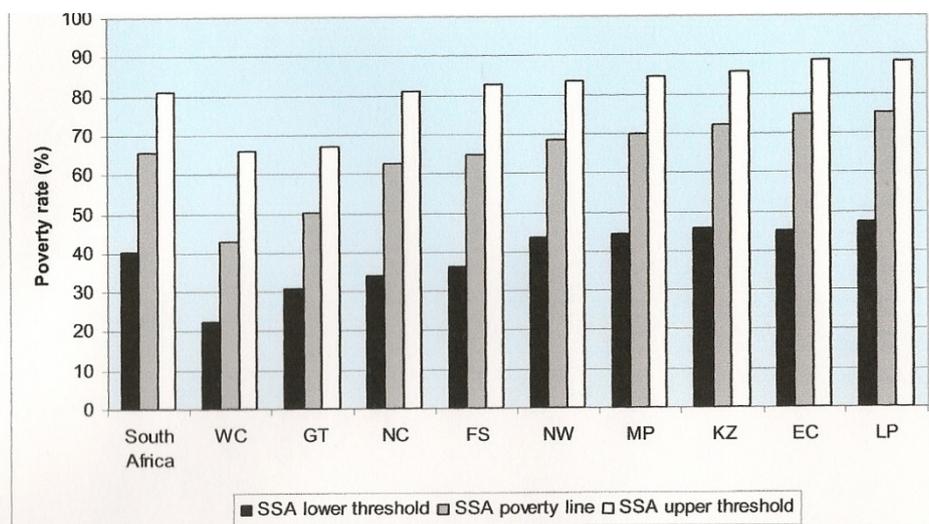
Source: Own analysis on CS 2007 post SRMI, institution cases deleted.
Note: All reported values are the average of the calculations on the ten imputed datasets. The poverty lines in 2007 Rand per month are: Stats SA lower threshold - 245, Stats SA poverty line - 444 and Stats SA upper threshold - 818.

Figure 2.10: Poverty rate – South Africa and individual provinces

Existing data suggests that people with disabilities in South Africa are disproportionately represented among the poor (Watermeyer *et al.*, 2006:221). For example, Stats SA's 1999 October Household Survey (OHS) data reveals that, while fewer than 2% of individuals living in households with monthly incomes above R10 000 were categorised as disabled, the disability rate was more than twice as high for individuals living in households with monthly incomes below R800 per month.

When CWPDs become ill they are often not given treatment but are left to the 'hand of God'. In addition, from the beginning of their lives, they are excluded from many of the day-to-day interactions that their typically developing peers take for granted. CWPDs are also at a huge

disadvantage as they grow up being excluded from both formal and informal education. This has an impact not only on their qualifications and experience but also on their levels of confidence and self-esteem. If, during childhood, children are not included in the community then, as they grow up, their non-disabled peers may not even be aware of their existence, let alone their value and rights as equal citizens.

Excluded from mainstream social, economic and political opportunities throughout their lives, CWPDs frequently sink deeper and deeper into chronic poverty, with little opportunity to escape of this cycle. In addition, those living in poverty often have limited access to land, healthcare, healthy food, shelter, education and employment. Du Plessis and Conley (2007:49) concur with this statement and maintain that it is for this reason that a long-term investment of resources and care in the lives of children is essential for the future.

CWPDs are engaged in an ongoing struggle to compensate in a world which is not adapted to their needs. However, specialised training in the foundation years may often make this struggle easier, and even allow CWPDs to live fully functional lives. Nevertheless, in the rural areas of South Africa facilities to help CWPDs are extremely limited, particularly for those children from poor homes (DA, 2008:13).

2.15.7 Conclusion

This chapter has reviewed and analysed the relevant literature on the definition of disability and poverty, as well as the implications of poverty for CWPDs living in rural areas. Certain of the important aspects which were covered in this chapter included the devastating effects of the apartheid era, and the vicious cycle of poverty and its destructive impact on the lives of CWPDs in South Africa, including discrimination against and the stigmatisation and exclusion of CWPDs. It is only by understanding the causes of poverty and its negative effects that poverty reduction strategies may have a real impact on the lives of CWPDs.

Chapter 3 will explore Urie Bronfenbrenner's Bioecological Model, which is central both to this research study and to the exclusion of CWPDs. As social and educational exclusion are two of the negative influences that CWPDs face in the rural areas, these two concepts will be researched extensively in the rural areas visited, especially as there is a large body of literature that suggests that the exclusion of CWPDs still takes place (discussed in chapter 3 in conjunction with an in-depth examination Bronfenbrenner's model).

CHAPTER 3

URIE BRONFENBRENNER'S BIOECOLOGICAL MODEL AND EXCLUSION

3.1   INTRODUCTION

If the children and youth of a nation are afforded opportunity to develop their capacities to the fullest, if they are given the knowledge to understand the world and the wisdom to change it, then the prospects of the future are bright. In contrast, a society which neglects its children, however well it may function in other respects, risks eventual disorganization and demise (Bronfenbrenner, 1999: preface).

Inclusion of *all* children is thus central to Bronfenbrenner's model. This chapter consists of an exposition of his theoretical system, which is used as a framework for illustrating the findings in this research study.

To begin with it is important to have an explanatory framework within which to address and understand the negative influences that children with physical disabilities face in rural areas. The explanatory framework that will be used is Bronfenbrenner's Ecological Model of Human Development. This is because his framework enables us to study the child and his/her family in the rural areas, caregivers, the school and the community as dynamic evolving systems influenced by change and by the many negative influences that impact on CWPDs. For optimal development of children to occur, the various ecological systems must create caring communities. To achieve a caring community in which the CWPDs can thrive, a clear understanding of Bronfenbrenner's model is crucial to the entire research of the negative influences that children with disabilities face. This model provides a 'whole picture' of the developing child and thus makes a valuable contribution to understanding the interconnectedness of CWPDs and the challenges of addressing the negative influences that lead to social and educational exclusion.

Tudge, Mokrova, Hatfield and Karnik (2010:2) argue that there should be a close connection between one's theory, the methods one uses and one's analytical strategy. The meaning of theory in any scientific study is to provide a framework within which to explain connections among the phenomena under study and to provide the discovery of new connections. In Bronfenbrenner's theory, everything is interrelated and interacts, but to varying degrees at different times. His theory focuses on the relationships both between people and between the different systems that constitute the lives of CWPDs and their world. Bronfenbrenner's

ecological theory has proven to be beneficial in providing an insight into all the factors that play a role in the growth and development of CWPDs. These relationships are crucial for understanding how CWPDs are excluded from family, schools and the community (Christensen, 2010:101).

3.2 BRONFENBRENNER'S ECOLOGICAL MODEL

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON HUMAN DEVELOPMENT

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child such as family & peers

This is the *Mesosystem.* It consists of linkages and interrelationships between two or more of the developing child's microsystems.

This is the *Exosystem.* Meaning outside, the child is not an active participant in this system eg. The school board.

This is the **Macrosystem.** It consists of the society and subculture to which the developing child belongs, with particular reference to belief systems and lifestyles

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

THE CWPD'S

Figure 3.1:   Bronfenbrenner's model of the developing child (Adapted from Bronfenbrenner, 1979)

One of the most important contributions to the field of human development comes from the psychologist Urie Bronfenbrenner. He postulates that it is not one or a few processes that determine how an individual will develop, but rather the interaction of many processes across time and space. Bronfenbrenner's theory emphasises how a person's biological characteristics interact with environmental forces to shape their environment. What he does offer is a model that shows that there may be many points of entry when looking to improve the life situation and developmental well being of an individual with a disability (Skelton & Rosenbaum, 2007:1).

The field of social ecology stems from human ecology and was largely developed by Lewin in the 1940s, who made an important contribution to Gestaltism through his work on the interdependency of the person and his or her environment. According to Albrecht *et al.* (2001:173), the ecology of human development comprises

> … [t]he scientific study of the progressive, mutual accommodation, through the life span, between a growing organism and the changing immediate environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the larger social contexts, both informal and formal, in which the settings are embedded.

In 1979, Bronfenbrenner, whose work was influenced by Lewin, developed his ground-breaking concept on the ecology of human development – the study of human beings and their interaction with the environment. His work has led to numerous directions in basic research and an understanding of the problems CWPDs experience. It has also led to new directions in designing policies affecting the wellbeing of children and their families in the United States. It is the hope of the researcher that, by using Bronfenbrenner's model, more insight into CWPDs in the rural areas of South Africa and the negative influences they experience will be obtained (Oncto Falls School District Community ABC Project, 2004–2005:5). The work of Urie Bronfenbrenner has been one of the most influential advances in the theory of human development over the past few decades (Rappleyea, 2009:12).

The CWPD's development takes place at home, within the family, at school, with classmates and teachers, in the park, with neighbours and, more generally, within a larger sociocultural environment. Development always takes place in a context, which often influences the course of that development. Understanding the interaction of these systems is key to understanding how a child develops and what factors can lead to developmental delay in CWPDs. The idea of interaction suggests that similar environmental conditions will lead to different outcomes in different people. A lack of and the breakdown of these influences in the rural areas are to the detriment of the CWPDs.

The notion of environment is "conceived topically as a nested arrangement of structures, each contained within the next" (Albrecht *et al.* 2001:174). Accordingly, Bronfenbrenner's ecological model will be used to elucidate the negative influences that the CWPDs face in the rural areas.

Bronfenbrenner is responsible for an approach that has moved to the forefront of the field of child development because it offers the most differentiated and complete account of contextual influences on children's development. Bronfenbrenner characterised his perspective as a bioecological model since the child's biologically influenced dispositions join with an environmental force to mould development. This model depicts the ideal environment for the child to grow up in (Ahuja, 2001: 2). It will become clear, however, as this study progresses that in the rural areas researched, ideal settings for CWPDs are sadly lacking. There is very little health care and access to it is difficult; families are mostly incomplete; and there is no early education and very little other community learning.

The most useful aspect of Bronfenbrenner's model is that we as a society in South Africa can together raise children with physical disabilities; if we work in harmony and provide a community that supports one other, the effect on this group of children can be profound. This bioecological model can be used to form an environment in which our children can live their lives in harmony (Ahuja, 2005:8).

In terms of the model, firstly, the individual (ontogenetic) child is at its centre. An individual child is a biological system in itself; development only occurs when genetic, biological and hereditary factors that ultimately become the system interrelate to each other. The model acknowledges that children are affected by the settings in which they spend time. The most important setting for a young child is the family, because it has the most emotional influence on them. Other important settings may include their caregivers, extended family, early care and education programmes, health care settings and other community learning sites such as neighbours, playgrounds or playing fields (sites that, in the rural areas, are sadly lacking). The experiences gained in these settings are called the *proximal* – or near – *processes* that a child has with the people and objects in these settings which are "the primary engines of human development" (Bronfenbrenner & Morris, 1998:997). Examples of enduring patterns of proximal process are found in parent–child and child–child activities, group or solitary play, learning new skills and performing complex tasks (Bronfenbrenner, 1998:38).

Proximal processes are more powerful than those of the environmental contexts in which they occur. According to studies (Tudge et al. 1999: 1-17) conducted, the proximal process is greatest in what emerges as the most advantaged ecological niche, that is, families with two biological parents in which the mother has some type of education beyond high school. Sadly, from the interviews conducted by the researcher in the rural areas not only are there

very few CWPDs with both biological parents, but very few if any have a parent with as much as a high school education.

The number and quality of interconnections between the settings in which children spend time also have important implications for their development. Other environments where the child does not spend much time can also affect the power of proximal processes to influence development (Friedman, S. L. & Wachs, T.D, 1999; 4-6).
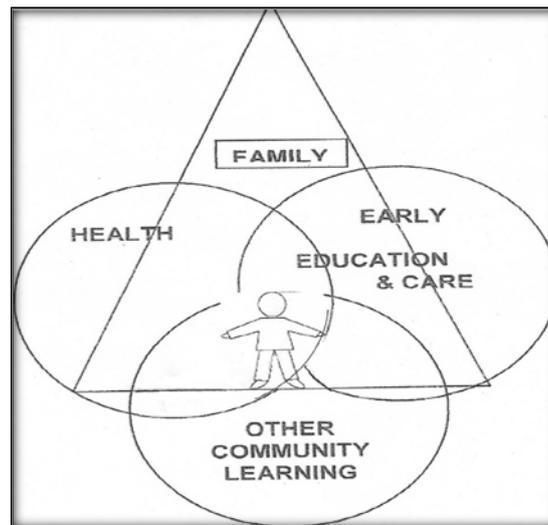
Figure 3.2:   The three contexts – family, school and community

Source: Adapted from Bronfenbrenner (1998)

The three contexts (see fig. 3.2) and the interconnections between them are important influences in the child's life. Bronfenbrenner's ecological systems approach to parent involvement provides a conceptual framework for understanding how families and schools are also influenced by the larger social, political and economic realities. His ecological systems theory therefore represents the family as a system nested in a number of other societal systems. Therefore, Bronfenbrenner's model can be useful for analysing the influence of any societal factors such as poverty, HIV/AIDS and negative attitudes (Landsberg, 2005:215–216). Our goal as a society is to nurture our children with love and respect and to care for them. If we as researchers in the academic field can assist parents, teachers and the rural communities and societies to work together, then our future as a nation will be one of success, good health, respect, love and equality.

In terms of Bronfenbrenner's model, the first and innermost system is the microsystem. This will be discussed in the following section.

3.2.1 The microsystem

What are the most significant contexts in which a child interacts?

Bronfenbrenner (1999: 24-36) defines a microsystem as a system of activities, roles and interpersonal relations experienced by the developing person in a face-to-face setting with particular physical, social and symbolic features that invite, permit or inhibit engagement in sustained, progressively more complex interactions with, and activity in, the immediate environment.

The first basic structure, which also means small (micro/small), refers to the activities and relationships with significant others experienced by a developing person in a particular small setting such as family, school, peer group or community (Berns, 2010:19). On a microsystemic level, this scenario clearly has major implications for close interactions around the child, as it is the setting in which they are actually participating.

3.2.1.1   The family

The family is the setting that provides nurture, affection and a variety of opportunities. It is the primary socialiser of the child in that it has the most significant impact on the child's development (Berns, 2010:19).

Furthermore, the microsystem possesses physical characteristics such as the size of the house, the amount of playground equipment, the number of books and other stimulating materials that the child has access to and can use to learn and take risks while feeling safe and protected (requirements that are sadly lacking in rural areas). This system also consists of people, including family members and other children in the area. These people, in turn, possess characteristics that may be relevant to the child's development, such as the socioeconomic status of the peer group and the educational background of the parents. Consequently, the microsystem is not constant but is constantly changing. All relationships here are bidirectional (functioning in two directions), which means that a positive attitude from the parents will build a relationship in which the child is happy and healthy development can be optimised.

If parents become stressed and irritable, child abuse may become more prevalent and parents may become less able to provide a secure home in which their children can use opportunities to learn and take risks while feeling safe and protected. The physiological consequences of

malnutrition, for example, may also negatively influence the child's ability to thrive (Landsberg, 2005:82). In this bioecological system, it is the richness of the environment in the microsystem that is important to the development of the child. Much of a child's motor development and behaviour is learnt in the microsystem, although as the child ages, the other, more distant systems will have an increasing influence. The first more distant system is usually that of the school where the child first spends time away from home.

3.2.1.2   School

The school is the setting in which children formally learn about their society. The school teaches reading, writing, numeracy and so on and teachers encourage the development of various skills and behaviours by being role models and by providing motivation for children to succeed in learning (Berns, 2010:20). It is here that the child comes into contact with new peers.

3.2.1.3   Peer group

The peer group is the setting in which children begin to be unsupervised by adults, thereby gradually becoming independent. In the peer group, children get a sense of who they are and what they can do by comparison with others. Peers provide companionship and support as well as learning experiences in cooperation and role taking (Berns, 2010:20). This often takes children into the community.

3.2.1.4   Community

The community or neighbourhood on a small scale is the main setting in which children learn by doing. The facilities available to children determine what real experiences they will have. Is there a library, are there parks? (Berns, 2010:20). This then takes us to the next system, which is the **mesosystem,** in which I will discuss how the child's significant contexts of development are linked to one another. According to Bronfenbrenner' model, the *mesosystem* describes how the different parts of the child's microsystem work together for the healthy development of children.

3.2.2   The mesosystem

The second basic structure, the mesosystem (*meso* meaning 'intermediate') consists of linkages and interrelationships between two or more of a developing person's microsystems, such as the family and the school, or the family and the peer group (Berns, 2010:21).

The African proverb 'it takes a village to raise a child' is accounted for in the mesosystem of a child's life. However, this study will show that at present the infrastructure of the village to raise a child is lacking in rural South Africa. Special attention is focused here on the synergistic effects created by the interaction of the developmentally instigative or inhibitory features and processes present in each setting (Arnold & King, 1997:314).

The mesosystem refers to the system of relationships in the children's microsystem. On a mesosystemic level, adverse conditions often lead to the isolation of families, thus greatly reducing networks or social capital within communities where this resource is pivotal, especially community isolation in rural areas. Contact between the home and the school, the church and the health care system becomes tenuous as families isolate themselves and become isolated by communities (Landsberg, 2005:82). In general, the more interconnected these contexts are, the more the child's development is likely to be supported in a clear and consistent way. In this study, family–neighbourhood connections are especially important for the already economically disadvantaged children with disabilities. The more numerous the qualitative links or interrelationships between the child's microsystems, the more impact they have on socialisation. Mesosystems, then, provide support for the activities going on in the microsystems (Berns, 2010:21). The micro- and mesosystems are systems in which the child is physically present. The next system in the model is the *exosystem*, in which the child himself is not physically present (*exo* meaning 'outside'), but what goes on in the exosystem still affects the wellbeing of the child.

3.2.3   The exosystem

How is the child influenced by settings in which it does not participate?

According to Bronfenbrenner, the exosystem comprises the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes within the immediate *setting in which the developing person lives (*Arnold & King, 1997:316). An example of this is when the exosystem refers to social settings that can affect the child but in which the child does not actively participate. Some examples are local governments, which decide on issues such as sanitation. The education department will also affect the child on this level as it needs to provide for schooling and access to schooling for CWPDs. This is a problem in rural areas where distances are vast, taxi drivers are not willing to accommodate CWPDs and roads are inaccessible for wheelchairs. On an exosystemic level, increasing violence in many

communities negatively impacts on children's safety and their freedom to move around safely in their community. Similarly, poor working conditions and unemployment have left many families without homes, electricity or running water, which has a negative impact on children's health and wellbeing. Families that are affected by unemployment, overcrowding, and poor social conditions show an increased incidence of stress that can lead to child maltreatment and neglect (Luo, M, 2009:1)
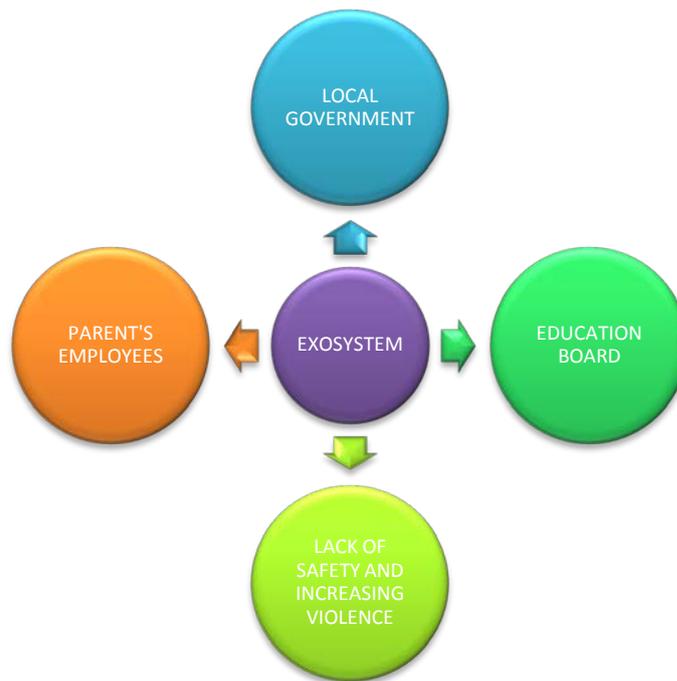
Figure 3.3:   The exosystem in which the child is not directly involved

This takes us to the next outer layer, in which neither parents nor children are active participants – the macrosystem.

3.2.4   The macrosystem

How do the characteristics of the larger society influence the child's development?

The fourth basic structure, the macrosystem (*macro* meaning 'large'), consists of the society and subculture to which the developing child belongs (Berns, 2010:23). This is the outermost level of Bronfenbrenner's model, which he defines as consisting of the overarching pattern of micro-, meso- and exosystems characteristic of a given culture, subculture or other extended social structure, with particular reference to the developmentally instigative belief systems, resources, hazards, lifestyles, opportunity structures, life course and patterns of social interchange that are embedded in such overarching systems (Arnold & King, 1997:317).

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The macrosystem involves the culture and subculture in which the child lives. This system affects the child's beliefs, attitudes and traditions. Generally, a child living in the rural areas of South Africa may be influenced and affected by the values and cultural traditions of his/her tribe or group. Comparisons made across cultures have the potential to provide very important information about the effects of culture on development. The macrosystem is a more stable system than any of the other systems, but it, too, can change as society evolves, depending on the political situation in the country. Public policy is a part of the macrosystem, determining the specific properties of the exo-, meso- and microsystems that occur at the level of everyday life and steer the course of behaviour and development (Bronfenbrenner, 1979:9).
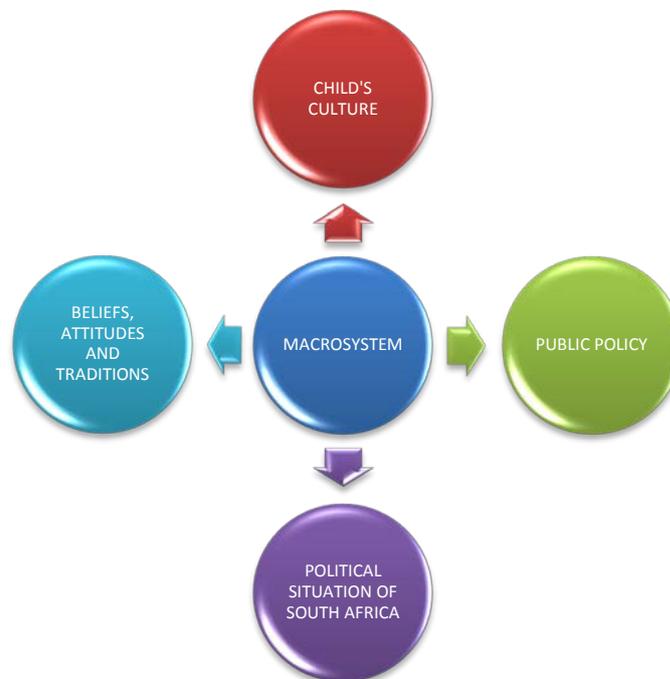
Figure 3.4:   The macrosystem

This brings us to the final system and the way these environmental conditions affect the child and the way the child, in turn, affects his or her community (Berns, 2010:26).

3.2.5   The chronosystem

The interactions that take place among the various systems in the child's world gradually change over time and as the child grows. A chronosystem encompasses change or consistency over time, not only in the characteristics of the person, but also of the environment in which that child is situated (e.g. changes over the life course in family structure, socioeconomic status, employment, place of residence). This source of influence,

which Bronfenbrenner calls the chronosystem, adds even more complexity and richness to the challenge of analysing children's development. In South Africa, the change of the apartheid system to one of democracy is an example of change in the chronosystem (Bronfenbrenner, 1999).

Various successful projects and models based on Bronfenbrenner's work have been developed for CWPDs and will now be discussed.

3.3   THE ABC PROJECT

As Bronfenbrenner's model will be used throughout this study, the researcher will start by using an example of a project, the ABC Project (Oncto Fall District Community:2004-2005), for CWPDs in the United States of America, which used this model and where it has been proven to be very successful. This project has shown that, if well organised, this model has the ability and capacity to work well in South Africa.

Project ABC emphasises that the central role of relationships during early childhood is to ensure that families, professionals and community organisations work together to support every child's healthy development through awareness of the central role that relationships play in building healthy lives. Here community refers to the entire group of people and organisations that has an interest in the wellbeing of the young child who resides in that community. The goal of the ABC Project is to include families, formal community agencies and organisations, and other citizens and informal groups in promoting positive child development, disease prevention, patient recovery and resilience for children and their families.

The ABC Project is directly linked to Bronfenbrenner's theory. When planning an ABC system it is necessary to consider what the community does to ensure all children have the experiences they need in the microsystem settings – such as families and child care centres, that is, where DO they spend time? In the rural areas visited it was found that CWPDs were confined to their homes, which were often isolated. Moreover, we should also consider how we can strengthen the linkages between settings. The ABC Project takes a child-centred approach because it is the one needed to ensure that all children have all they need to develop optimally. Every child has the right "to a standard of living adequate for the child's physical, mental, spiritual and social development … State Parties … within their means shall assist

families when in need with, for example clothing, food and housing. An adequate standard of living involves spaces to play freely and to learn" (Alderson, 2008:33).

According to the A.B.C Project (2004-2005) The ABC stands for the following:

- The first letters of the alphabet – A, B, C – remind us about how critical it is to begin life at the beginning. Experiences in the early weeks, months and years of a child's life determine the kind of foundation the child will have for later life, learning and achievement (microsystem).

- Learning ABCs is important for school readiness. School readiness is tied to success later on in school and later in life.

- Research shows that young children will be more successful in school and later life if their early lives include specific health, family and early education experiences that protect them, that promote their development, and that connect their families with other important community institutions. The ABC Project calls these the "building blocks of development" and it works to help communities ensure that all their young experience all the life skills in a timely manner.

- A wide variety of different structures can serve children well. Even when they include the same kinds of foundational building blocks and the same planning steps, different communities are likely to find different ways to best serve their own families with young children (if they have the resources).

- The letters ABC, which are often used as grades, are reminders of how important evaluating progress is toward meeting the goal of creating caring communities for young children and their families.

- Careful planning of community resources to support children and their families is essential. This is particularly important in our rural areas where parents need help with CWPDs. Following particular steps (A, B, C) is likely to help communities discover how to make more efficient use of limited resources and to effectively promote the potential of all young children.

According to Bronfenbrenner's model, the young child's social, physical and cognitive development is closely related and builds on each other. Children who are not provided with early experiences that support their development in one area may later have additional problems to overcome. In the rural areas this is exacerbated by the many negative influences

they have to overcome (Oncto Falls School District, 2004–2005:6). This will be discussed in the following section.

3.3.1 Bronfenbrenner and early childhood education

Bronfenbrenner's theory of ecological development seeks to provide a unified but highly differentiated conceptual scheme for describing and relating structures and processes in both the immediate and the more remote environment, as they shape the course of human development throughout the life span – in this study with particular reference to CWPDs. This integrative effort is regarded as a necessary first step in the systematic study of development in its human context (Bronfenbrenner, 1979:11). This bioecological model will be used throughout this research study to highlight the lack of functionality on all Bronfenbrenner's levels for CWPDs and how this lack adversely affects their development. This lack of functionality is also a major contributory factor to the social and educational exclusion that our CWPDs continue to be faced with.

In summary, Bronfenbrenner's model has been chosen for this research as his work has had a significant impact on the development of taxonomies of environmental factors and systemic understandings of simultaneous proximal, community and societal environmental levels influencing the disability process (Albrecht *et al*., 2001:173).

Another model, based on Bronfenbrenner's, is the portage model, which is important in light of the developments that are taking place in the rural areas. Moreover, literature studies show that community-based rehabilitation (CBR) that is rehabilitation with the community areas and especially within the home is on the increase in rural areas throughout South Africa.

3.4   THE PORTAGE MODEL

No study of CBR and disability would be complete without a word about portage, which is practised in 90 countries and has been translated into 34 languages. This model is crucial to Bronfenbrenner's microsystem.

The portage model postulates that parent/primary caretaker involvement is critical to successful early intervention; the home or other least restrictive environments are natural and significant learning environments; intervention objectives and strategies must be individualised for each child and family based on their concerns, priorities and resources; and

data collection is important to reinforce positive change and make ongoing intervention decisions (Rodgers, 1998:59).

Portage is known for early intervention and the development of intervention systems in the community. It relies heavily on parental involvement in enhancing the development of young children with disabilities. In terms of this model, the parent must first understand that the development of the child is sequential in nature. Secondly, they must believe that the child's development can be influenced by their efforts. A final assumption that needs to be met if family involvement is to be implemented is parental acceptance of their role in actively facilitating their child's development (Rodgers, 1998:60). Portage learning activities stimulate the acquisition of developmental milestones that will lead to greater independence and continued parental involvement.

The strengths of portage (Rodgers, 1998: 59-64) are the following:

- Portage uses a highly structured yet modifiable teaching package.
- It is highly adaptable to daily living skills because it is home and community-based.
- It is inexpensive, available and easy to translate and adapt.
- It is more continuous and holistic than most other segmented service approaches.
- It helps the family to accept and bond with the child.
- It can be used for older children with a range of impairments if the curriculum is modified.

It is clear that this could be a very good system for our rural children where early childhood education is unavailable and there is a lack of clinical intervention.

Bronfenbrenner's theoretical framework of ecological development has now been discussed in relation to CWPDs. The issue of disability and in particular physical disabilities (visible disabilities) will now be explored because CWPDs are the researcher's target group and are central to this study.

Until Bronfenbrenner's death in 2005 he was always re-thinking the theory regarding his model his model and updating it to keep up with current trends and changing society. Pertinent to all studies of Bronfenbrenner is his theory of person–process–context–time. The following section will examine these processes.

3.5   PERSON–PROCESS–CONTEXT–TIME

Bronfenbrenner was in a continual state of development, he changed aspects of his model to be in keeping with society as it changed. In the 1990s, he defined *proximal processes* as a key factor in development. It was also at this time that he started discussing the person–process–context–time model (PPCT) which has now become the essence of his theory. His full theory in its developed form deals with the interrelationships of these PPCT concepts.

This model allows for an assessment of not only the interactive nature of CWPDs and their environments, both proximal and distal, but also the processes of development that are at work. The PPCT model requires that research consider the interactive ways in which developing CWPDs are influenced by and simultaneously influence the context that envelops them (Rodgers, 1998).

Context cannot be restricted simply to the microsystem, but incorporates linkages between the systems from micro to macro. Bronfenbrenner had in mind factors such as material, physical and social resources, the stability of these resources and the extent to which they are organised or disorganised. These aspects of the physical, social and symbolic environment may be viewed from all levels – from the most proximal (microsystem) to the most distal (macrosystem). The macro-level effects (although not examined in depth in this research study) clearly have their effects in the exosystem, the mesosystem and the most distal macrosystem (Tudge, Shanahan & Vaalsiner, 1999:99).

For Bronfenbrenner, processes of development are at the core of his theory, with activity between developing CWPDs and social patterns being the key to understanding social stability and change. These interpersonal interactions are, of course, most fully understood by considering them in broad contexts. Moreover, the relations between them are synergistic (Tudge *et al*., 1999:99).

A brief description of PPCT will now follow:

- *Process* – This, the first concept, plays a crucial role in development. Proximal processes feature in two central 'propositions' that appear in several of Bronfenbrenner's later publications. The first states:

"Human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the

persons, objects and symbols in its immediate external environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of *time*. Such enduring forms of interaction in the immediate environment are referred to as *proximal process*."

- *Person* – Bronfenbrenner acknowledged the relevance of the biological and genetic aspects of the person and gave more attention to the personal characteristics that individuals bring with them into any social situation. According to Bronfenbrenner, two children may have equal resource characteristics, but their development trajectories will be quite different if one is motivated to succeed and persists in tasks and the other is not motivated and does not persist. In his later writings, Bronfenbrenner provided a clearer view of individuals' roles in changing their context.

- *Context* – The environment or context involves four interrelated systems. The first is any environment, such as home, school, peer group, in which the developing person spends a good deal of time engaging in activities and interaction (i.e. the microsystem). As people spend time in more than one microsystem, Bronfenbrenner wrote about the interrelations among them (i.e. the mesosystem). The mother's work has an exosystemic effect, as although the child spends no time there, it has an indirect influence on him/her. Finally, Bronfenbrenner defines the macrosystem as a context encompassing any group ("culture, subculture or other extended social structure") whose members share value or belief systems, "resources, hazards, lifestyles, opportunity structures, life course options and patterns of social interchange".

- *Time* – The final element of the PPCT model is time. As in any theory of human development, time plays a crucial role. In the same way that both context and individual factors are divided into sub-factors, Bronfenbrenner and Morris (1998) write about time as constituting micro time (what is occurring during the course of some specific activity or interaction), meso time (the extent to which activities and interactions occur with some consistence in the developing person's environment), and macro time (the chronosystem, the term used by Bronfenbrenner).

Time and timing are equally important because all aspects of the PPCT model can be thought of in terms of relative constancy and change. This is true whether thinking about the developing individuals themselves, the types of activity and interaction in which they engage, or the various microsystems in which they are situated.

It is impossible to understand a study if its design does not involve a focus on the critical element of process, or an assessment (observation, or from interviews or questionnaires) of the type of activities and interactions believed to be relevant for the study participants' developmental outcomes of interest. To understand how *person* characteristics influence those proximal processes, the minimum requirement would be to assess the ways in which a demand characteristic, such as age, appearance or gender, altered these activities and interactions, although a richer design would examine the ways in which relevant resource or force characteristics of the study participants influence the ways in which they acted or interacted. *Context,* too*,* influences proximal processes and the minimum requirement would be to evaluate the differential influences of two microsystems (home and schools for example) on the activities and interactions of interest. Finally, regarding *time,* the study should be longitudinal (to evaluate the influence of proximal processes, as they are mutually influenced by person characteristics and context, on the developmental outcomes of interest) and should take into account what is occurring in the group being studied at the current point of historical time.

In this research study, interactions among personal characteristics, proximal processes, contexts and time contribute to the developmental outcomes of the CWPDs. The measures of proximal processes that the researcher took into consideration in this study were the quality of family functioning, as this research study concentrates on the microsystemic and mesosystemic levels.

Bronfenbrenner's bioecological model of development and his emphasis on inclusion in both the community and schools has been discussed in depth. The next section will discuss the issue of exclusion and will begin by outlining the key aspects of social and educational inclusion of children with disabilities (Moen, G. H., Elder, Jr & Luscher, K. 1995: 619-62).

"You're not my friend – I don't like people like you" (Sapon-Shevin, 2003:1).

Children with physical disabilities face a host of negative attitudes that result in exclusion and have an adverse effect on their physical and mental development. The vast majority of these children receive little education, are absent from school data sets, and are invisible in the macrosystem on the national policy agenda. Many of them are a curse to their families, and are discriminated against and stigmatised at home, in schools and in the rural community. CWPDs are probably the most neglected group in all spheres (African Child Policy Forum, 2009:1). Exclusion must be one of the most demoralising negative influences witnessed by the researcher.

This section is intended to systematise the way CWPDs in rural areas of South Africa remain excluded from both mainstream education and social activities. Although South Africa has embraced inclusion for all children, part of this chapter will explore and probe the social contexts of the inclusion debate and show that CWPDs in the rural areas of KwaZulu-Natal are in danger of being forgotten and the goals of both education and social inclusion are far from being reached. As discussed above, these children are often limited by both negative attitudes and physical barriers. Moreover, poverty and HIV/AIDS are other contributory factors to this perpetual exclusion.

This study will present current evidence concerning the exclusion of CWPDs and their families. Furthermore, it will show that adequate resources must be matched with political will, and constitutional pressure must be maintained on the government to live up to its obligations.

This discussion will take the following format:

- It will begin with definitions of inclusion and will then explore the historical perspectives of inclusion.
- This will be followed by a discussion of the legislation and policies in South Africa that promote equality and inclusion.
- Then Bronfenbrenner's theoretical framework for inclusion will be explored.
- Finally, the discussion will conclude by discussing the feasibility of inclusion in the rural areas of South Africa.

3.6.1 Definitions of educational inclusion

All children and young people of the world, with their individual strengths and weaknesses, with their hopes and expectations, have a right to education. It is not our education systems that have a right to certain types of children. Therefore, it is the school system of a country that must be adjusted to meet the needs of all children (Education for All, 2005:13).

> Inclusion is the practice of establishing heterogeneous classrooms in neighbourhood schools, where every child strives to accomplish individual goals while fully participating in social and academic activities. Inclusive education is a system that supports and accommodates the diverse needs and abilities of all students within a typical education setting (Ajodhia-Andrews & Frankel, 2010:1).

Inclusive education means welcoming all children, without discrimination, into regular and ordinary schools. Indeed, its focus is on creating environments that are responsive to the differing developmental capacities, needs and potentials of all children. Inclusion means a shift in services from simply trying to fit the child into 'normal settings'; it is a supplemental support for their disabilities on special needs and promoting the child's overall development in an optimal setting. It calls for a respect of difference (Agegnehu, 2000:4).

Inclusion is, firstly, the active participation of young children with disabilities and typically developing children in the same classroom, schools and community settings. Secondly, services should be provided that support the child in accomplishing the goals established for him or her parents and a team of professionals. Thirdly, these services are usually provided through the collaboration of professionals from different disciplines. Fourthly, the effect of the inclusion programmes on children with disabilities is evaluated to determine if the child with disabilities is making progress towards goals established by parents, teachers and other professionals (Odom, Peck, Hanson, Beckam, Kaiser, Lieber, *et al.,* 1996:1). Worldwide, different countries have different ideas on inclusion, with some countries still making special provision for children with severe disabilities, often with the aim that, with intensive therapies over a few years, the children will then be able to make a transition to a mainstream school. In South Africa, *on paper,* no child may be excluded from attending any full-service school. South Africa promotes a sense of belonging so that all children, staff and families experience a sense of worth in the learning community (Guidelines for Full-service and Inclusive Schools, 2010:7).

In the context of education, inclusion means the creation of barrier-free and child-focused learning environments, including in the early years. It means providing appropriate support to ensure that all children receive education in a non-segregated local setting, whether formal or informal. This is framed by Article No. 29, of the Convention of the Rights of the Child, (United Nations Convention on the Rights of the Child, 1989) which requires that the child's education be directed to develop personality, talents and mental and physical disabilities to their fullest potential; to the preparation of the child for a responsible life in a free society, in a spirit of understanding and tolerance (Innocenti Digest No. 13, 2007:1). Article 23 of the Convention of the Rights of the Child refers to 'children' only; however, it is important to remember that every article in the Convention which refers to 'the child' also applies to CWPDs. The priority needs of CWPDs are not special, they are basic: children with disabilities need food, shelter, love and affection, protection and education (Stubbs, 1997:1).

Inclusion respects and values the diversity of each child, acknowledging that they are a contributor to society, regardless of abilities. Furthermore, the United Nations Convention on the Rights of the Child declares that all children (with or without special needs) have a basic right to an education, and to experience full involvement in society (Ajodhia-Andrews & Frankel, 2010: 1). In keeping with the pledge of Education for All, the Salamanca Statement

highlights the rights of those with special needs to obtain an education within any regular education system (UNESCO, 1994). This statement also asserts that regular classrooms should accommodate the needs of all children as a means of reducing prejudiced attitudes, and promoting a more accepting society (UNESCO, 1994). It argues that regular schools with an inclusive orientation are: "… the most effective means of combating discriminatory attitudes, building an inclusive society and achieving education for all" (Guidelines for Inclusion, 2011:9).

3.6.2   The difference between integrated and inclusive education

The change from 'integration' to 'inclusion' is far more than merely a fashionable change in politically correct semantics. Although the terms are often used interchangeably, there are real differences between them in terms of values and practice (Mittler, 2000:10).

Inclusion is not the same as integration, which implies bringing children with disabilities into a 'normal' mainstream or helping them to adapt to 'normal' standards. For example, in the context of schooling, integration means placing children with disabilities in regular schools without necessarily making any adjustments to school organisation or teaching methods. Thus, *integration* involves preparing children for placement in ordinary schools. It implies a concept of educational or social readiness for transfer from special to ordinary schools. The child must adapt to the school and there is no necessary assumption that the school will change to accommodate a greater diversity of children (Mittler, 2000:10).

Inclusion, on the other hand, requires that schools adapt and provide the support needed to ensure that all children can work and live together (*Innocenti Digest*, 2007:1). Put simply, the school must change, not the child.

Thus, inclusive education

- acknowledges that all children can learn
- acknowledges and respects differences in children: age, gender, ethnicity, language, disability, HIV status etc
- enables education structures, systems and methodologies to meet the needs of all children
- is part of a wider strategy to promote an inclusive society
- is a dynamic process that is constantly evolving

This practice of meeting the needs of all children in the same school is known as *inclusive education* and is not a new idea. As Stainback and Stainback (in Albrecht *et al*., 2001:509) state:

> Full inclusion does not mean that special educators are no longer necessary; rather it means that special educators are needed even more to work with regular educators in teaching and facilitating challenging, supportive and appropriate educational programmes for all children. However, special educators do need to be integrated into and in effect, instructional, curricular and assessment areas.

The goal of inclusion is achieved only when a child is participating in the class as a member who belongs with the supports and services they need. No matter where a child with a disability is placed, an individualised education plan (IEP) must be developed around the child's needs. The IEP objectives must continue to be met in the regular class. The same applies to the related services a child needs: they must continue to be provided for in the regular settings (Kids Together Inc, 1996:2). Inclusion in school requires a shift in paradigm: instead of getting the child ready for the regular class, the regular class gets ready for the child.

In the *White Paper No. 6* (Department of Education, 2001), the following is distinguished:

MAINSTREAMING	INCLUSION
Mainstreaming is about getting learners to 'fit into' a particular kind of system or integrating them into this existing system.	Inclusion is about recognising and respecting the differences among all learners and building on similarities.
Mainstreaming is about giving some learners extra support so that they can 'fit in' or be integrated into the 'normal' classroom routine. Learners are assessed by specialists who diagnose and prescribe technical interventions, such as the placement of learners in programmes.	Inclusion is about supporting all learners, educators and the system as a whole so that the full range of learning needs can be met. The focus is on teaching and learning actors, with the emphasis on the development of good teaching strategies that will be of benefit to all learners.

3.6.3   Education for all (EFA)

The issue of inclusion has to be framed within the context of the wider international discussions around the United Nations agenda of Education for All, which has been stipulated by the 1990 Jomtien Declaration.

UNESCO (United Nations Educational, Scientific and Cultural Organisation 20050 leads the global Education for All movements, aiming to meet the learning needs of all children by 2015. By 'all children', it includes children of all races, gender, religious groups, socioeconomic groups and CWPDs. Education should not be seen as a privilege, but as a right. Education is a development imperative and should open the doors for all individuals and communities. It is central to giving children, youth and adults the knowledge and skills to make informed decisions and acquire better health, better living standards and safer, more sustainable environments. A world of peace, dignity, justice and equality depends on many factors of which education is central (UNESCO, 2005). Education really is for all; however, discrimination still exists against woman and girls in education worldwide. Other groups of children have also been neglected, including indigenous populations and remote rural groups, street children and linguistic and cultural minorities.

A rights-based approach to education is founded on three principles:

- access to free and compulsory education
- equality, inclusion and non-discrimination
- the right to quality education content and processes (EFA, 2005:12)

3.7   DEFINITION OF SOCIAL INCLUSION

Socialisation is the process by which individuals acquire the knowledge, skills and character traits that enable them to participate as effective members of groups and society. This includes the way in which other children accept CWPDs into their social groups. If they do not then CWPDs face attitudinal barriers. Socialisation takes place if it enables CWPDs to participate in social groups and society (Berns, 2010:6). Socialisation begins at birth and continues throughout life. Ideally, it is a reciprocal process but when CWPDs are excluded we have to turn this process around. To be human is to be caring and have a conscience. Accordingly, socialisation methods vary in effectiveness according to the person implementing them, the situation, and the child at whom they are directed.

While mainstreaming is limited to putting a person with a disability next to typical people in the hope that each will adapt to and learn about the other, inclusion argues that the whole of society, its physical accessibility and its social attitudes should exist with a universal design in mind, thus ending marginalisation by ending the idea that a body that is different is incapable of self-management. Although the concept of inclusion began as a way to ensure that CWPDs were educated at the same school they would have attended if not disabled, inclusion today is considered an all-encompassing practice of ensuring that people of differing abilities belong, are engaged and are connected to the goals and objectives of the whole wider society (www.wikipedia, 2010). The attitude of inclusion, which has a great deal in common with the social model of disability, alleges that this entire approach is wrong and those who have physical, sensory and/or intellectual impairments are automatically put on a much more effective and fulfilling road to full participation in society if they are, instead, looked at and valued by society from the outset as totally 'normal' people who just happen to have these 'extra differences'. A sense of belonging, being loved, having relationships and friendships with others enriches children's lives. Feelings of loneliness and alienation can have a negative impact on all areas of CWPDs' lives (King et al. 1997: 47-60).

Concentrating on the rural areas of South Africa, in particular KwaZulu-Natal, there are families whose children are more likely to experience academic failure or exclusion, in particular CWPDs. This can be attributed to factors such as a lack of early childhood education, a lack of early intervention and a lack of opportunities at an early age to develop social competence and confidence.

The government has made a strong commitment to a more inclusive society and a more inclusive schools system. At present, it is not possible to work towards a more inclusive system when thousands of children without physical disabilities in KwaZulu-Natal do not have access to decent schooling, buildings, toilets and other necessities for the activities of daily living.

3.8 SOCIAL INCLUSION AND JUSTICE

Social exclusion emerged as an important policy concept in Europe in the 1980s in response to the growing social divides that resulted from new labour market conditions and the inadequacy of existing social welfare provisions to meet the changing needs of more diverse

populations. Social inclusion is not, however, merely a response to exclusion (Donnelly & Coakley, 2002:5).

The concept of inclusion is not monolithic. In terms of education it is becoming increasingly evident that inclusion has different meanings in different contexts, in spite of the fact that various countries share a commitment to inclusion. Although varieties of inclusive practices are beginning to emerge, each offering different solutions, some critical aspects fundamental to this concept are commonly agreed on, such as the principles of social justice. The implementation of this can and should first of all be evaluated against a framework of relevant education policies. Since a democratic dispensation was introduced in South Africa in 1994, the country has been in the process of social, political and educational transformation aimed at developing a more inclusive society (Pottas, 2005:23). South Africa's constitutional commitment to the principle of social justice requires sustained efforts towards the equal realisation of constitutional rights for all

Language is powerful and the choice of words used can either perpetuate social exclusion or promote positive values. Accordingly, the term 'children with disabilities' rather than 'disabled children' will be employed in this research to emphasise children's individuality rather than their condition. This is the latest terminology used by the ICF (International Classification of Functioning.

Inclusive education based on the principles of human rights and social justice is a global imperative supported by a number of international and national documents. National documents include the *White Paper No. 6,* the Constitution and the Bill of Rights. Some theories of social justice emphasise that inequality must be eliminated through the distribution of social resources, but with a bias in favour of those who are at a 'disadvantage'. Social justice is about making sure that all children are able to participate as valued, respected and contributing members of society. It is, therefore, a normative (value-based) concept, a way of raising the bar and understanding where we want to be and how to get there. Social justice reflects a proactive, human developmental approach to social wellbeing that calls for more than the removal of barriers or risks. It requires investments and actions to bring about the conditions for inclusion as the international human development movements have taught us (Donnelly & Coakley, 2002:5; Carson, 2009:15).

According to Donnelly &Coakley (2002) social justice involves recognising the importance of difference, and diversity has become central to new understandings of identity at both a national and community level. Social justice goes one step further: it calls for a validation and recognition of diversity, as well as recognition of the commonality of lived experiences and the shared aspirations among people, particularly evident among families with children.

This strongly suggests that social inclusion extends beyond bringing the 'outsiders' in, or notions of the periphery versus the centre. It is about closing physical, social and economic distances separating people, rather than only about eliminating barriers between *us* and *them.*

The enjoyment of human rights by children with disabilities can be fully realised only in an inclusive society, that is, a society in which there are no barriers to a child's full participation and in which all children's abilities, skills and potential are given full expression.

Some of the poorest countries in the world are now leading the way through a combination of political will, partnership with local communities and, above all, the involvement of children and adults with disabilities in the decision-making process.

The researcher intends to help raise the profile of childhood disability and to give impetus to the challenge, ensuring that children with disabilities are fully included in efforts to promote the human rights of all children and reduce negative influences wherever possible.

3.9   THE CORNERSTONES OF SOCIAL INCLUSION

Social inclusion is a complex and challenging concept that cannot be reduced to only one dimension or meaning. Although there are many such dimensions, Donnelly and Coakley (2002:6) have helped to identify five critical dimensions, or cornerstones of inclusion:

- **Valued recognition –** conferring recognition and respect on individuals and groups. This includes recognising differences in children's development and, therefore, not equating disability with pathology; supporting community schools that are sensitive to cultural and gender differences; and extending the notion to recognising common worth through universal programmes such as health care
- **Human development** – nurturing the talents, skills, capacities and choices of children to live a life they value and to make a contribution both they and others find worthwhile. Examples include learning and developmental opportunities for all children and adults;

and community child care and recreation programmes for children that are growth-promoting and challenging rather than merely custodial.

- **Involvement and engagement** – having the right and the necessary support to make/be involved in decisions affecting oneself, family and community, and to be engaged in community life. Examples include youth engagement and control of services for youth; parental input into school curriculum or placement affecting their child.

- **Proximity** – sharing physical and social spaces to provide opportunities for interactions, if desired, and to reduce social distances between people. This includes shared public places such as parks and libraries (if they exist in rural areas) and integrated schools and classrooms.

- **Material wellbeing** – having the material resources to allow children and their parents to participate fully in community life. This includes being safely and securely housed and having an adequate income.

Inclusion is about everyone being able to have opportunities for choice and self-determination. Inclusion is a vision, a road to be travelled, but a road without ending and a road with all kinds of barriers and obstacles, some of them invisible and some of them in our own heads and hearts (Mittler, 2000: xi).

3.10   RATIONALE FOR INCLUSION

According to a recent report for the World Bank Disability Group, "[e]ducation is widely seen as a means to develop human capital, to improve economic performance and to enhance individual capabilities and choices in order to enjoy freedoms of citizenship" Furthermore, education is an important vehicle through which economically and socially marginalised children can be empowered to change their life chances, and obtain the means to participate more fully in their communities (EFA, 2005:28).

The right of every child to an equal education is proclaimed in the Universal Declaration of Human Rights and forcefully reaffirmed by the World Declaration for All (Haile & Bogale, 1999:3). Studies in other countries have proven that children develop better physically, psychologically and socially if they learn together with other children. Similarly, families prefer it when all children are accepted within the same school and programmes (Haile & Bogale, 1999: 3). The basic problems of children with disabilities cannot be solved by moving these people away from where they live or are educated. Negative attitudes, prejudice

and discriminating behaviour will continue unless rural communities open their doors to their members with disabilities and give them the opportunities they deserve and have been deprived of for so long (Haile & Bogale, 1999:4).

Disability advocacy groups, such as Kids Together Inc., state that the principal goal for inclusion is to make non-disabled children understand and value diversity. Kids together states that: "Meeting all their needs together increases their [students with disabilities] ability to achieve academic and physical growth to reach their potential, which also enhances their quality of life [for students with disabilities]." Through inclusive education, teachers place children with disabilities on a path that teaches them how to be a participating member of society and their community. Another goal of this type of education is to promote teamwork and ways of functioning and interaction with people with different disabilities

3.10.1 Benefits of inclusion

Benefits for CWPDs include the following:

- Inclusion helps to develop friendships between peers and prepare children for adult life in the community (Matson, 2007; Renblad, 2003).
- Only inclusion has the potential to reduce fear and insecurity, build friendship, and increase respect and understanding of fellow beings (Brodin, 2009; Ljusberg, 2009).
- Learning does not exist in a vacuum but in social interaction with other human beings, and inclusion gives all children the opportunity to learn together with others (Palaestra, 1999).
- Inclusive education is also a more efficient use of educational resources (e.g. economical and staff).
- Inclusion assists in changing attitudes so that children are not devalued or discriminated against or excluded because of their disability.
- Children belong together and do better academically and socially in integrated settings than in segregated settings (Tomasello, 2003).
- It provides more stimulating environments.
- It provides role models who facilitate communication, social and adaptive behaviours.
- It improves competence in IEP objectives (Palaestra, 1999)
- It provides opportunities to make new friends and share new experiences (Palaestra, 1999).

- It allows for membership in a class and in the school (Palaestra, 1999).

The benefits for children without disabilities according to Palaestra, 1999 include:

- more accepting of individual differences
- more comfortable with children with disabilities
- become more helpful in general
- acquire leadership skills
- improved self-esteem

The benefits of inclusion for teachers include

- awareness/appreciation of individual differences in all children
- access to specialists/resources that can help all children
- learning new teaching techniques that can help all children (Palaestra, 1999:1)

The current educational environment presents legislative, ethical and moral imperatives stating that all children shall have an equal opportunity and equitable opportunity to learn. However, this does not seem to be spilling over into our rural areas. Government is bound by international and constitutional law to give effect to children's rights, including the rights of CWPDs.

Seeing education through the inclusion lens implies a shift from seeing the child as a problem to seeing the education system as the problem that can be solved through inclusive approaches. This is based on the social model. Figure 3.6 below illustrates education based on the social model.

Inclusion is much larger than just placement in a regular class within a school. It is being included in all aspects of life and participating in activities in the community; that is, societal inclusion.

The concept and development of inclusion will now be discussed in depth from an international perspective

Changing the education system
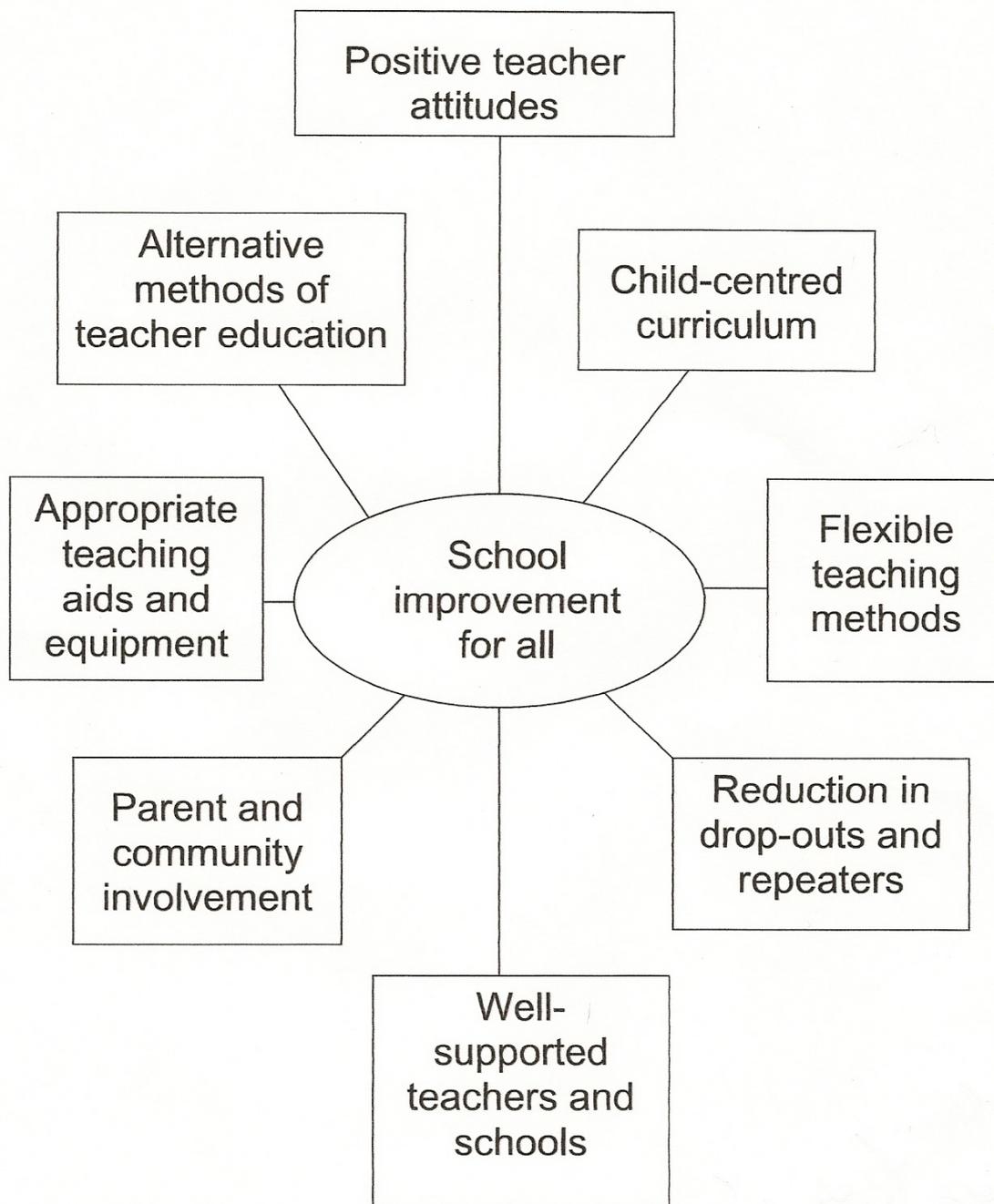
Figure 3.5: **Education for all (this is what Bronfenbrenner advocates on the microsystemic and mesosystemic levels). This figure is relevant to how successful school improvement for all is vital from many sources and angles.**

3.11 INCLUSION FROM AN INTERNATIONAL AND GLOBAL PERSPECTIVE

In this section the research gives an exposition of the inclusive movement and the associated paradigm shift. The way in which various countries address the issues of inclusive education and an inclusive society will be explored. More than 600 million people worldwide have a disability. While some countries have evidenced a degree of success in terms of inclusion, the efforts of many have been fraught with economic, political and social challenges. Large classes and the absence of related services, which provide medical and physical supports, are hindrances to the inclusion of CWPDs in general education settings. In developed countries, legislation and social policies have helped to remove many of the barriers to education and inclusion for all children (Schwartz, Blue, McDonald & Pace, 2010:108).

This new paradigm requires a reconceptualization of disabilities; this was discussed in chapter 2. Thus, in the field of special education a paradigm shift is occurring. The move, both national and international, has necessitated changes to education policy, legal frameworks for education and practice in schools. These changes are fundamental and are largely a reaction to violations of human rights, discrimination, oppression and social control. A growing body of growing literature is now emerging documenting and discussing a concomitant paradigm shift away from a reductionist approach to teaching and learning towards a more holistic social constructivist approach (Smith, 2005:1).

3.11.1 World initiatives for inclusive education

During the 1960s the idea of 'normalisation' emerged in Western societies as one of the outcomes of a series of earlier socioeconomic and cultural transformations. Changes in worldviews, the explosion of media technologies and political shifts led to the development of liberal-progressive societies in which acknowledgement of diversity and equality of opportunities began to be promoted. In the 1970s, these changes in liberal, critical and progressive democratic thoughts had a direct influence on the education system, as the traditional practice of segregating learners with special needs in separate schools was challenged to an increasing extent (Pottas, 2005:20).
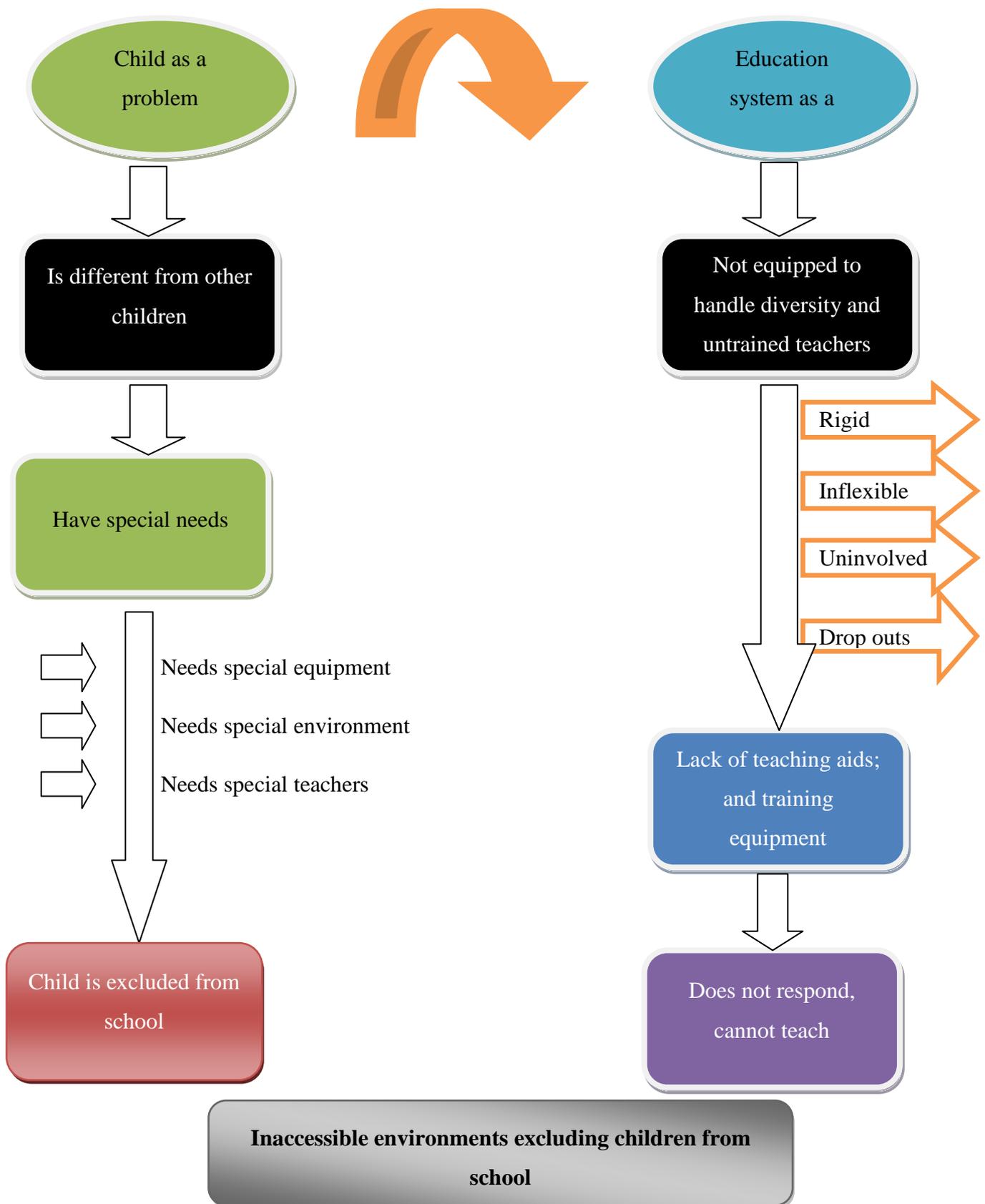
Figure 3.6:   Education as seen from the medical model. It is clear from this diagram that this model is discriminatory and is outdated.

Since 1975, education for individuals with disabilities has received worldwide attention and commitment, both as a result of United Nations (UN) activities and through global statements and initiatives endeavouring to bring about Education for All. In the Declaration of the Rights of Disabled Persons, UN member countries confirmed their support for human rights, education, integration and full employment, and conditions of economic and social progress for persons with disabilities. Since 1981, different initiatives have been published to promote the rights of the disabled (Pottas, 2005:21).

From the time of the Salamanca Statement (1994) (World Conference on Special needs Education: Access and Quality) up to the Dakar Framework (2000) (World Education Forum0, it is easy to see how the world community has moved beyond the basic idea of acceptance. In April 2000, the Dakar Framework for Action: Education for All was adopted at the World Education Forum in Dakar, with the aim of achieving worldwide education for all by 2015. The global challenge for educators is to establish viable ways to make the changes needed for accessible and equitable education for all.

3.11.1.1   Dakar framework for action (2000)

The Goal of the Flagship has been agreed to as follows; recognizing the universal right to education, the Flagship seeks to unite all EFA partners in providing access and promoting completion of quality education for every child, youth, and adult with a disability.

In order to reach this goal, the Flagship will:

- Have the full participation of persons with disabilities and families in the flagship activities.
- Promote the full participation of persons with disabilities and families in the development of policies and practices related to the education of persons with disabilities at local, national, regional and global level
- Seek to ensure that all government entities, donors, and NGO's endorse the universal right of education for all children and adults with disabilities
- Act as a catalyst to fully incorporate the Flagship Goal into national plans of action and regional policies.
- Work in partnership with all other EFA Flagships to fully endorse and incorporate the right of educating every person with a disability into their efforts

- Mobilize resources in support of the flagship goal through obtaining commitment of new resources from national and international entities and leveraging existing EFA resources
- Seek to ensure that EFA monitoring Process includes specific quantitative and qualitative statistics and indicators related to persons with disabilities and documentation of resources allocated to the implementation of EFA for these individuals
- Identify and disseminate effective practices and stimulate research and studies related to the Flagship Goal to include such areas as;
- Quality teacher education
- School organization including adequate and accessible facilities
- Curriculum and pedagogy
- Assistive devices and appropriate materials
- Promote the right of every child and youth with a disability to express their view pertaining to their education and life skills as defined by Article 23.1 of the Convention on the Rights of the Child

In order to provide legally binding standards for protecting the rights of people with disabilities in every country, the UN voted to start planning a Convention of the Human Rights of People with Disabilities in November 2001 (Pottas, 2005:22).

Moreover, the educational rights of CWPDs have been recognised throughout the world. The initial need for acceptance and inclusion has moved on to access, reform and an examination of education practices.

3.11.2 United Nations initiatives

3.11.2.1 Children's rights

The UN Convention on the Rights of the Child was finally signed in 1989, after 18 years of negotiation. Governments that ratified the convention are under a legal obligation to implement and to report on progress to the UN. Article 2 specifically mentions disability in calling for the implementation of the convention without discrimination of any kind. Article 23 is directly concerned with children with disabilities (Mittler, 2000:20).

3.11.3 United Nations Educational, Scientific and Cultural Organisation (UNESCO)

UNESCO is undoubtedly the key UN agency that has stimulated global awareness and actively promoted national development in the field of special needs and inclusive education.

UNESCO's work can be summarised under the headings information dissemination, consultancies and teacher education (Mittler, 2000: 21).

3.11.4 Organisation for Economic Cooperation and Development (OECD)

The OECD has been described as a policy think tank and sometimes as the 'rich man's club' because its members are drawn predominantly from Europe and North America and include New Zealand and Australia. The work of the OECD in the field of inclusive education is not as well known as that of UNESCO but undoubtedly has been influential (Mittler, 2000:22).

3.11.5 Jomtien

In 1990, delegates from 155 countries, as well as representatives from some 150 governmental and non-governmental organisations, agreed at the World Conference on Education for all in Jomtien, Thailand (5–9 March 1990) to make primary education accessible to **all** children and massively reduce illiteracy before the end of the decade.

The delegates adopted a World Declaration on Education for All, which reaffirmed the notion of education as a fundamental human right and urged countries to intensify efforts to address the basic learning needs of all. The Framework for Action to Meet the Basic Learning Needs defined targets and strategies to meet the basic learning needs of all by the year 2000. The goals included

- universal access to learning
- a focus on equity
- emphasis of learning outcomes
- broadening the means and scope of basic education
- enhancing the environment for learning
- strengthening partnerships by 2000

However, the **targets** set were not achieved by the year 2000 (World Conference on EFA, Jomtien, 1990, UNESCO).

3.11.6 The Salamanca Statement

Although the Jomtien documents make explicit references to children with disabilities, very few governments reported new initiatives to enable children with disabilities to go to school. It was therefore necessary to take some positive steps to ensure that governments committed

to EFA (Education for All) did not 'forget' children with disabilities or deliberately give them a low priority. The Salamanca conference marked a major milestone on this road.

From 7–10 June 1994, the delegates of the World Conference on Special Needs Education representing 92 governments and 25 international organisations assembled in Salamanca, Spain to reaffirm their commitment to Education for All, recognising the necessity and urgency of providing education for children with special educational needs within the regular education system and to endorse the Framework for Action on Special Needs Education.

The Salamanca Statement and Framework for Action on Special Needs Education states

> … schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalised areas or groups (paragraph 3).

The underlying belief is that regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities and building an inclusive society and achieving EFA; moreover, they provide an effective education for the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system. South Africa together with 93 other countries and 20 NGOs worldwide adopted the statement. After the declaration of the Salamanca Statement, many countries embarked on reform initiatives of their education policies. The Salamanca Statement fits in with Bronfenbrenner's Bioecological Model as it looks beyond the child, from family to school and to governments.

Salamanca Statement

The Salamanca Statement of the UNESCO World Conference on Special needs Education: Access and Quality states that:

- Every child has the fundamental right to education and must be given the opportunity to achieve and maintain acceptable levels learning;
- Every child has unique characteristics, interests, abilities and learning needs;

- Education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs;

- Those with special educational needs must have access to mainstream schools which should accommodate them within a child-centred pedagogy capable of meeting those needs;

- Mainstream schools with this inclusive orientation are the most effective means of combating discriminating attitudes, creating welcoming communities, building an inclusive society and achieving education for all. Moreover, they provide an effective education for the majority (without special needs) and improve the efficiency and ultimately the cost-effectiveness of the entire education system

- Those with special educational must have access to mainstream schools which should accommodate them within a child-centred pedagogy capable of meeting these needs.

3.11.7   World Summit on Social Development, Copenhagen, 1995

The Social Summit, which was attended by world leaders and NGOs, made a triple commitment to the eradication of poverty, unemployment and marginalisation. Representatives of disabled persons, who formed a strong advocacy group in Copenhagen, argued strongly that because all three of these were priorities for disabled people, their interests should feature prominently in Summit resolutions. The final report included the following statement: "6f) Ensure equal educational opportunities at all levels for children, youth and adults with disabilities in integrated settings, taking full account of individual differences and situations" (Mittler, 2000:19).

3.12   INCLUSION FROM AN INTERNATIONAL AND GLOBAL PERSPECTIVE

3.12.1   The USA

The United States can offer lessons in changing the paradigm in special education from recognising the right to be included to offering educational equity and access (Schwartz *et al*., 2005:109). The public education system in the United States continues to be unequalled in the world. Rather than serving the needs of certain groups of children, such as those who are wealthy, those with academic potential, or those of certain genders, the US education system caters for all children. It attempts to offer 13 years of free, equal education opportunities to all children, including those with parents who are not educated and those from families without financial means. Children with disabilities and those with learning or behavioural problems

are included in the educational system. Children do not have to pass certain tests to attend various schools, nor do their families need to pay for a comprehensive educational programme.

The US Constitution, which guarantees equal opportunities for all its citizens, is the basis for the free public educational system. Since their beginning in the mid-1800s, public schools have evolved into a system that provides educational opportunities for all learners. Initially this was not the case: girls did not secure their right to equal opportunities until the early 1900s, racial minorities not until the 1950s and 60s, and students with disabilities not until the 1970s and 80s. Litigation and legislation played an important role as each group secured the right to participate in educational programmes (Smith, Polloway, Patton & Dowdy, 2002:4).

Prior to federal legislation passed in the mid-1970s, many schools did not provide any programmes for children with disabilities, or the programmes they provided were very minimal. Until the 1970s, it was estimated that 3 million children with disabilities received inappropriate or inadequate services, while up to 1 million were totally excluded from the educational system (Smith *et al.*, 2002:4).

In a few schools, students with physical disabilities or cognitive difficulties were provided with services; however, these services were nearly always in self-contained, isolated classrooms, and the students rarely interacted with non-disabled students. Services for this group of children were slow to develop because of limited financial resources and public apathy (Smith *et al.*, 2002:4).

Since the mid-1970s, services for children have changed dramatically. Not only are more appropriate services provided by schools, but they are also frequently provided in both resource rooms and general education classrooms with collaboration between special education and general classroom teachers. Many different developments brought about this change, including parental advocacy, legislation and litigation. The federal government also played a major part in the evolution of special education services, primarily through legislation, litigation and funding. While the changes in special education over the past 25 years have been dramatic, probably the most significant change has been acceptance of the idea that special education is a service not a place (Implementing IDEA, 2001).

3.12.2 Italy

The researcher will provide a brief contrast in terms of an international perspective by using Italy as an example. This is because Italy's approach to inclusion offers a striking contrast to the UK, Australia and New Zealand, which are cited in most articles. This is also because little literature is available in English.

Italy is generally credited as being the first country to legislate for and introduce a radically new system. The original legislation, which was introduced in 1971 and legislated in 1975, was radical even by today's standards because it involved the closure of most special schools and the transfer of all their pupils to local neighbourhood schools (Mittler, 2000:24).

Buzzi (in Mittler, 2005:25) sees the integration movement as an expression of wider reforms involving the abolition of segregation through academic selection, both being based on articles in the Italian Constitution that refer to the rights of all citizens to education .

The impetus for school integration came from a parallel revolutionary movement known as *psychiatric democratic.* This involved the closure of large psychiatric hospitals and a wholesale transfer of mental health services to the community. The legal basis for integration was laid down in law 118/1971, which states that compulsory education should take place in the regular class "except for those children who suffer from mental or physical impairments that make regular education impossible or very difficult". No criteria were given to identify such children, with the result that many were included in regular classes from an early stage.

Later laws and regulations made provision for support. Free transport had to be provided and school buildings had to be made accessible. No more than two children with special needs were to be placed in any one class and the total number of pupils in such classes was not to exceed 20. A school is entitled to one support teacher for two children with severe disabilities. External support teams are made available, consisting of psychologists, speech therapists and education officers (Mittler, 2000:25).

However, as with all inclusive educational programmes they are experiencing difficulties in the following areas:

- teacher training not changing to meet the needs of the new system, with content being more theoretical than practical
- support teachers not being well trained and often performing poorly in the classrooms

- poor collaboration between class teachers and support teachers

Even active supporters of inclusion refer to this early period as *integrazione salvaggio* (wild integration) because it was not carefully planned and because it was carried out as an ideology. Despite these problems, Italy seems committed to the principle of integration and is taking steps to develop a more effective system. As a strongly child-centred society, there is every chance of success. Furthermore, Italy emphasised that its aims were not only educational but social in so far as they wanted to ensure that the next generation of Italian adults would have had the experience of going to school with children who would previously have been excluded from mainstream schools. They hope to build a society that celebrates difference and diversity (Mittler, 2000: 26).

3.12.3 Scotland

According to Smith (2005:5), the education system in Scotland has failed to be 'comprehensive' on two counts: it has failed to include all children in mainstream education and it has never found a satisfactory way of appropriately addressing the needs of young learners. This is due to the absence of a paradigm shift in attitudes and methodologies to accompany the comprehensive system. The Standards in Scotland's Schools (2000) Act has partially addressed the inclusion of all children in mainstream education. This Act brought in a "presumption of mainstreaming" which requires that children with special educational needs should attend their local school unless there are good reasons for alternative provision to be considered. However, the Act also places a duty on education authorities to ensure that the education provided is directed towards the "development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential". However, little has happened in this regard. The current system continues to reflect a belief that some learners learn in substantially different ways from other learners. This belief generates a need for different contexts and settings, for different curricula and methodologies and for different types of teachers with different training and expertise. The structures in place serve to exclude and not include. As a result children continue to be categorised and labelled in relation to their perceived differences and deficits.

3.13 INCLUSION FROM AN AFRICAN PERSPECTIVE/DIMENSION

Disability creates considerable social, economic and emotional costs for persons with disabilities, their family and the wider community. The burden falls disproportionately on

those in the developing world where children with disabilities often live without dignity and therefore live with daily exclusion (Agegnehu, 2000:1)

3.13.1 Uganda

Uganda has shown that a commitment (at the Dakar framework for Action) to universal primary education can at the same time be a commitment to inclusive education. Despite being devastated by civil strife and now by AIDS, Uganda has been able to bring schooling to an additional two million children in a period of two years; four children in every family will be able to have access to free primary school education; and any child who has a disability will receive first priority. It is all matter of political will and priorities, unlike India and Pakistan who still spend much more on armaments than on education (Mittler, 2000:172).

3.13.2 Lesotho

The researcher has chosen Lesotho as it is small, land-locked, mountainous kingdom in the middle of South Africa, with a population of just under two million. It is an independent country and is one of the poorest countries in the world.

Despite major economic and social problems, the government of Lesotho sees education as a priority, which in turn reflects a national commitment to education by the population at large. Compared to other countries in sub-Saharan Africa, this is reflected in a relatively high level of primary school enrolment, especially for girls.

As part of its commitment to EFA it launched a pilot programme in 1993 in which ten rural primary schools included all local disabled children in a regular classroom exclusion (Agegnehu, 2000:1)

About 300 disabled children took part in the pilot programme of over 9000 pupils (Mittler, 2000:27). Teachers with 50 to 100 children in a class never lost track of the need to include all children in a lesson. The fact that the children seemed highly motivated to learn and were naturally supportive of one another provided strong natural foundations for a programme that extended the already wide range of pupils in the classroom. The researchers felt that these teachers were 'naturally inclusive' in their practice.

This brief overview shows that progress towards inclusive education is possible in settings with fundamental differences in culture and very limited resources.

Bronfenbrenner's model has once again proved that very little would be achieved without parent groups, associations of disabled persons, churches and business and community leaders that have worked for inclusion of children with disabilities into the local schools and have demonstrated that partnership with government and with professionals can be a powerful instrument of change. The leadership provided by UN initiatives and the commitment of nearly all governments to EFA have helped strengthen these programmes, but very little would have been achieved without the initiative of local communities (Mittler, 2000:28).

3.13.3 Ethiopia

According to a WHO estimate, there are about 3 million children with disabilities in Ethiopia. However, only 2300 of these children have access to some sort of educational service. As indicated in the table below, these services are organised within the traditional methods of welfare conceptions, segregated settings and protective environments. An overwhelming majority of these service settings were until very recently either fully supported by or partially dependent on religious groups, NGOs and foundations (Haile & Bogale, 1999:2).

Government involvement in special education has until recently been nonexistent and hence children with disabilities were not considered as children that are entitled to formal schooling as any other children. Thus, the education of children with disabilities was not included in the educational planning and budget allocation of the Ministry of Education until very recently. A survey was undertaken by the Youth Affairs Organization (CYAD) focusing on variables such as the type and extent of the problem, cause, prevention, attitude and availability of services. The survey created the basis for a detailed policy recommendation on how the needs and problems of CwDs are to be addressed. One of the recommendations was the need for special assistance and training to promote the integration of these children (Haile & Bogale, 1999:3).

The CYAD organised an awareness-raising workshop where a ten-year plan was prepared. There are changes of policies and the activities undertaken by the government, NGOS and even the community. Parents have come together and established an association to advocate for the rights of their children, people with disabilities have strong associations and the activities of the government are encouraging, although they are below what is expected.

The new policy of the Ministry of Education regarding children with disabilities and their access to education states that education shall be provided to children with disabilities as long as the resources of the country permits. The policy does not provide a clear plan of action as to how this will be achieved and it demonstrates a lack of commitment by the Government, the local authorities and the community to that section of the population that needs more support and recognition from society.

The Convention on the Rights of the Child, to which Ethiopia is a signatory, recognises the rights of every child to education. However, the policies and practices regarding children with disabilities in Ethiopia are of a discriminatory nature. The policies do not provide clear guidelines as to how the various need of CwDs are to be met (Haile & Bogale, 1999:10).

However, there are pockets of successful inclusive education attempts with children having visual impairment and mental retardation in one government primary school and the German Church Primary School. Furthermore, a study conducted on blind students integrated in Mulugeta Gedle School at Sebete showed positive experiences on the part of the teachers, sighted children as well as blind children. However, a shortage of adapted materials, an inconvenient school environment and lack of back-up support were considered obstacles in course of their education. However, these are all the beginnings of positive indications of a movement towards inclusive schooling (Agegnehu, 2000:5).

South Africa needs to learn from the shortcomings and mistakes of other countries and not fall into traps as Ethiopia (Schools for All-Save the Child, 2002:15).

3.14 SOUTH AFRICA

3.14.1 South African legislation and policies for promoting inclusion of CWPDs

The rights of CWPDs have become paramount as a result of the international initiatives discussed above. There is a strong commitment in South Africa to human rights and in particular to the rights of children. South Africa has demonstrated its commitment through the ratification of the United Nations Convention on the Rights of the Child.

The period since the 1994 elections has since been a time of significant change in South Africa's history. There is probably not one sector of society where some level of transformation has not taken place. Changes have been implemented at the policy and

legislative level as well as at the level of service delivery and government accountability (Dube, 2005:17).

In November 1997, the government adopted the White Paper on an Integrated National Disability Strategy known as INDS. The INDS provides government and society as a whole with guidelines that will promote non-discriminatory development planning, programme implementation and service delivery. The INDS is not yet legislation; however, government departments are required to formulate their disability policies and strategies in line with the provisions of the INDS (Dube, 2005:17)

Apart from the INDS, the government has passed legislation that is aimed at enforcing the rights of children with disabilities. Legislation and policies that integrate the needs of children with disabilities are either specific to the needs to children with disabilities or general mainstream laws. Essential policies/legislation with disability components include the

- Employment Equity Act (Department of Labour- South Africa)
- Labour Relations Act (No.66 of 1995).
- Amendments to the Social Security Act (No.9 of 2004).
- White Paper on Special Needs Education (2001)
- Rehabilitation White Paper
- Convention on the Rights of the Child (CRC) (1996)
- Constitution of South Africa (no. 108 of 1996).
- African Charter on the Rights and Welfare of the Child (AC) (2000)
- Children's Act 38 0f 2005
- Children's Bill (while still in the making, this is aimed at giving effect to some of the constitutional rights of children. It stipulates that barriers that face CWPDs must be removed and that the necessary support services be provided to facilitate equal opportunities and equal access.)
- Children's Amendment Act 41 of 2007

The following are NGOs that promote the rights of children with disabilities:

- Disabled People South Africa (DPSA)
- Save the Children Sweden (SCS)
- National Division for Person's with Cerebral Palsy (NDPCP)

- National Council for Persons with Physical Disabilities in South Africa (NCPPDSA)

- Disabled Children's Action Group (DICAG)

- Western Cape Cerebral Palsy Association

3.14.2   South Africa's history of exclusion

"We should not give the Natives any academic education. If we do, who is going to do the manual labour in the community?" (JN le Roux, National Party politician, 1945).

In 1948, while the South African government was embarking on a campaign of organised discrimination, the Universal Declaration of Human Rights was established to ensure the right to free and compulsory elementary education for all children. This declaration continued to gain momentum and Verwoerd, South African Minister for Native Affairs openly spoke about his government's education policies in the 1950s when he stated

There is no place for [the Bantu] in the European Community above the level of certain forms of labour … What is the use of teaching the Bantu child mathematics when he cannot use it in practice? That is quite absurd. Education must train people in accordance with their opportunities, according to the sphere in which they live.

Today in South Africa we continue to reap what was sown by the National Party. The history of disability is for the most part one of exclusion, discrimination and stigmatisation. Often segregated from society, persons with disabilities and, in particular, children with disabilities have been regarded as objects of charity and passive recipients of welfare. This charity-based legacy persists in many countries and effects the perception and treatment of children with disabilities (*Innocenti Digest* 2001:5). Because society is changing so rapidly, a major concern for parents, professionals and politicians is how to socialise CWPDs for an unknown future (Berns, 2007:1). The impact of the historical events on CWPDs has been discussed in chapter 2, so that we can learn from our mistakes and help us to deal with the future.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON HUMAN DEVELOPMENT PERTAINING TO THE EFFECTS OF APARTHEID

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child such as family & peers . Due to the Apartheid Governments's pass laws, most families in rural areas were split up when parents had to migrate to urban areas in search of employment.

This is the *Mesosystem.* It consists of linkages and interrelationships between two or more of the developing child's microsystems. As parents were not living with their children there was no contact with peers, schools,and neighbours..

This is the *Exosystem.* Meaning outside, the child is not an active participant in this system eg. The school boards made exclusion law and promoted seperation, stigmatisation and discrimination

This is the **Macrosystem.** It consists of the society and subculture to which the developing child belongs. The effects of the Apartheid era are visible in poor schooling, health facilities, transport etc.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

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Figure 3.7:   Bronfenbrenner's biological perspective on the effects of apartheid (adapted from Bronfenbrenner, 1999).

South Africa's education history is one of segregation, inequality and exclusion. (Education in South Africa. www.wikipedia) Not only were learners segregated and excluded on the grounds of race, but also on the grounds of dis(ability). In the 1980s, when the UN Convention of the Rights of the Child was established that ensured the right for all children to receive education without discrimination on any grounds, Robert McNamara, ex-president of the World Bank stated in his 1982 visit to South Africa, "I have seen very few countries in the world that have such inadequate educational conditions. I was shocked at what I saw in some of the **rural areas**. Education is of fundamental importance. There is no social, political or economic problem you can solve without adequate education". The researcher uses an older reference to illustrate that not much has changed since 1982; conditions at schools in the rural areas remain shocking.

Today, transforming the education system will require that all stakeholders embrace beliefs and practices in education that support integration rather than segregation, equality rather than inequality; and inclusion rather than exclusion (Walton, 2006:1).

Since the new government came to power in 1994, South Africa has embarked on an intensive national transformation programme aimed at transforming government, civil society, and the economy. Education in particular, has undergone a dramatic change: a single unified system based on the principles of equity and redress has been built from the formerly fragmented and racially divided education system (Education Rights Project) (ERP: 2). To succeed at this we need to look at and follow examples from countries where inclusion has been part of their framework for decades (ERP: 2).

It is important to be aware of the current trends of countries in the North, as in the past they have been followed in the South. Hopefully, there will be a more genuine sharing of experience and lessons learnt in the future since the Northern countries have a great deal to learn from the South about overcoming resource barriers, as their resources become more and more over-stretched (Miles, 2000:3).

> For many learners, attending school with their peers in their neighbourhood schools, learning the core curriculum that their school community deems essential, participating in all facets of school life, and having relationships with people of their own choosing are reality (Pottas, 2005:19).

Barriers	Solutions
Children are passive learners;	Children become active learners;
Children are unaware of their rights;	Children claim their right to education;
School attendance is poor;	Children's participation leads to improved attendance;
Traditional attitudes prevent disabled children from attending school;	Children challenge these attitudes by convincing the parents to send their children to school;
Traditional practices prevent children from expressing their opinions;	Children are introduced to democratic practices in the classroom and become very vocal;
Curriculum is not relevant to local needs.	Children help to transform the curriculum to suit local needs.

For years the traditional education systems worldwide have provided special education and related services to learners with disabilities. As the educational, social, political and economic needs of society underwent rapid change, it became increasingly evident that these traditional ideas of schools and classrooms were becoming outdated. It was now clear that increasing learner diversity and changing economic and social conditions were straining the capacity of any education system to produce well-educated learners. The effectiveness of current education systems was questioned and as a result thereof, the concept of 'inclusive school practices' was widely discussed as a philosophical basis for the development of one education service delivery system to serve all learners (Pottas, 2005:19).

3.15 THE FEASIBILITY OF INCLUSION IN THE RURAL AREAS

3.15.1 Barriers and challenges to inclusion in the rural areas

A barrier is an obstacle or circumstance that keeps people or things apart; it prevents communication and bars access to advancement. Applied to the social scene of South Africa, it forces educators and education policy makers to take cognisance of the changing social issues that impact on successful learning (Landsberg, 2005:27). As the government of South Africa in policy moves to improve and strengthen inclusive education, identifying and addressing the systemic barriers to implementing the inclusive education model will be necessary.

According to Bronfenbrenner's model, the barriers are all interlinked. The child at the micro level and the involvement of his parents with the school and the community play a vital role. At the meso level the school needs support from paraprofessionals and local government. The attitudes at this level, if negative, will be impact on the child. At the macro level is government commitment to CWPDs; this will filter through the levels and directly impact on the child. This takes place in the chronosystem which changes over time, and it was hoped that the MDGs would be reached by 2015.

The rural stability, with its strong traditional and cultural practices, can provide a very positive setting within which to promote inclusive education. However, the particular vulnerabilities of CWPDs are created and perpetuated by a number of factors. Despite key achievements in terms of the legal framework, CWPDs still do not have the access to an inclusive society (Philpott, 2004:272). This will be discussed in detail in chapter 5.

3.15.2 Disability is a cross-cutting issue

By its very nature disability is a cross-cutting issue. The lack of coordination and communication among programmes, within government departments and between government and civil society (NGOs and disabled people's organisations [DPOs]) remains a critical factor undermining the prioritisation of disability needs. The lack of coordinated strategies means that service provision focusing on children continues to be fragmented and thus available resources have limited impact. Another critical factor that hinders the implementation of policy is a lack of information in regard to the prevalence of childhood disability, the needs to children with disabilities, as well as the resources available in the rural areas (Philpott, 2004:273).

One of the main reasons why legislative discrimination continues to take place is that discrimination is not always merely reading from a statute. Problems often arise when the law or statute is applied.

According to Paquette & Ryan 2001 these include:

- the way regulations governing specific acts are drawn up (macrosystem)
- the way acts and/or their regulations are administered (macro and exosystems)
- inappropriate and/or ignorant interpretation of the law (micro- to macrosystems)
- poor monitoring of the law (macro- and exosystems)

To understand change at all levels, it is important to know what change looks like from different points of view. How the parent, the teacher, local (exosystem) and national government (macrosystem) see change is vital for understanding how individuals and groups act and, indeed, react to each other. Reforming school systems to become inclusive is not only about putting in place recently developed inclusive policies that meet the needs of all learners, but also about changing the culture (chronosystem) of classrooms, districts and so on (EFA, 2005:20).

This section will provide an exposition of Bronfenbrenner's socio-ecological theory as a basis for conceptualising the different levels of inclusion in the community and the value of using an ecological framework to make sense of this inclusion.

3.16   BRONFENBRENNER AND INCLUSION

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON THE INCLUSION OF CHILDREN WITH PHYSICAL DISABILITIES

This is the *Microsystem* and refers to the activities and relationships with the immediate and extended family. If the family accept the child and include them in all family aspects, the foundations of inclusion will be solid.

This is the *Mesosystem.* It consists of linkages and interrelationships between two or more of the developing child's microsystems. If parents involve their children in all community activities and are themselves involved promoting inclusion, the child will be accepted by the community.

This is the *Exosystem.* Meaning outside, the child is not an active participant in this system. If school boards promote workshops and training, and parents workplaces are understanding inclusion is further promoted.

This is the **Macrosystem.** It consists of the society and subculture to which the developing child belongs. Almost the entire success of inclusion lies here in what the government does in terms of laws and necessary provisions.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development such as repairing the damages of the apartheid era

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Figure 3.8:   Bronfenbrenner's perspective on inclusion (adapted from Bronfenbrenner, 1999)>

Looking at Bronfenbrenner's model of ecological development from the microsystem through to the macrosystem, one thing is clear: schools and the education system do not function in isolation. A society's values, beliefs and priorities will permeate the life and work of schools and do not stop at the school gates. Those who work in schools are citizens of their society and local community, with the same range of beliefs and attitudes as any other group of people; so are those who administer the wider education system, including appointed and elected members of local government, school directors and the Minister of Education (Mittler, 2000:1).

3.16.1   Bronfenbrenner's ecological systems framework

Teachers, parents, communities, school authorities, curriculum planners, training institutes and entrepreneurs in the business of education are among the actors that can serve as valuable resources in the support of inclusion. Some (teachers, parents and communities) are more

than just a valuable resource; they are the key to supporting all aspects of the inclusion process. Ideally, effective inclusion involves implementation both in school and society (EFA, 2005:21).

3.16.1.1 Level 1: The microsystem

In this level the microsystem contains the factors within a child's immediate environment such as family members and the school. The family is the child's introduction to society and therefore bears the major responsibility for socialising the child. It is the child's first reference group for values and relationships. Unfortunately, in the rural areas of South Africa because of the negative attitudes towards many children with disabilities they are hidden and therefore deprived of this first social opportunity. Family members include siblings, grandparents, uncles and aunts who play a pivotal role in the child's life. The lack of parental involvement in schools in rural areas is largely attributed to long distances, lack of both money and transport and t

The peer group is a microsystem in that it comprises relationships, roles and activities. Peers are supposedly equal individuals of the same gender, age and social status. Although outwardly the peer group appears to comprise equals, inwardly dynamics of the peer group reveal that some members are more equal than others as some, for example CWPDs, are not accepted members.

Research highlight that fragmented services can be disruptive to children and parents, and reduce the overall family time available for leisure. However, barriers to interaction are unable to provide this leisure time as the exosystem has failed in providing parks and facilities where this much needed interaction can and should be taking place.

Socially imposed barriers to participation and inclusion for CWPDs and their immediate families are thus entrenched and reinforce the negative attitudes implicated in exclusion (Clarke, 2006:i).

3.16.1.2 Level 2: The mesosystem

The second level is the mesosystem; this encompasses the "interrelations of two or more settings on which the developing child actively participates (such as, for a child, the relations between home and school, school and neighbourhood and peer groups)." Family members' beliefs about inclusion and the family's relationship with the school affect the inclusion

process. In the rural areas 'the hidden children' are deprived of developmental possibilities at the mesosystemic level as well.

The neighbourhood in which a child lives influences whether the peer group has a positive or negative effect. Neighbourhoods that include parents who are involved in schools, who participate in organised activities for children and who monitor their children tend to have children who provide positive peer influences on one another. Parents can influence whether a child's peer group experiences are positive or negative by knowing who their child's friends are and by being involved in the child's activities. This is the ideal. However, in our rural areas there is no way that this is even a possibility. There are no parks and recreation centres, no libraries and no groups such as scouts. Access to mainstream leisure activities is an important issue for many families, whose outings are limited by lack of funds, lack of transport, and lack of disability facilities (toilets). A lack of affordable accessible and inclusive activities can significantly restrict CWPDs' involvement with other children throughout the year, as is noted in a particularly long holiday such as the one to accommodate the 2010 Soccer Cup Final.

The school
The school acts as an agency of society in that it is organised to perpetuate society's knowledge, skills, customs and beliefs. Child care has become an important socialisation agent because of societal changes in the amount of time children spend being cared for by individuals outside the family (the mesosystem). It is for this reason that an investigation into the lack of inclusion in schools is so vital and central to this study, and why the school plays such an important part. As so many parents work, aftercare facilities exist at many schools and so children spend a large part of the day at school (Berns, 2007:160).

The school is a society's formal institution where learning takes place. To better understand the socialisation function of the school, macrosystem influences (political ideology, economics, culture/ethnicity, religion and science/technology and their changes over time [chronosystem influences] are discussed. Also relevant to understanding the school's function as a socialisation agent are linkages, or mesosystems, between school and family, school and peer group, school and media and school and community (Berns, 2007:197).

The school's function as a socialising agent is that is provides the intellectual and social experiences from which typically developing children can develop the skills, knowledge, interests and attitudes that can promote inclusion.

The primary purpose of education, of society's perspective, is the transmission of the cultural heritage: the accumulated knowledge, values, beliefs and customs of society (macrosystem). If inclusion is to start at an early age, schools need to transmit this knowledge so that the CWPDs are valued members of society, and culture is instilled and transmitted, this knowledge can then be maintained. However, to do this, schools need trained teachers and professionals who can assume specialised roles especially in the poor rural areas of South Africa. The exploratory study in this research revealed that the teachers have received no training and are therefore negative towards inclusion.

The purpose of education from the CWPDs' perspective is to acquire the necessary skills and knowledge to become self-sufficient and to participate effectively in society (Berns, 2007:198).

The school reflects macrosystem influences of society – specifically, its traditional values and future goals. The members of the rural community implement these values. Influential macrosystem factors in educational policy are political ideology, economics, culture/ethnicity and religion.

For CWPDs the main aim of socialisation within the school context should be to minimise the effects of their disabilities and to maximise the effects of their abilities; for example, the assumption that CWPDs are incapable can lead to ostracism and thus exclusion. The school is also responsible for extracurricular activities, camping activities, sporting activities and involvement in the community.

3.16.1.3   Level 3: The exosystem

The third level (moving outwards) is the exosystem and consists of 'settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what is happening in the setting containing the developing person" (Odom *et al*., 1996:6). The service delivery agency responsible for an inclusion programmes provides an example of the exosystem setting. How the agency, district or group is organised will affect programme implementation. In a study that followed programmes in Washington State over a five-year period, the programmes that were able to sustain inclusion services

turned out to be those organisational structures that had been re-shaped explicitly to support the inclusion process (Odom *et al*., 1996:6). Other examples of factors operating at the exosystemic level include the interactions of the professionals responsible for inclusion programmes, formal and informal policies of the school system and social services and policies that connect organisational layers. Any of these exosystemic factors can affect the experiences of individual children in individual programmes and overall inclusion. There is convincing evidence that families that have CWPDs are more likely to be marginalised economically. This may be for a number of reasons such as employers giving parents extra much-needed time and parental ability to access work (e.g. availability of appropriate childcare), as well difficulties when employers fail to recognise parental responsibilities.

Today, the effects of apartheid are still felt in the exosystem, for example, government policy and its practical implications in the lives of South African citizens, as in the cases of affirmative action and outcomes-based education (Hook, Watts & Cockcroft, 2009:319).

3.16.1.4   Level 4: The macrosystem

Bronfenbrenner's suggestion is that developmental interactions should occur preferably at the level of the macrosystem, because macrosystem changes impact on all lower levels of development (Hook *et al*., 2009:319).

The macrosystem envelops the micro-, meso- and exosystems. Bronfenbrenner defines the macrosystem as "[c]onsistencies in the form and content of lower-order systems … that exist at the level of the subculture or the culture as a whole, along with any belief system or ideology underlying such consistencies. All settings at each level operate within a cultural context". The culture of special education, for example, values inclusion as a practice. Influenced over time by the movement towards "normalization" (Odom *et al*., 2006:6) by advocacy organisations, many families and professionals now endorse the inclusion of children with disabilities in typical settings and everyday community activities.

Macrosystem influences on the peer group involve reinforcing the values and traditions of society. The peer group in turn provides the setting and the means for children to achieve some of the expected developmental tasks of early childhood. This means that children must learn to get on with others, develop morals and values, learn appropriate social and cultural roles, and achieve personal independence while formulating an identity (Berns, 2007:285).

Bronfenbrenner differs from many developmental psychologists in the sense that the recommendations he makes for inducing productive and beneficial changes in the developing child are not necessarily limited to the microsystem. Indeed, one only needs to consider the macro role of apartheid in influencing all other spheres of development contained within it, particularly in the life of the black child (Watts, Cockcroft & Duncan, 2009) .,Ecological Systems Theory Essay @hotessays.blog.spot.com.

The influence of such a system of government did not stop at the macrosystem and exosystem levels of racist ideology and segregation, but spread also to the mesosystem where families were broken up by pass laws, where police violence and intimidation reached into homes and schools and where racialised poverty and subsequent problems like malnutrition and inadequate education ensured development deficits at the small levels of development (Hook *et al*., 2009:320).

3.16.1.5   Level 5: The chronosystem

Chronosystem influences on the school include its adaptation to societal change in general and to specific developments such as health and safety. Schools do not execute their functions in a vacuum; they are affected by macrosystems such as culture and politics which are linked to other microsystems such as the family and community. Chronosystem influences on families, socialisation and children include socio-political and technological changes (Berns, 2007:115).

Social policies that guide the implementation of inclusion require a full understanding of the multidimensional nature of the inclusion process. An ecological systems perspective such as that advanced by Bronfenbrenner provides an essential framework for building a programme of research that could identify barriers to and facilitators of inclusion. This conceptual framework pushes researchers to look closely at the types of research question being asked, to understand how the questions are embedded within the ecological context, and to select methodologies that yield information that is both useful and accurate for policy makers and practitioners.

Socialisation must pass on the cultural heritage to the next generation while also enabling that generation to become competent adults in society – this means all adults even those with disabilities. Thus, every socialising agent from the micro to the macro level engages in preparing children for both stability and change. Training for stability, which is implemented

by passing on the cultural heritage and the status quo to children, involves making their behaviour somewhat predictable and conforming, but paradoxically, is preparation for change, enabling all children to become competent for a future society and very likely involves disrupting some stable patterns and encouraging new ways of thinking and behaving. What is distinctive about Bronfenbrenner's theory is it relevance to South Africa and the chronosystem which consisted of an apartheid regime for decades and the change to a democratic government of equality and fairness to all. Moreover, this change now encourages inclusion of all races at schools in South Africa and all disabilities EFA, 2005:19).

This form (of equality and inclusion) of implementing developmental change obviously has an important bearing on the South African context. Indeed, one only needs to consider the macro role of apartheid in influencing all other spheres of development contained within it, particularly in the life of the black child, and especially in the rural areas. The influence of such a system of government did not stop at the macrosystem and exosystem levels of Verwoerd's racist ideology and segregation (respectively), but also spread to the mesosystem and microsystemic levels where families were broken up by pass laws and migrant labour, and where police violence and intimidation reached into township homes, schools and the rural areas; Moreover, where racialised poverty and subsequent problems like malnutrition and inadequate education ensured developmental deficits at the smallest levels of development (Duncan *et al*., 2009:319). Fifteen years into democracy the effects of apartheid and the exclusion of CWPDs are still both seen and felt. This includes ongoing racism, the culture of violence and crime, and the strongly racialised lines of poverty and affluence (Hook *et al*., 2009:319).

In summary, to understand change at all levels, it is important to know what change looks like from different points of view. How the parent, the teacher, local (exosystem) and national government see change is vital to understanding how individuals and groups act and, indeed, react to each other. Reforming school systems to become inclusive is not only about putting in place recently developed inclusive policies that meet the needs of all learners, but also about change in the culture (chronosystem) of classrooms, districts and so on (EFA, 2005:20).

Post-apartheid South Africa has found it difficult to assess the full extent of the damage of apartheid's large-scale and governmentally institutionalised forms of racism on South African society. In many ways, of course, the effect that this form of government has had particularly

on the lives of black South Africans remains unquantifiable. While it obviously cannot quantify the damage of apartheid, Bronfenbrenner's model of developmental influence can be used to raise a series of possible developmental deficits stemming from the implementation of the apartheid system.

On the level of the microsystem, one has to remember that the lives and upbringing of many black children were fundamentally affected by the absence of parents. Segregated living arrangements, created by the old 'homelands' system and by the pass-law system meant that parents could not always work where they chose to and were removed from their homes. This is in total contrast to Bronfenbrenner's ideal micro- and mesosystem and ultimately led to the disintegration of the family. The pass laws were designed by the apartheid government to tighten state control over the movement of black South Africans (Hook *et al.* 2009.320).

In terms of the exo- and macrosystems, education was a particularly important developmental focus of the apartheid repression as signalled by the Soweto Uprising in 1976. Apartheid also worked on a strong ideological level, and mass media reports were dramatically slanted towards supporting the National Party government, and dissenting voices were quickly silenced.

Clearly then, the influence of the apartheid system made itself felt in virtually every conceivable aspect of Bronfenbrenner's model of developmental influence from the base level of the health of the child, through to the levels of the family, the neighbourhood, the church, the schools, the community, basic public amenities and resources, recreational and health facilities, religion and fundamental social values, beliefs, discourse and ideology (Hook *et al.*, 2009:321).

Bronfenbrenner's model provides, in total, a strong theoretical and research means through which the influence of the environment as a whole can be factored into individual or social accounts of child development. This chapter discussed in depth Bronfenbrenner's bioecological model and how it relates to inclusion. The benefits of educational inclusion were also discussed, as well as legislation and policies formulated to ensure that inclusive education is provided for. In chapter 6 a discussion will follow as to whether inclusive education is a reality in the rural areas.

In order to determine and understand the impact of the negative influences on CWPDs in the rural areas, the researcher had to determine the best way to do it. The purpose of chapter 4 is therefore to discuss the research design and methodology in depth.

CHAPTER FOUR

METHODOLOGY

4.1   INTRODUCTION

As discussed in chapter 1, the negative influences affecting children with physical disabilities (CWPD) in rural areas in South Africa involve both health and social issues. However, in order to address these issues there needs to be a basic understanding of the problems with which they are beset. The goal of this study is to provide a scholarly description of the impact of these negative influences on CWPDs in rural areas based on a theoretical framework.

This chapter will discuss the aims of this research study, the research paradigm and research design, research tools (interviews and observations) and postulates, the selection of the sample, the research method and the data analysis process. If the research aims of the study, as discussed in chapter 1, are to be realised, it is incumbent on the researcher to determine the best way in which to do this. The **main** research question sought to understand and explain the impact of the negative influences facing CWPDs in rural areas.

4.2   RESEARCH PARADIGM AND DESIGN

4.2.1   Research paradigm

The design of a research study begins with the selection of both a research topic and a research paradigm.

> A paradigm may be viewed as a set of *basic beliefs* ... that deal with ultimate or first principles. It represents a *worldview* that defines for its holder, the nature of the "world", the individual's place in it, and the range of possible relationships to the world and its parts. The beliefs are basic in the sense that they must be accepted simply on faith (however well argued); there is no way to establish their ultimate truthfulness. If there were, the philosophical debates would have been resolved millennia ago (Guba & Lincoln, 1994: 107–108).

Roberts (2004:111) concurs with this viewpoint and maintains that researchers seek a holistic picture − a comprehensive and complete understanding of the phenomenon that they are studying. In this study this complete picture comprises both the societal and educational exclusion of CWPDs.

The research paradigm in this study is advocacy/participatory. The basic tenet of the advocacy/participatory worldview is that research should contain an action agenda for reform that may change the lives of the research participants, the institutions in which they live and work or even the life of the researcher. It is of paramount importance to study the issues facing these marginalised groups of poor black children with physical disabilities who, for example, have lived, and continue to live, with oppression, domination, suppression, alienation and hegemony (Creswell, 2009:227). As these issues are studied and exposed, it is hoped that the researcher will provide a voice for the research participants, as well as raise their consciousness and improve their lives. This is, indeed, exactly what this research study aims to do by studying the impact of the negative influences affecting CWPDs in the rural areas of South Africa. In addition, it is hoped that this study will help to unshackle children from the constraints of the irrational and unjust structures (exclusion) that limit both their self-development and their self-determination. In an effort not to marginalise further those individuals who participated in this research, the advocacy/participatory research paradigm was selected as this paradigm involves collaboration with the research participants and, thus, the "voice" of the participants may be heard throughout the research process. In addition, what is of vital importance for this study is the fact that the research itself encompasses an action agenda for reform, that is, from exclusion to inclusion − a specific plan for CWPDs (Creswell, 2009:10).

The procedures of qualitative research (its methodology) may be characterised as inductive procedures and they emerge and are shaped by the researcher's experience in collecting and analysing the data. In other words, the qualitative researcher adopts an inductive logic which is from the ground up, rather than being handed down in its entirety from either a particular theory or from the perspectives of the inquirer (Creswell, 2007:19). The researcher deemed this logic to be eminently suited to this research study.

In qualitative research, the research process commences with the researcher's making philosophical assumptions in terms of the decision to undertake a qualitative study. Five philosophical assumptions may lead to an individual's choice of qualitative research: ontological, epistemological, axiological, rhetorical and methodological (Creswell, 2007:16). As illustrated in Table 4.1 below, the paradigm framework in this research study comprises philosophical, ontological, epistemological and methodological assumptions.

Table 4.1:   The researcher's philosophical inductive assumptions with their practical implications for this research design

ASSUMPTION	QUESTION	CHARACTERISTICS	IMPLICATIONS FOR PRACTICE
Ontological	What is the nature of reality?	In this study reality is both subjective and multiple, as perceived by the several different participants in the study context	Quotes from interviews held with the participants, as well from questionnaires completed by them, will provide evidence, as will drawings and photographs
Epistemological	Epistemology describes the relationship between the researcher and the topic being researched, i.e., the negative influences affecting CWPDS on a daily basis	The researcher moves as close to the participants as possible by living with them and actively participating in their lives. Accordingly, the researcher will spend a prolonged time in the rural areas with her gatekeeper.	The researcher will live and work amongst the community members in the rural areas, thus, becoming an "insider". The researcher's epistemological stance in respect of this study may be formulated as follows: data will be obtained from the perspectives of people living in the rural areas of KwaZulu-Natal as regards CWPDs. It is, thus, incumbent on the researcher to engage with the participants while collecting the data.
Axiological	What is the role of values?	The researcher acknowledges that this research is value-laden and, thus, that biases are present. Is it, thus, possible to suspend values in order to understand, or do values always mediate and shape that which is being understood?	The researcher openly discusses the values that shape the narrative (the verbal description which is part of qualitative research). In addition, she includes in her findings her own interpretation of these findings as well as the interpretations of the community members from their interviews.
Rhetorical	What is the language of research?	The language of qualitative research becomes both personal and literary, and is based on definitions that may evolve during the study, especially should the study not be conducted in the researcher's first language.	The researcher uses terms such as "credibility", "transferability", "dependability" and "confirmability". In addition, the researcher continually revises the questions based on experiences in the field.
Methodological	What is the process of the research?	The researcher uses inductive logic which emerges from and is shaped by the researcher's experiences	During the data analysis, the researcher will analyse the data with the aim of acquiring knowledge

Source: Creswell (2007:17)

4.2.2 The qualitative research design

The research design provides the glue that binds a research project. Accordingly, a design is used in order to structure the research and to demonstrate how all the major aspects of the research project − the samples or groups, measures, treatments or programmes and "methods of assignment" − work together to address the central research questions. Understanding the relationships among designs is important when you need to make design choices, which involves thinking about the strengths and weaknesses of different designs (Trochim & Donnelly 2006:1).

Ethnography is a qualitative design in terms of which the researcher describes and interprets the shared learning patterns of values, behaviours, beliefs and language of a culture-sharing group over a period of time. As a process, ethnography involves extended observations of the group, mainly through *participant observation,* during which the researcher becomes *immersed* in the day-to-day lives of the research participants. Culture is both abstraction and something that a researcher will attribute to a group when looking for patterns within the group's social world. Culture may be apparent in behaviours, language and artefacts (Maritz &Visagie, 2010:13). Despite the fact that are several definitions of the term "culture", the concept usually consists of the origins, roles and material items associated with a particular group of people. It, therefore, follows that an effective research design will commence with the selection of the research topic, problem or areas of interest as well as the research paradigm (Groenewald, 2004:6).

As a broad research design, ethnography addresses the following question: "What is going on here?"

> Go out into the world. Live among the peoples of the world as they live. Learn their language. Participate in their rituals and routines. Taste of the world. Smell it. Watch and listen. Touch and be touched. Write down what you see and hear, how they think and how you feel.

> Enter into their world. Observe and wonder. Experience and reflect. To understand a world you must become part of that world while at the same time remaining separate, a part of and apart from.

Go then and return to tell what you see and hear, what you learn, and what you come to understand (Patton, 2002: 330).

In an ethnographic study, there is no preset limit to what will be observed, neither is there a real ending point. Furthermore, in ethnographic studies, the orientation of the researcher is either etic (outsider's view) or emic. In this research study the researcher's orientation will be emic, as in the term "phonemic", in terms of which the concern is to capture the subjective meaning ascribed to situations by participants (Cohen, Manion & Morrison, 2009:169). However, the term "emic" is further defined by Patton (2002:85) as capturing and being true to the perspectives of those studied (the insider's perspective).

The topic of this research study also necessitated that a literature study on disability, inclusion (both societal and educational), poverty, violence, abuse and neglect in the rural areas be conducted. This, in turn, led to an in-depth study of Bronfenbrenner's Ecological Model of Human Development, which encompasses a paradigmatic perspective.

The study of documentation from the United Nations, World Bank, Innocenti, the Salamanca Statement and UNICEF enabled the researcher to gain an understanding of the perceptions of community members in respect of disability and inclusion in KwaZulu-Natal. In addition, literature from the disability rights movement, relating both to individuals and to groups, provided secondary data (Philpott, 1997:54). Oka and Shaw (2003:3) reiterate the value of this secondary data when they maintain that it is essential for qualitative researchers to be aware of the influence of beliefs and doctrines on their strategies because, without knowledge of related philosophies, researchers are apt to become confused when analysing qualitative data.

The following section aims, firstly, to explain the nature and characteristics of qualitative study in terms of the research being undertaken; secondly, the researcher will describe how the research was conducted using the qualitative method; and, thirdly, the researcher will discuss the way in which the data were collected, analysed and displayed in a qualitative manner.

The research design of this specific study is represented diagrammatically in Figure 4.1. This figure, in turn, illustrates a logical pattern.
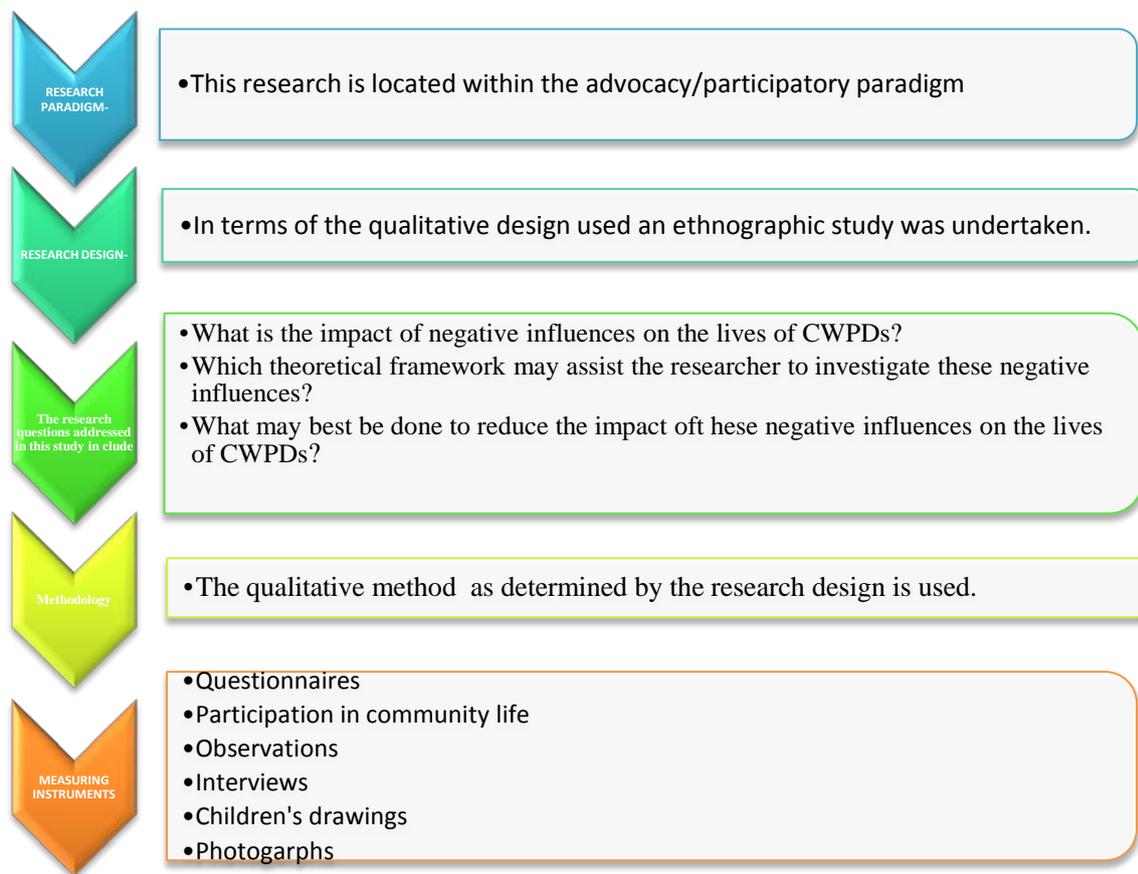
Figure 4.1:   The research design

Source: Adapted from Dreyer (2008:105)

As is illustrated by Figure 4.2, the research questions to be answered in this study are investigative in nature. In order to answer these questions a comprehensive investigation into, and study of, CWPDs in rural areas was embarked upon.

4.2.2.1   Nature and characteristics of qualitative research

Broadly speaking, qualitative research is interested in the way in which individuals and groups perceive and understand their world, and how they construct meaning from their experiences.

Denzin and Lincoln (1994) define qualitative research as being multi-method in focus and involving an interpretative, naturalistic approach to its subject matter. This, in turn, implies that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. In other words, qualitative research involves the studied use and collection of a variety of empirical materials, case studies, personal experience, introspections, life story interviews and observational,

historical, interactional and visual texts that describe both routine and problematic moments and meaning in individual lives. Creswell (1994) affirms this statement when describing qualitative research as an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. In other words, the qualitative researcher builds a complex, holistic picture, analyses words, reports the detailed views of informants, and conducts his/her study in a natural setting. Accordingly, qualitative research involves the collection, analysis, and interpretation of comprehensive narrative data in order to gain insights into a particular phenomenon of interest.

Maritz and Visagie (2010) corroborate Denzin and Lincoln's views and identify the following eight unique characteristics of the qualitative approach (In this study the researcher upheld all these characteristics.):

- The researcher immerses him/herself in the situation.
- The data reflect the perspectives of the participants.
- The sources of data are real-world situations or natural contexts.
- The data are both narrative and descriptive in nature.
- Researchers focus on their personal interactions with participants.
- Researchers avoid early decisions or assumptions about the study.
- Data are analysed inductively.
- The methods adopted provide clear, detailed information reflecting the participants' voices.

Accordingly, for the purposes of this research in the rural areas, the researcher deemed Creswell's definition of qualitative research to be suitable in that it defines a qualitative approach as an approach that calls for learning about the participants' views, reporting their stories, situating them within their specific settings or context, and building an understanding from the ground up (Creswell, 2006). In other words, qualitative research is exploratory in nature. Mnyaka (2006:29) agrees that qualitative research is exploratory in nature and defines qualitative research as follows: "Qualitative research is a broad term that encompasses a variety of approaches to interpretative research. Yet, each approach can be distinguished from the others by its unique focus, research methods, strategies for data collection and analysis, as well as specific ways of communicating results." Thus, qualitative research describes, either explicitly or implicitly, the purpose of the qualitative approach, the role of the researcher, the stages of the research and the method of data analysis.

In a research study of this nature it is essential that the researcher be flexible. Qualitative researchers are often termed "*bricoleur*" because they promote research by using whatever is immediately available (Oka & Shaw, 2001:3). The interpretive *bricoleur* produces a bricolage, that is, a pieced together set of representations that is fitted to the specifics of a complex situation. The qualitative researcher, as *bricoleur,* uses the aesthetic and material tools of his/her craft, deploying whatever strategies, methods and empirical materials are at hand. Choices regarding which interpretative practices to employ are not necessarily made in advance (Denzin & Lincoln, 2002:4). In addition, qualitative research is flexible in nature. In this vein, Rubin and Rubin (2005:36) maintain that

> [a]djusting the design as you go along is a normal, expected part of the qualitative process. As you learn how the interviewees understand their world, you may want to modify what you are studying and rethink a pattern of questioning. Such flexibility is much better than persisting in a design that is not working well or does not allow you to pursue unexpected insights.

Initially, this research study was exploratory in nature to enable the researcher to determine the optimum methods of collecting data. The departure point of exploratory research is based on the inductive approach and, furthermore, exploratory research aims to arrive at a dense (thick) description of the phenomenon under inquiry in order to satisfy the researcher's desire for a better understanding (Maritz & Visagie, 2010:13). In view of the fact that the purpose of this research study was to investigate, understand and then evaluate the impact of negative influences on CWPDs in the rural areas, the researcher immersed herself in the community in the four rural areas identified in an attempt to identify a population sample, the areas to be investigated, the community leaders and other influential persons such as the *Induna* and *sangomas* as well as a "gatekeeper".

4.3   RESEARCH PURPOSE AND PROCESS

The research in this study took place within an advocacy/participatory paradigm while adopting a qualitative ethnographic approach in order to ascertain the impact of negative influences on CWPDs in rural areas in South Africa.

4.3.1 Purpose statement

The interrelationship between the research design and the research approach is carried through to the purpose statement, which is a statement that outlines the major objective or intent ("road map") of the study. The purpose of this qualitative study is to investigate, understand and describe the impact of the negative influences affecting CWPDs in rural areas in South Africa (Creswell, 2007:103).

4.4   RESEARCH METHODOLOGY

The research methodology comprises a description of the particular methods that a researcher uses for a research study. The choice of which method to employ is dependent upon the nature of the research problem. The advocacy/participatory paradigm was adopted in this study as this is an approach to the creation of knowledge through research which emphasises the model of natural science. The researcher collected facts about the social world of a specific community in a rural area in South Africa and, thus, information about the negative influences affecting CWPDs within that community. This, in turn, enabled the researcher to build up an explanation of social life in the rural areas by arranging these facts in a chain of causality (Noor, 2008:1602). Research methodology is concerned with the way in which the design is implemented and how the research is carried out, with the methodology being used often determining the quality of the data set generated. Methodology specifies when and how often to collect data, the construction of the data collection measures, the identification of the sample or test population, the choice of strategy for contacting subjects, the selection of statistical tools and, finally, the presentation of findings (Welman *et al.* 2005:2).

4.4.1   Research population and sample

The researcher focused on CWPDs in specific poor, rural areas in the province of KwaZulu-Natal and within a 30-kilometre radius of the Kwazamokuhle School. These areas included Zwelisha, Bhekuzulu, Loskop and Wembezi. The researcher proceeded to collect the research data at these sites at which the CWPDs' experiences of negative influences were being investigated. This up-close information was gathered by the researcher's living in the community, talking directly to the community members and observing them behave and act within their own context − a major characteristic of an advocacy/participatory study. This process provided the researcher with a thorough understanding of the impact of negative influences on CWPDs. This interaction with the community took place during 2009 and 2010

and, thus, the researcher's face-to-face interaction in these natural settings took place over an intermittent period of two years. In addition, it was essential that the researcher had a "gatekeeper" to introduce her to the areas and to assist with language translations and an understanding of the culture.

Patton maintains that there are no rules for sample size in qualitative inquiry (De Vos *et al.,* 2008:328). In other words, sample size depends on what the researcher wants to know, the purpose of the inquiry, what will be useful, what will have credibility, and what may be done with the available time and resources. It is for this reason that large numbers are often not selected as 'saturation levels would be reached". Accordingly, this qualitative research study, which sought not only to identify behaviour but to understand the meaning of that behaviour in an in-depth, complex manner, lent itself to the use of a small sample approach. In other words, such a research study focuses on the detail and quality of an individual's or a group's preferences, rather than the way in which behavioural traits or individuals with specific characteristics are distributed within a known population (Sidogi, 2001:120).

Gaining entry to the community was a very important and complex process and the researcher's anxiety in this regard was based on issues such as safety, acceptance and an inability to communicate in Zulu. Thus, in accordance with Bronfenbrenner, the researcher sought key informants in the rural areas who would represent various contextual factors and multiple levels of interaction from family members, and members of the community that the CWPDs has contact with to members of the community such as ward councillors who have no contact with the CWPDs. The researcher discussed the essence of Bronfenbrenner's Ecological Model and the community in which the child lives in chapter 3 − see Figure 3.1. The researcher, therefore, interviewed members in the community from the micro-, meso- and exosystemic levels (the ward councillor represented the highest level accessible in the model). According to DeLaKerns (2006:52), sampling is always more dependent on the richness of the interviews rather than the number of interviews. Thus, purposeful sampling was used in the selection of the interviewees for this study, with the research being expanded by using snowball sampling as well as by following up leads and any additional information provided by the interviewees. Those participants who recommend other community members and volunteer assistance are termed *key actors* or *key insiders* (Groenewald, 2006:7).

The identification of the families was carried out with the assistance of the social worker at Kwazamokuhle School. She listed the parents/caregivers according to the researcher criteria,

namely, children with visible physical disabilities, residing in rural areas, and with parents/caregivers who were deemed to be reliable in the information they would provide.

The chiefs and ward councillors, health professionals and other members of the communities were identified by the gatekeeper who also assisted in identifying other stakeholders crucial to the study. Accordingly, sampling refers to is the process of selecting a number of individuals for a study in such a way that these individuals represent the larger group from which they are selected. The individuals selected comprise a sample while the larger group is referred to as a population. The population is the group of interest to the researcher − the group to which he/she would like to generalise the results of the study (Roberts, 2004:135).

The participants in the study included the following:

- Nine children with physical disabilities at Kwazamokuhle School (primary school) − no specific age group specified.
- The nine families of these children who represented the children's microsystems. These families comprised mothers and fathers, grandparents or a single mother.
- The *Induna* (tribal councillor), as the *Induna* represents the community and has close links with the chief.
- The *Nkosi*(the Chief) as he is powerful in the area and enjoys a great deal of respect.
- Two clinic sisters at the local clinic
- Three *sangomas* from three of the rural areas and who consented to be interviewed
- The head ANC ward councillor
- Two church ministers
- Twenty nine typically developing (a typical developing child is a child that reaches their milestones during predictable time periods)children in Grade 7 at a primary school
- One police officer (Special Crimes at Estcourt Police Station)
- The head social worker at the Estcourt Police Station as she has considerable insight into the problems facing the community.
- Twelve teachers at a mainstream school (Clernville Primary School). These were the only teachers who completed the questionnaires. The principal of the school had handed the questionnaires out but only 12 were returned. The principal had not insisted that the filling in of the questionnaires to be compulsory as he was of the opinion that this may result in flawed answers. However, 12 questionnaires were deemed to be sufficient as the

answers were so similar that the researcher felt that that saturation level had, in any case, been reached.

4.4.2 Data collection methods

Data collection is a vital aspect of research. All data collection is based on observation which may, in turn, be sensory or else be as a result of either questioning or measuring (Maritz & Visagie, 2010:31). People's words and actions represent the data in qualitative inquiry and this necessitates methods that allow the researcher to capture both language and behaviour.

Qualitative researchers typically gather multiple forms of data through, for example, interviews, observation and documents rather than relying on a single data source. The researcher then reviews all of the data collected, makes sense of it, and organises it into categories or themes that cut across all of the data sources (Creswell, 2009:175).

In identifying the data collection instruments suited to this study, the researcher took the following into account (Creswell, 2009:68).

- Will the outcome produce answers that identify the impact of the negative influences on the CWPDS in rural areas?
- Will the research findings be credible to both the community and other professionals?
- Will the data collection process open up avenues for participation in the social change process from exclusion to inclusion?

This data collection process is affirmed by DeLaOKerns (2006:45) as an iterative process beginning with research questions which lead to the generation, the interpretation and analysis of data which, in turn, leads to further research.

4.4.2.1 Field notes

Field research may be regarded as either a broad approach to qualitative research or as a method of gathering qualitative data. The essential idea behind field notes is that the researcher "goes into the field" to observe the phenomenon in its natural state or situation of situ. As such, field notes are probably most closely related to the method of *participation observation.* However, field notes represent a secondary data storage method in qualitative research as, in view of the fact that the mind tends to forget quickly, field notes are both crucial and indispensible in qualitative research as a way of retaining the data which have been collected (Groenewald, 2006:15). At this juncture it is important to note that field notes

are already a 'step towards data analysis'. In this research study there were so many negative influences that kept arising that it would have been impossible to remember information without the use of a journal.

4.4.2.2 Observations

The experience of observing provides the observer with both experience and observations with the interconnection between the two being cemented by reflection. No less an authority than William Shakespeare gives us the following assurance.

> *Armado:* "How hast thou purchased this experience?"

> *Moth:* "By my penny of observation." (Patton, 2002:329).

Data collection is not a passive process but is rather conducted "with" and "for" the community. In this study the researcher followed the advice of DeLaOKerns (2006:46) and ensured a cycle of planning, acting and observing the process and potential consequences of change, and then reflecting on both the process and consequences. This, in turn, led to more planning, acting and reflection.

Observation, particularly participant observation, is a tool commonly used in qualitative research. Despite the fact that participant observation has been described as "the most intimate and morally hazardous" form of research it is also one of the most common methods used in qualitative data collection and also one of the most demanding (www.socialresearchmethods.net). In this study this form of data collection was extremely demanding because of the very sensitive nature of a topic such as poverty and CWPDs with it also being extremely difficult to witness the poverty and difficulties of the children and their families who were being observed and interviewed.

In view of the fact that the researcher was venturing into unfamiliar areas and cultures and was also unable to communicate in the mother tongue, the gatekeeper was essential to this study. She introduced the researcher into both the field and the community and helped build relationships.

There is a continuum between overt and covert observations. In this research the study was overt in nature although there was also the possibility that, when the researcher visited the areas to conduct the interviews, she would observe and unintentionally uncover interesting data and several themes that may give rise to further research (Oka & Shaw, 2001:5).

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Direct observations also took place. Direct observation is distinguished from participant observation in a number of ways. Firstly, in this study, the researcher observed life in the rural areas with these observations being more focused than participatory. Much of this observation took place during the interviews which the gatekeeper conducted in Zulu while the researcher explored the areas and observed life in the homes. The rationale for this mode of conduct was to enable the researcher to gain a better understanding of, as well as insight into, life in these areas.

One interviews people in order to find out from them those things which are not possible to observe directly. However, the issue is not whether such data is more desirable, valid, or meaningful than self-report data. The fact is it is not possible to observe everything, neither is it possible either to observe feelings, thoughts, and intentions, nor situations that had arisen at some previous point in time or situations and that precluded the presence of the observer. It is also not possible to observe how people have organised the world or the meanings they attach to what goes on in the world. Instead one has to ask people questions about these things (Patton, 2002:341) and this calls for reflexivity.

Qualitative research, thus, requires that the researcher be reflexive. This, in turn, means that the researcher is conscious of the biases, values and experiences that he/she brings to a qualitative research study (Creswell, 2009:233). Reflexivity calls for self-reflection, self knowledge and a willingness to consider how/who is affected, and what one is able to observe, hear and understand in the field as both an observer and an analyst. Accordingly, it is incumbent on the observer to observe self as well as others and also interactions with self and others during observation. Reflexivity has entered the qualitative lexicon as a way of emphasising the importance of self-awareness, political/cultural consciousness and ownership of one's perspective (Patton, 2002:64).

4.4.2.3   Interviews and questionnaires

Without a doubt, the most popular data collection method in qualitative research studies is the interview (Oka & Shaw, 2001:5). Accordingly, in this study, the researcher used primarily the structured interview − sometimes termed the standardised interview – which is a form of interview often used in qualitative research. The purpose of these interviews was to allow the researcher access to the perspectives of other people In other words, the researcher conducted interviews in order to find out what is in and on the minds of the members of the community and to gather their stories (Patton, 2002:241) (Addendum 2).

In structured interviewers, the researcher asks the same set of questions, in the same order, and using the same words. Structured interviews are, thus, convenient for comparing different interviewees' responses to the same questions. However, the answers given in the structured interviews may give rise to an unstructured interview − also termed the conversational interview (Oka & Shaw, 2001:5). This type of interview does not involve a predetermined set of questions but rather it offers the researcher an opportunity to talk freely and to gather additional information and data. As will be discussed below unstructured interviews are often used in combination with participatory observation. However, unstructured interviews may pose problems for a novice researcher as the researcher is required to generate and develop questions according to what the interviewees say. The researcher will, thus, need to be spontaneous. Nevertheless, as stated previously, these two types of interviews may be used in combination. For example, after conducting a structured interview, an unstructured interview may follow, or vice versa.

The use of *questionnaires and interviews,* based on the experiences and perceptions of the community members in rural areas in respect of the implementation of inclusive practices, both educational and societal, may be significant in relation to the strategy that needs to be planned in order to realise the objectives of inclusion and the reduction of negative influences. However, not all the information was acquired in the interviews as, in order to save time and to reach a larger percentage of the population, questionnaires were filled in by both teachers and professional members of the community.

In this study, questionnaires and interviews were used in order

- to try to gain an understanding of the most significant negative influences affecting CWPDs
- to ascertain the attitudes of mainstream teachers towards CWPDs
- to ascertain both the degree to which inclusion was practised in the rural areas in which the study was undertaken, as well how much teachers and the community understand about CWPDs.

However, even with the above questions, depending on the answers, the researcher in this study needed to probe further, although the information gathered from the interviews and questionnaires did provide the researcher with insights into the huge impact which the negative influences have on CWPDs on a daily basis.

During the interviews/completion of questionnaires, the researcher and the researcher's assistant (gatekeeper) conducted conversations with the interviewees wherever possible and this helped to establish a relationship of trust.

4.4.2.4 Photographs and drawings

In this study both visual and audio ethnography were used with photographs and, especially pictures drawn by CWPDs, being used. These all helped explain the family dynamics. Both photographs and drawings constitute an unobtrusive method of collecting data and also provide an opportunity for the participants to share their reality directly. In addition, they are creative in that they capture the attention visually (Creswell, 2009:180).

Photographs

Discussions of photography in the emergent traditions of visual sociology and anthropology have focused on two principal areas, namely, the use of still photographs as a methodological tool in social research, and the use of photographs as a means of presenting social research (Schwartz, 2005:1). Photographs may be used to reflect real life situations in rural areas. The researcher would look at the content of each photograph which would reflect the people in the rural areas, their life in terms of housing and geographical isolation and their lack of essential resources. According to Stainback and Stainback (1988, 115-120), a holistic description of events, procedures and philosophies in occurring natural settings is often needed to make accurate situational decisions. The latter clearly involves multiple perspectives, identifying the many factors present in a situation, and, generally, sketching the larger picture that emerges. A visual model of several facets of a process, or a central phenomenon, aids in establishing this holistic picture (Creswell, 2009:176). Photographs capture invaluable, contextual evidence (Anning & Ring, 2004:17).

Children's drawings

Children's drawings are thought to reflect their inner worlds, depict various feelings and convey information concerning status and interpersonal style (Malchiodi, 1998:1). In addition to the interviews conducted in this research study, the drawings were an additional way of understanding expression and were both necessary and helpful. Central to an understanding of a child's drawing is the recognition that the child draws his/her neutral impression and not his/her visual observation (Malchiodi, 1998:29).

Until the twentieth century interest in children's drawings was limited to a few enthusiasts, often teachers or parents who kept collections of the drawings of 'exceptional children' (Anning & Ring, 2004:10). However, in about 1940, the idea began to take hold that drawings could be used to determine emotional aspects and personality as it was possible to study drawings as visual representations of internal psychological states (Malchiodi, 1998:1). Later in the 19th century, the following two sources of interest generated research into children's drawings. The first source was the exponential growth in the field of developmental psychology. Malchiodi combined her clinical experience with a grasp of research in this field of developmental psychology. She argues in favour of the importance of acknowledging the multi-dimensional aspects of children's drawing: a combination of the stage of development, individual experiences and context within which the children draw or paint (Anning & Ring, 2004:25).

> From the perspective of "natural" development it is clear that children use drawings as a tool for understanding and representing important aspects of their own personal, lived experiences of people, places and things. In addition, beyond coming to terms with personal experiences, their representations serve the function of exploring the "big ideas" common to all our lives, for example, dependence and dominance, good and evil, danger and adventure (Anning & Ring, 2004:25; Malchiodi, 1998:2).

Prosser (in Anning & Ring, 2004:17) argues that "[q]ualitative research uses words and occasionally numbers and only very rarely uses images, except as representation of words and numbers".

Malchiodi raised the issues of validity and reliability in projective drawing tasks. Children's art expressions, like children themselves, are individual and must be considered as such and within the larger context of their developmental, emotional, social and cultural experiences (Malchiodi 1998:25). The researcher in this study has deemed the drawings of the children to be valid (accurate). The group of children in the study was small (15 children) and both the teacher and social worker were aware of the home circumstances of the children and it is for this reason that purposeful sampling took place. The following procedure was adopted:

1   The children were given crayons and paper by the teacher.

2   The teacher asked the children to draw a picture of their families and then their houses.

3   There were no individual instructions given, neither was any no pressure exerted on the children to conform to any layout. In addition, they were given ample time to complete their drawings.

4   The teacher then asked the children to tell her about their pictures and who appeared in the pictures. The teacher then discussed the drawings with the researcher and, as a result of her knowing the backgrounds of the children, was able to advise the researcher whether the drawings were an accurate reflection of the children's homes and families. This, in turn, helped the researcher to determine both the validity and the reliability of the drawings.

4.5   DATA ANALYSIS

Although qualitative analysis is as much an art as a science, it does have its own logic and techniques (Babbie, 2007:377). According to Creswell (2007:148), the data analysis in qualitative research consists of preparing and organising the data (i.e. text data as in transcripts, or image data as in photographs) for analysis, then reducing the data to themes through a process of coding and, finally, representing the data in a discussion. Mouton (2006:67) agrees with Creswell and maintains that the data analysis in a qualitative study would include processes such as thematic and content analysis.

As mentioned above, there are several different philosophical backgrounds to qualitative research. Qualitative researchers build their patterns, categories and themes using a bottom up approach with the researcher grouping data and information as they are collected. The different bases of epistemology give rise to a wide variety of ways in which data may be analysed.

It is in data analysis that the strategy of triangulation really succeeds, not only in providing diverse ways of looking at the same phenomenon but in adding to the credibility of the data by enhancing the confidence in whatever conclusions are drawn. The following four types of triangulation may contribute both to the verification and validation of qualitative analysis:

•   *Methods triangulation.* Checking out the consistency of the findings generated by different data collection methods

- *Triangulation of sources.* Checking out the consistency of different data sources within the same method

- *Analyst triangulation.* Using multiple analysts to review findings

- *Theory/perspective triangulation.* Using multiple perspectives or theories in terms of which to interpret the data (Patton, 2002:556).

Triangulation and member checking are discussed in detail in section 4.6.1.2.

The researcher adhered to the following advice offered by Oka and Shaw (2001:6).

- *Analyse the data while it is being collected.* The researcher should never collect data without simultaneously conducting substantial analysis. In other words, allowing the data to accumulate without a preliminary analysis may prove disastrous. In qualitative research, conducting the data analysis whilst collecting data is termed the "principle of interaction between data collection and analysis".

- *Be aware of context.* It is vital that the qualitative researcher consider the context in which the data are obtained, as contexts are never be intimidating.

- *Be reflexive.* Oka and Shaw (2001:7) maintain that reflexivity implies that "the orientations of researchers will be shaped by their socio-historical locations, including the values and interests that these locations confer upon them".

- *Be flexible.* In view of the fact that flexibility is one of the principles of qualitative research qualitative researchers are permitted to use as many strategies as they choose.

- *Decisions need to be clear.* The researcher will need to describe the decisions that will be made and the actions that will need to be taken during the process of analysis.

- *The researcher needs to make his/her decisions clear.* In other words, in the report it is incumbent on the researcher to be able to describe the decisions that were made and the actions that were taken during the process of analysis. In addition, it is essential that all decisions be clarified. Miles and Huberman (1994:90) state that "[k]eeping a precise record of the actual criteria and decision rules used is essential". When applying this rule to qualitative research, the researcher will regard a concept as important if that concept has been confirmed by at least two interviewees.

- *Include all the quotes from the interviews that support the researcher's findings.* In this study the researcher intends to do this in full. However, in this study, despite the fact that it was impossible to use the questionnaires in their entirety as they were extremely

lengthy, the salient answers were used. All the interviews were taped with the permission of the interviewees.

The analysis of the data is usually straightforward once the onerous task has been completed of defining the research problem, developing and implementing a sampling plan, conceptualising and operationalising the sample plan, testing the measures and developing a design structure (Trochim, 2006:1). Patton maintains that qualitative analysis transforms data into findings although no formula exists for that transformation (Patton, 2002:432). However, Maritz and Visagie (2010:15) are of the opinion that data analysis comprises three aspects: description, analysis and interpretation.

In this study the researcher will analyse the data using Seidel's Qualitative Data Analysis model (similar to that of Creswell). Seidel's QDA model is based on three necessities: noticing, collecting and thinking.
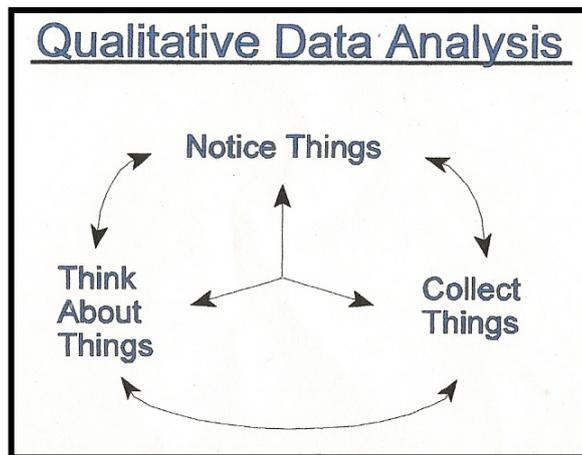
Figure 4.2:   Seidel's model of qualitative data analysis (QDA)

4.5.1   Seidel's qualitative data analysis

In other words, the analysis of qualitative data is, essentially, a simple process and consists of three aspects: noticing, collecting and thinking about interesting things.

According to Seidel (1998:2), when a researcher conducts a QDA the researcher does not simply notice, collect and think about things and then compile a report but rather the analysis process has the following characteristics:

- *Iterative and progressive.* The process is iterative and progressive because it is a cycle that keeps repeating. For example, when the researcher is *thinking* about things the researcher will start to *notice new things in* the data. For example, in this study, the researcher needed to use the outside toilet one night when it was raining. Besides having to go out into the rain in the dark there are no flushable toilets which, in turn, led to the researcher's noticing a lack of basic resources, such as toilet paper. This was, in turn, followed by a realisation that there was neither sanitation nor water (nor soap with which to wash her hands) which, in turn, raised her awareness of the possibility that this might lead to germs being spread. The researcher then *thought about and collected* these things. In principle, the process is an infinite spiral.

- *Recursive.* The process is recursive because there is always a possibility that the researcher will be called back to a previous part of the data analysis. For example, Seidel states that, while the researcher is *collecting* things the researcher might simultaneously start *noticing* new things to *collect.*

- *Holographic.* The process is holographic in that each step in the process contains the entire process. For example, when the researcher first *noticed* things she was already mentally *collecting* and *thinking* about these things. This is exactly what happened in the exploratory phase of this research.

- *Noticing.* An example of noticing in regard to the interviews occurred when the researcher began coding the interviews by carefully reading a sample of the transcripts in order to develop sustentative and general topic codes. The researcher then photocopied the original transcripts (after they had been transcribed) and marked each appropriate comment with the code in the margin using a different colour highlighter. However, it must be mentioned that the noticing began early in this ethnographic study when the researcher first became a member of the rural community as it was at that point that the researcher had already begun making field notes and taking photographs.

- *Collecting.* This stage commences when the researcher returns from conducting his/her fieldwork with all the data. In this research study it was at this point that the researcher made comments on different cards and sorted these cards into different piles. It soon became evident that the poverty pile was the "thickest". Weber suggests that it is preferable to retrieve text based on categories rather than single words as categories tend to retrieve more than single words by drawing on synonyms (Cohen *et al*., 2009:481).

- *Thinking.* It is at this stage the researcher compares and contrasts answers, drawings and other data and writes and writes. In this study it was at this point that, through this process of thinking, it became apparent to the researcher that the most significant negative influence affecting CWPDs was poverty and, secondly, the negative attitudes towards the CWPDs which, in turn, result in exclusion, abuse and neglect.

The researcher may then make use of *dendrograms* − tree diagrams − in order to demonstrate the relationship and connection between categories, for example, in this research study, the relationship and connection between the categories of poverty and disability. This method proved to be the most suitable for the researcher in this study. However, there are a plethora of similar coding methods including open, axial and selective coding. Nevertheless, all these methods finally arrive at "themes" − major themes, unique themes and leftover themes (Maritz & Visagie, 2010:44). De Vos *et al*. (2008:338) maintain that these themes, which they view as a "family" of themes with children or subthemes and grandchildren, are represented by segments of data. The process of winnowing the data involves reducing the data to a small manageable set of themes to write into the final narrative.

Thus, while there was a simple foundation to the QDA, the process of conducting qualitative analysis is, nevertheless, a complex process. In this study, the key was for the researcher to root herself in this foundation.

The researcher started to categorise and code using Seidel's qualitative data analysis process, and assigned the different negative influences to similar headings until it became evident that poverty had "outstripped" all the other negative influences. Once poverty had been identified as a key issue it was divided up into sections using Bronfenbrenner's Model.

The researcher embarked on a general level of noticing which entailed making observations (phase 1), writing field notes (journal), doing tape recordings, gathering documents, etc. In doing all this, the researcher was, in fact, producing a record of all those things that she had noticed. Once the researcher had produced a record she focused on this record and started to notice the interesting things recorded, especially in the children's drawings and the interviews. This was accomplished by the researcher's reading the *record. As she noticed things in the record she named or 'coded' them.* The researcher could simply have named them A, B, and C etc (Seidel, 1998:2) but, instead, she chose to give them more descriptive

names − poverty, violence, lack of resources and other negative influences. This, in turn, led to the next step − *coding*.

4.5.2 Coding

Maritz and Visagie (2010:8) explain that coding represents the operations by which data are broken down, conceptualised and then put back together in new ways. After the researcher has compiled and processed all the information, the challenge is to reduce the huge amount of data to manageable and understandable texts (Welman, Kruger & Mitchell, 2002:13). Accordingly, the purpose of coding things is to make sense of the data that have been collected. Codes are tags or labels that attach meaning either to raw data or to the notes collected during field work. These tags or labels are used to retrieve and organise chunks of text in order to categorise it according to particular themes (i.e. the different negative influences affecting CWPDs). In this study a wealth of different types of codes had become evident in the literature review, for example, descriptive coding and interpretative coding, pattern codes and reflexive remarks. It was an onerous task to try to find the most appropriate code. However, this did emerge and the most appropriate of the data was then analysed (Welman *et al*., 2002:14).

Raw field notes and verbatim manuscripts constitute the undigested complexity of reality, while simplifying and making sense out of this complexity constitute the challenge of content analysis. The first step of analysis comprises compiling a manageable classification or coding scheme as, without classification, there is chaos and confusion (Patton, 2007:463). According to Silverman (2008: 377) "… coding is putting data into theoretically defined categories in order to analyse it" – a relatively easy definition to understand and to put in to practice.

Although coding data is a simple process it is essential that researchers know how to do it. In this study coding comprised identifying common threads such as poverty and then placing them into different categories − thus sorting the data that the researcher had collected. Accordingly, with the facts broken down into manageable segments, the researcher then sorted and sifted through them, searching for types, classes, sequences, processes, patterns and wholes. The aim of this process was to be able to assemble or reconstruct the data in a meaningful or comprehensible fashion (Seidel, 1998:4). Seidel maintains "… researchers use codes to pull together and categorize a series of otherwise discrete events, statements and observations which they identify in the data, after studying them the researcher begins to create order".
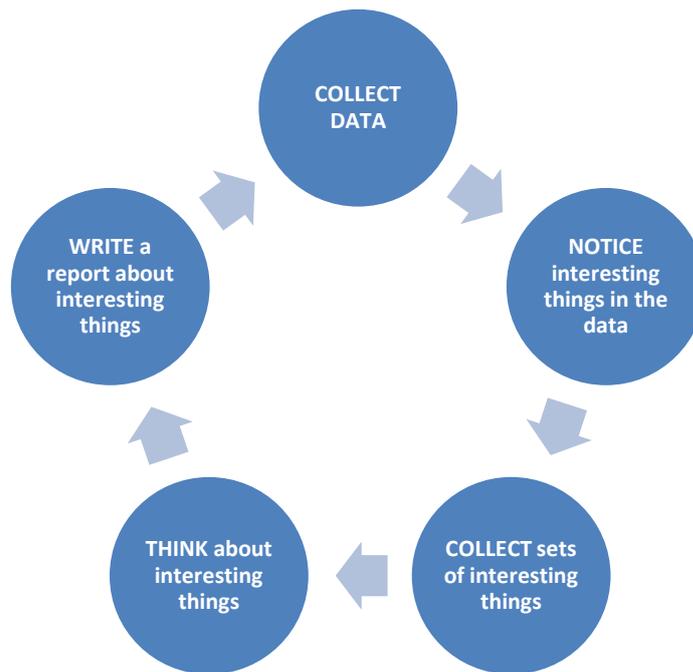
Figure 4.3:   Seidel's coding process

Source: Adapted from Seidel (1998:11)

4.5.2.1   Heuristic codes

In terms of a heuristic approach code words are primarily flags or signposts that point to things within the data (Seidel, 1998:14). In this study, the role of code words such as poverty and exclusion helped the researcher to collect the things she had noticed in order to subject them to further analysis. The reports of heuristics researchers are filled with the discoveries, and personal insights and reflections of the researchers. Heuristic codes help to reorganise the data and to provide different views of the data. In other words, heuristic codes facilitate the discovery of things and also help to open up the data to further, intensive analysis and interpretation. In a heuristic approach code words more or less represent the things that have been noticed. However, according to the heuristic approach, coding is never enough but is rather the beginning of a process that requires that the researcher to work deeper and deeper into the data. It is for this reason that the researcher in this study made use of other methods such as analysing the children's drawings.

The classifying and coding of qualitative data produce a framework for organising and describing what has been collected during the fieldwork. This descriptive phase of analysis builds a foundation for the interpretative phase during which meanings are extracted from the

data, comparisons are made, creative frameworks for interpretation are constructed, conclusions are drawn, significance is determined and theory is generated (Patton, 2002:465).

The coding of the data leads to the next step in the research process, namely, the consolidation and interpretation of the data collected.

4.6   DATA CONSOLIDATION AND INTERPRETATION

Researchers engage in interpreting data when they conduct qualitative research (Creswell, 2007:154). The results of this qualitative study will be detailed in the findings phase in Chapter 5.

4.6.1   Validity and reliability

In order to understand the meanings of the concepts of "reliability" and "validity", it is necessary to present various definitions of these two concepts. In qualitative research validity and reliability are not treated separately but, instead, terminology that encompasses both these concepts, such as credibility, transferability and trustworthiness, is used (Golafshani, 2003:600).

4.6.1.2   The role of the researcher

Qualitative researchers collect the data themselves through gathering information, observing behaviour and interviewing participants. Although they may use a protocol − an instrument for collecting data − it is still the researchers themselves who actually gather the information. In addition, they do not rely on questionnaires developed by other researchers (Creswell, 2009:175). In qualitative inquiry the researcher is the instrument. According to Dreyer (2008:127), qualitative research places great reliance on the personal integrity of the researcher. Patton (2202:122) concurs with this statement and postulates that the credibility of qualitative methods, thus, hinges to a great extent on the skill, competence and rigour of the person carrying out the fieldwork.

McMillan and Schumacher (2:374) are in agreement with both Dreyer and Patton and affirm that the researcher becomes 'immersed' in both the situation and the research phenomenon. As a result of their interactive roles skilled, experienced, prepared and trained researchers record both their observations and their interactions with respondents in many different situations and in the most objective and scientific way possible. Despite the fact that the data that have been obtained from informants and respondents may vary it may also represent a

particular view or even the subjective view of the researcher. The recording of the data becomes problematic when the data are claimed to be beyond the context of what is being studied. The following measure may be implemented in order to prevent data from becoming either valid or invalid: Extended time available to collect data will allow the researcher both to corroborate data and to identify those sources that would most probably produce artificial, contrived or biased information. The reactions of the respondents, independent corroboration, and confirmation of data carried out at all stages of the research process are the most effective techniques with which to identify either observer effect or researcher bias (Sidogi, 2001:123).

4.6.1.3 Triangulation and member checking

Triangulation strengthens a study by combining methods (Patton, 2002:247). Member checking − also known as informant feedback − was used by the researcher in this study to help improve the accuracy, credibility, validity and transferability of the study. Member checking may be carried out either during the interview process, at the conclusion of the study or both in order to increase the credibility and validity of a qualitative study (Ratcliff, 1995:20).

In this study the researcher collected all the data by using different types of interviews, observations and participation. This is important because, if the data collected using different methods show this same pattern, then that pattern becomes more credible. Although this technique has been the object of considerable criticism because "it assumes a single fixed reality that can be known objectively" (Patton, 2002:248), the researcher in this study did, nevertheless, deem it to be an extremely useful tool for the purposes of this particular qualitative study. In the report the researcher will clearly demonstrate evidence of triangulation. By using different types of interviews the researcher managed to collect adequate and sufficient data to reach saturation (Oka & Shaw, 2001:4).

Although the "validity" and "reliability" of qualitative research have been discussed by several researchers, the most often quoted problem of establishing validity is probably the notion of trustworthiness, as developed by Lincoln and Guba (in Oka & Shaw, 2001:10). The notion of trustworthiness comprises four elements, namely, credibility, transferability, dependability and confirmability. These four elements are analogous to "internal validity" in conventional criteria.

4.6.1.4   Credibility

As a result of the fact that qualitative research differs from a quantitative inquiry, the former requires different criteria or merit and rigour. Trochim and Donnelly (2008:149) describe credibility as those criteria that are involved in establishing that the results of qualitative research are credible or believable from the perspective of the participants in the research.

According to Patton (2002:552) the credibility of qualitative inquiry depends on three distinct, but related, inquiry elements:

- *Rigorous methods* for conducting fieldwork that yield high-quality data that are systematically analysed with attention to issues of credibility
- *The credibility of the researcher.* This depends on the training, experience, track record, status and presentation of the researcher. In this research study the researcher's training comprised a Teacher's Diploma, a BA degree, an honours degree (cum laude) and a master's degree in Augmentative and Alternative Communication. In addition, the researcher's track record is good and the researcher is still teaching CWPDs after 19 years and is, at present, head of department at Forest Town School, a school for children with special needs.
- *A philosophical belief in the value of qualitative inquiry.* This comprises a fundamental appreciation of naturalistic inquiry, qualitative methods, inductive analysis, purposeful sampling and holistic thinking.

As qualitative research has evolved various authors and scientists have established different criteria for scientific adequacy. Dependability may be compared to reliability and confirmability may be compared to objectivity. In this study all the interviews were recorded and transcribed word for word. Having already carried out an exploratory study the researcher and gatekeeper were aware of the extremely delicate nature of the questions being posed and for the degree of sensitivity needed in dealing with the caregivers.

As parents want the best for their children, the truth value also determined that the credibility in this study was high. In addition, the fact that the context and settings of the community were all extremely similar in every respect meant that saturation was soon reached and it was not necessary to extend the study into different areas.

4.6.1.5   Transferability

Transferability refers to the degree to which the results of a qualitative study may be generalised or transferred to other settings. The qualitative researcher may enhance transferability by describing in detail both the research context and the assumptions central to the research. The individual who wishes to "transfer" the results to a different context is then responsible for making judgement of how sensible the transfer is (Trochim & Donnelly, 2008:14). In this research study, it should be possible to use the same data collection methods to investigate the same topic, but in another province/s of South Africa.

4.6.1.6   Dependability

Dependability pertains to the importance of the researcher's accounting for or describing the changing contexts and circumstances that are fundamental to qualitative research. The notion of dependability emphasises the need for the researcher to account for the ever-changing context within which research occurs. In other words, the researcher is responsible for describing the changes that occur within the research setting as well as how these changes affect the way in which the researcher approached the study (Trochim, 2006:2). Dependability is analogous to reliability, that is, the consistency of observing the same findings under similar circumstances, for example, investigating negative influences in another rural province.

4.6.1.7   Confirmability

Qualitative research tends to assume that each researcher brings a unique perspective to a study. Confirmability refers to the degree to which it is possible for the results to be confirmed or corroborated by others. There are a number of strategies for enhancing confirmability. The researcher may document the procedure for checking and re-checking the data throughout the study. Another researcher may take the role of 'devil's advocate' with respect to the results, and this process may be documented. The researcher may actively search for and describe *negative influences* that contradict prior observations. In addition, after the study, it is possible to conduct a *data audit* that examines both the data collection and analysis procedures and makes judgements about the potential bias for distortion (Trochim & Donnelly, 2008:149). In this research study all the interviews are recorded and, furthermore, all the information may be confirmed by the gatekeeper.

4.6.2   Ethical considerations

As CWPDs are central to this research study it was essential that all ethical considerations were take into account in order to guard against any possible harmful effects. This was difficult as children do not have sufficient understanding to give their consent. The researcher took the following issue of confidentiality into account at all times, while also bearing in mind the issue of sensitivity in a research study of this nature.

4.6.2.1   Confidentiality

It is possible that very few members of the community would have provided their personal details or expressed their opinions and emotions if their names were to be made known. In view of the fact that reprisal is a very real fear, especially in a study of this nature, the questions had to be of an extremely sensitive nature. Accordingly, confidentiality was an essential requirement for credibility in this research and, indeed, all the participants were guaranteed confidentiality. The Kwazamokuhle School gave consent for the children to participate provided their social worker was present. In addition, the parents were also contacted by the gatekeeper.

4.6.2.2   Informed consent

Informed consent is essential for all sorts of research and the flexible nature of the qualitative research design may cause particular problems. Accordingly, because the qualitative research design is such an emergent design, Bartunek and Louis (1996:58) emphasise the importance of repeatedly confirming informed consent. In a qualitative research project such as this "[p]rospective participants often do not have full knowledge … of the types of events that will unfold during a study … *informed consent* must then reflect an awareness that such events cannot be entirely predicted" (Oka & Shaw 2001:13).

The ethical principles of informed consent, beneficence, nonmaleficence, justice, veracity and paternalism were all addressed as the research study progressed. The nature of the study was explained to the participants so that they understood what was entailed before the interview/questions. It was also explained that they could withdraw if they chose to do so. The researcher's goal was to "do good" (beneficence) and "do no harm" (non-maleficence). Accordingly, operating with fairness (justice) honesty, integrity and genuineness (veracity) created a firm foundation for the study.

The researcher devised a specific informed consent form (See addendum 1) for the participants in their mother tongue. The form contained the following information:

- The respondents are participating in the research
- The purpose of the research
- The procedure of the research
- The benefits of the research
- The voluntary nature of research participation
- The subject's (informant's) right to withdraw at any time
- The procedures adopted in order to protect confidentiality (Groenewald, 2006:10)

As many of the participants were illiterate the form was read to them by the gatekeeper. The researcher has all the voice recordings stored.

4.7   SUMMARY

"Civilization does not depend on a lesser degree of refinement, but on an awareness shared by a whole people" (Albert Camus www.albertcamus quotes.com).

In chapter 1 it was discussed that the researcher's secondary aim was to propose recommendations and guidelines to reduce the impact which negative influences have on CWPDs. Without conducting an ethnographic study in the situation in order to be able to understand the contextual factors, it would be impossible either to make any recommendations or to devise any form of intervention or programme. The incorporation of the known contextual variables of the communities in the rural areas enhanced the effectiveness of any possible interventions, either designed or suggested, by building community capacity and by providing a foundation for future action. Accordingly, this research was conducted in poor rural communities and it yielded far more negative influences than the researcher had anticipated.

Chapter 5 will provide an in depth discussion of the findings in respect of the impact of negative influences affecting CWPDs in rural areas in South Africa.

CHAPTER 5

NEGATIVE INFLUENCES OF POVERTY AND EFFECT ON CHILDREN WITH PHYSICAL DISABILITIES

5.1 INTRODUCTION

The purpose of this study was to identify the impact of negative influences on CWPDs in rural areas in South Africa. In chapter 4 the research aims and methodology of the study were discussed. Having lived with the community in the rural areas the researcher ascertained that poverty is the most debilitating of all negative influences. This chapter explores, in depth, the many negative influences that arise from poverty and which impact on the lives of CWPDs.

The Children's Act No. 38 of 2005 (Proudlock & Jamieson, 2008:1)is the result of many years of work on the part of advocates working for children's rights in both government and civil society. Section 11 of Act No. 38 of 2005 defines the state's obligation to ensure the care, development and protection of children living with a disability. This Act aims to give effect to a range of constitutional rights for children and also, specifically, their rights to family or alternative care, social services and protection from abuse and neglect. In addition, the Act makes government responsible for ensuring that *all* children are provided with a comprehensive range of social services. The challenge now facing South Africa is to ensure both that the Act is implemented in full and that all children, particularly the poorest and the most vulnerable, receive the services that to which they are entitled. This, in turn, implies that CWPDs in rural areas should be enabled to live healthy and happy lives.

This chapter will explore the ways in which, and the reasons why, these children continue to suffer, and also how both policy and practice are failing to meet their needs. It was extremely important to collect information that was relevant to the rural areas and which went beyond the research and statistics already known. As discussed in chapter 4, this entailed an ethnographic study to discover the actual difficulties facing CWPDs on a daily basis. The results of this ethnographic study enabled the researcher both to develop guidelines for the implementation of a framework and to make recommendations aimed at reducing the impact of the negative influences facing CWPDs. This programme will be discussed in depth in chapter 6.

The data collected were organised into themes which had emerged from observations, drawings, photographs, interviews and questionnaires. The findings of these themes reflect,

not only the barriers that CWPDs face, but also the resilience they demonstrate in their coping with a disabling environment and their ability to make a contribution to society if given equal opportunities and access to socio-economic rights (Clacherty *et al*., 2004:9).
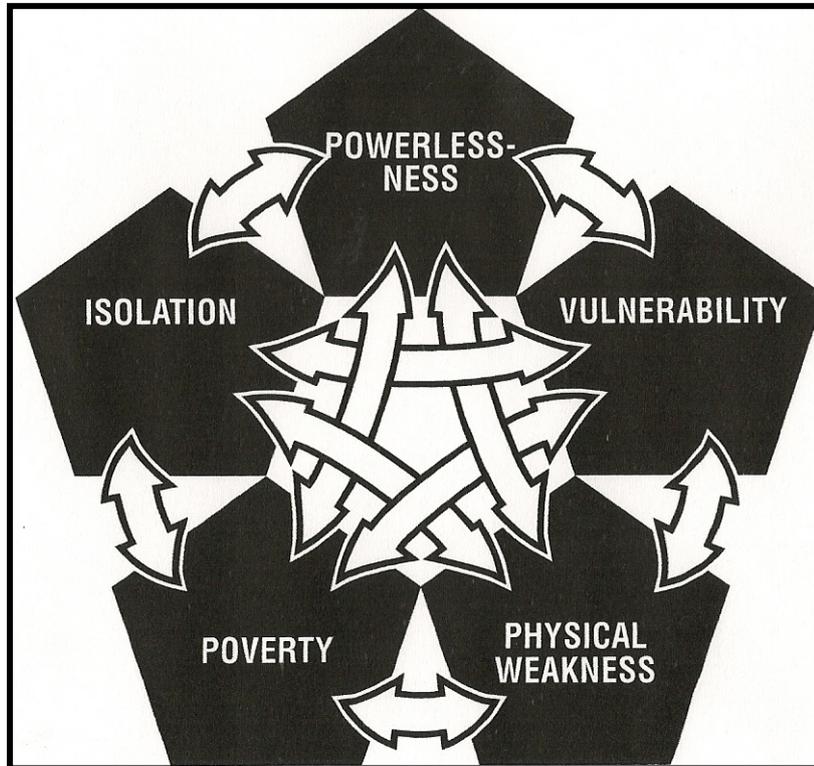
Figure 5.1:   The deprivation trap

Source: Chambers (1983)

Both the impact of poverty on CWPDs and its negative influences may be illustrated in several different ways with, as may be seen below in Chambers' deprivation trap (Chambers, 1983:112), all the negative influences being interlinked. The impact of the deprivation trap and the way in which it prevents people in the rural areas from improving their lives may be illustrated by examples involving shelter, employment opportunities or the lack thereof, clean water, drainage and health facilities (Swanepoel & De Beer, 2009:5). In view of the fact that his model pertains to rural areas, Chambers' model of the deprivation trap will be used as a point of departure for discussing the findings of this research study. The four themes indicated by Chambers and which will be discussed in this study include lack of adequate shelter, unemployment, inadequate health facilities and isolation (exclusion). However, as being pertinent to this study, the researcher has added to Chambers's model the issue of

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CWPDs and the fact that life, for them, is more difficult than for their typically developing peers who also face poverty.

The deprivation trap was designed by Robert Chambers (1983) to represent poverty in the rural context.

The home and the lack of adequate shelter will be the first theme discussed.

5.2   THEME 1: SHELTER

5.2.1   Lack of adequate shelter

Section 26 of the Constitution of South Africa (South Africa Information: Chapter 2 Bill of Rights) stipulates that "everyone has the right to adequate housing", while section 28(1)(c) accords children "the right to … shelter".

Article 27 of the United Nations Convention on the Rights of the Child states that "every child has the right to a standard of living adequate for his/her development". In addition, Article 27 obliges the state in "cases of need" to "provide material assistance and support programmes, particularly with regard to … housing". Not only is there a lack of adequate housing in the rural areas, but overcrowding is also a problem in many of the homes. This, in turn, contributes to both chaotic living and school settings. For the CWPDs, who have other problems with which to deal, crowded settings are often over stimulating, confusing, and characterised by a high degree of unpredictability and uncontrollability (Evans, Eckenrode & Marcynyszyn, 2007:1).

If one studies the homes in the photographs in this chapter it is clear why Lake, Pendlebury & Smith.(2010:83) argue that, while the majority of children (71%) live in formal housing, over 2,3 million children still live in either shacks or backyard dwellings. Many of these houses are similar to the home in the photograph below. Forty percent of children living in informal housing are younger than five years and these children are particularly vulnerable to burns caused by open fires as a result of candles that have fallen over as well as paraffin poisoning. Despite the rollout of the National Housing Subsidy Scheme, the number of children living in informal housing is associated with increased exposure to communicable diseases such as tuberculosis. Overcrowding may also compromise the children's access to other services, such as free water. Table 5.1 below provides an indication of the type of houses in KwaZulu-Natal.

The lack of adequate housing is exacerbated in the rural areas as the shelters in these areas are often built with traditional building materials which require ongoing maintenance. In addition, the shortage of these materials (e.g. thatch during droughts) often makes it difficult

Table 5.1: **An indication of the number of traditional houses in KwaZulu-Natal**

Table 7a: Number and proportion of children in formal, informal and traditional housing, 2008

	EC	FS	GT	KZN	LP	MP	NW	NC	WC	SA
FORMAL	49.7%	77.4%	77.6%	54.5%	88.0%	84.6%	76.0%	80.9%	80.4%	70.5%
	1,377,000	812,000	2,669,000	2,229,000	2,104,000	1,284,000	982,000	345,000	1,438,000	13,235,000
INFORMAL	6.5%	18.4%	22.3%	5.5%	4.7%	8.9%	20.2%	10.3%	19.4%	12.0%
	180,000	193,000	766,000	226,000	113,000	135,000	261,000	44,000	347,000	2,261,000
TRADITIONAL	43.8%	4.2%	0.1%	40.0%	7.3%	6.5%	3.9%	8.8%	0.2%	17.4%
	1,215,000	44,000	5,000	1,637,000	175,000	99,000	50,000	37,000	4,000	3,275,000

for these people to maintain their dwellings properly and, invariably, they often do not have either the time or the physical strength to do so. This situation is exacerbated by the high number of woman headed households as a result of HIV/AIDS, migration and, in this study, by fathers who have left their CWPDs. Living in poor conditions affects the health of both

CWPDs and their families, and it is often difficult for an unhealthy person to find and, then to

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keep, a job. The rural poor face an additional problem in that they are "out of sight" and officials are often not aware of their problems. As a result, the rural poor are, in many cases, isolated. On a macrosystemic level, this isolation is compounded by the tendency of government to invest in urban areas and to neglect rural development (Swanepoel & De Beer, 2009:6). The photograph above depicts a home visited − note the ramp leading up to the front door.

As Bronfenbrenner observed, the processes in terms of which economic deprivation affects children's development are both multiple and complex. Consequently, in view of the complex and multiple paths in terms of which poverty may affect the development of CWPDs, the ecological systems model which provided an appropriate framework to guide both this research and a selection of appropriate interventions will be discussed in chapter 6 (Eamon, 2001:2).

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON THE LACK OF ADEQUATE HOUSING AND SHELTER

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child at home. Aspects such as hygience, cleanliness and safetly of the home play a role

This is the *Mesosystem.* It consists of linkages and interrelationships between two or more of the developing child's microsystems. Neighbourhood conditions have the potential to hinder or improve the child's development.

This is the *Exosystem.* The child is not an active participant in this system. Neighbourhood resources e.g. community centres and parks along with the provision of community services that promote healthy development

This is the **Macrosystem.** It consists of the society and subculture to which the developing child belongs. Is government providing water, electricity, sanitation, and accessible roads.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

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Figure 5.2:   A bioecological perspective on the lack of adequate housing in the rural areas (Adapted from Bronfenbrenner, 1999).

This bioecological perspective on the lack of inadequate housing and shelter is founded on Bronfenbrenner's belief that a child's development is embedded within social settings and those aspects such as cleanliness, house disrepair and lack of sanitation, and water and electricity may have a detrimental effect of the child's development. His model highlights aspects of a child's home environment that may significantly influence the child's development.

5.2.1.1   Findings

The photograph and drawing below indicates the poverty and poor housing and the accuracy

"An accurate depiction"
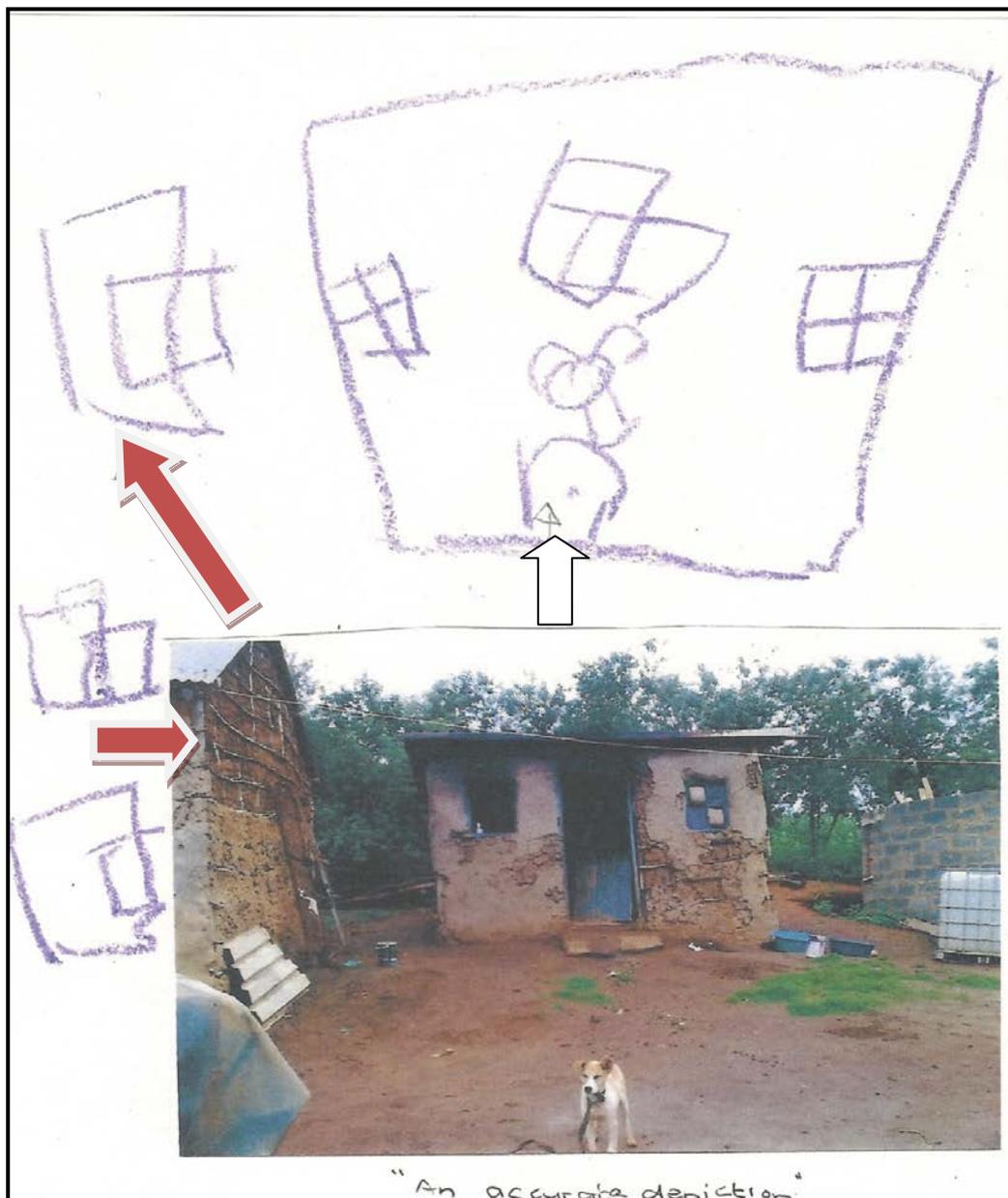
of a drawing of a child who drew "my house".

The lack of adequate housing was obvious to the researcher. Not one of the homes was of a standard that the researcher would consider adequate. The criteria used by the researcher included whether a house is weather resistant and does not leak in the rains. The researcher also considered the following to be of importance: Electricity and a flushing toilet in the house, furniture such as a sofa or a lounge suite and a suitable bed. Whilst the absence of any or all of these may affect any child, the impact on CWPDs is more severe than on typically developing children. Many CWPDs are not able to turn themselves at night and, if left on a straw mat, they risk bedsores and increased spasticity in their muscles. This also applies to inadequate seating and they need to be lifted off the floor and seated correctly. A child that is correctly seated has increased upper trunk control, is in a better position for feeding and is more comfortable. A typically developing child is able to walk to an outside toilet while the CWPD is either left waiting for assistance or is put into nappies. The latter is often an easier option for the caregiver than taking the CWPD to an outdoor toilet, especially as most outside toilets are inaccessible to the CWPDs. This results in many of the children not being toilet trained and this, in turn, results in "learned helplessness". (Thomas, 1979:1).

Below a typical house in the rural areas visited.
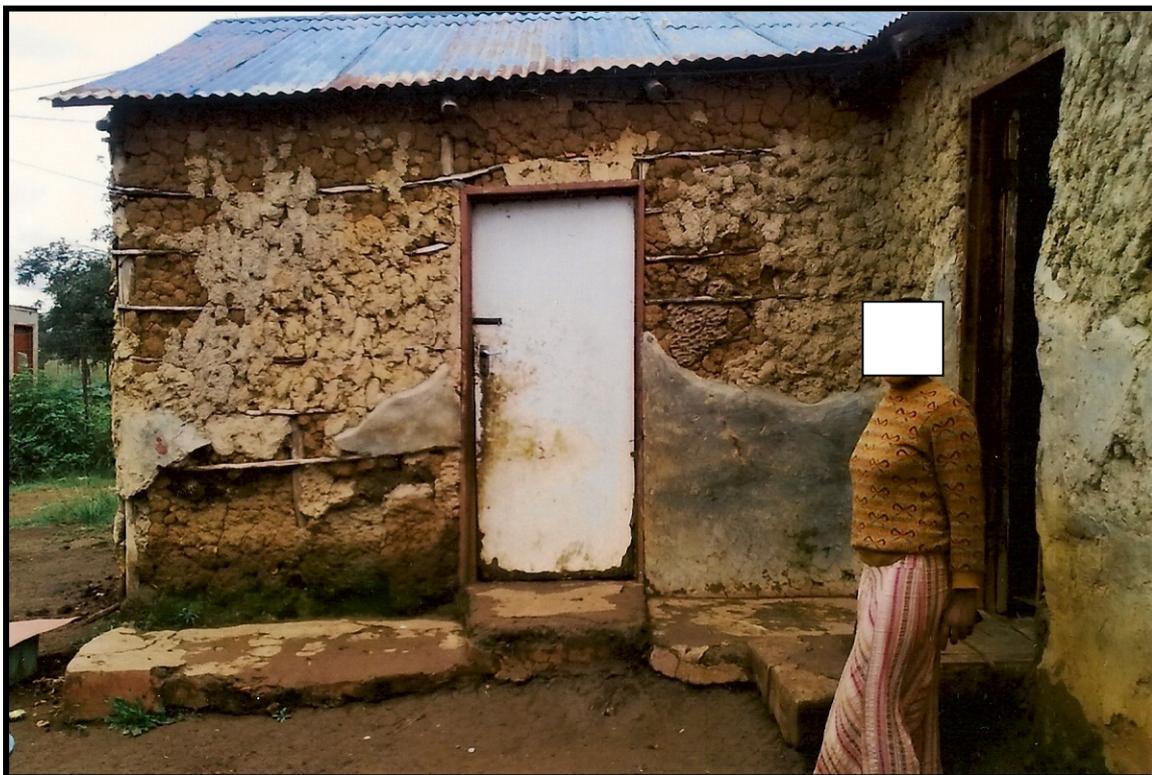
Observing and living in the rural areas emphasised to the researcher how inadequate the housing in these areas is. This is clearly depicted in the photographs contained in this chapter.

However, no matter how small or dilapidated the house, every single caregiver was, nevertheless, extremely proud of his/her home and each home proved to be spotlessly clean as can be seen below.

Despite the fact that KwaZulu-Natal has a population of 9,4 million (21% of the total population of South Africa and, thus, the most densely populated province), 53,2% only of the population has access to electricity (Cullinan, 2004:3).

5.2.2   Lack of electricity

It is a fact that 61,2% of rural households in KwaZulu-Natal are without electricity, while 57% use wood for cooking (http://afra.co.za accessed on 2010/04/05). In today's world most communities rely on the use of electricity and modern living without electrical energy is, in fact, unthinkable. Indoor electricity provides electrical energy to homes for light, telephones, refrigerators, irons, stoves and heating. ESKOM has brought electricity to approximately four million homes and, according to government plans, 300 000 homes are to be electrified annually. However, sadly, in the rural areas, as is clear from the cited figures above, there is still a lack of electricity (http:// afra.co.za accessed on 2010/04/05.).

This lack of electricity is particularly damaging to the rural schools in KwaZulu-Natal and a major problem for the poorer children, particularly for the CWPDs. CWPDs are often able to use computers, especially for the purposes of communication, but no electricity means no computer, no internet, no lighting for reading and no videos. Accordingly, without electricity,

literacy, numeracy and information technology skills will never to be given the chance to develop and the students thus affected will, predictably, underperform and, ultimately, join the ranks of the 30% of South Africans who are unemployed (http://www.totalsolarenergy.co. accessed 2011/06/27).

5.2.2.1   Findings

In this study participant observation proved that this lack of electricity was, without a doubt, one of the more difficult negative impacts of poverty that the researcher observed. The only sources of light in unelectrified houses are paraffin lanterns, candles or wood which has been gathered from the environment. In addition, this lack of electricity had led to illegal

connections in seven out of nine of the homes the researcher visited – see photographs above.

The researcher spent time in the rural areas in winter. While typically developing children were running around outside and, thus, keeping warm, the CWPDs were often left on straw mats in the unheated houses. They had no means of keeping themselves warm and were also excluded from social participation. There were no heaters and they were also excluded when the rest of the family sat around the fire at night. The illegal connections did, however, enable families to cook at night and, thus, to have warm food, especially in winter, as well as to watch TV − their only means of entertainment. The researcher was able to understand and to identify with the need for these illegal connections and, thus, with the reasons behind this activity.

The lack of electricity had led to the disfigurement of one of the children who featured in one of the interviews. The mother shared the following story with us.

"As you can see, we have no electricity. One night my child, she was sleeping over there (she pointed to a small room). The candle fell over and a big fire came. Me and my mother, we could not get my child out. When we did she was full from the fire. It was terrible. We could

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not get my child to the hospital for two days, and the ambulance cannot come here, as you can see, there is no road." Sadly, the little girl's primary disability was that she was unable to walk. However, the fire had resulted in a secondary disability, as not only is she now unable to walk, but she is also severely disfigured and unable to use her hands. Had the child been able to walk it is possible she may have been able to run out of the room instead of having to call and wait for her mother to rescue her. The mother also told us that the child was "very much teased and laughed at and no children will play with her."

Lack of adequate sanitation is also a consideration when deciding whether a house fulfils the criteria of adequate housing. There was a lack of sanitation in all the homes visited by the researcher with not one house having a flushable toilet. As will be elucidated upon below this lack of sanitation exacerbates the problems faced by CWPDs.

5.2.3   Lack of sanitation and fresh water

Article 24(1)(c) of the UN Convention on the Rights of the Child stipulates that State Parties should "recognize the right of the child to the enjoyment of the highest attainable standard of health and this should include the provision of safe drinking water". In addition, Article 14(1)(c) of the UN Convention on the Rights and Welfare of the child obliges the State to "ensure the provision of … safe drinking water".

The Constitution of South Africa guarantees the right to sanitation to all South Africans, with Section 27(1)(b) of the Constitution of South Africa stating that "everyone has the right to have access to … sufficient … water" and Section 24(a) stating that "everyone has the right to an environment that is not harmful to their health or well-being".

Although the South African government has made significant strides in improving access to basic services, still more needs to be done. Approximately 36% of children in South Africa still do not have access to drinking water on site. In addition, although the proportion of children with access to basic sanitation increased from 47% in 2002 to 61% in 2008, eight million children are still using unventilated pit latrines, buckets or open land. Young children are extremely vulnerable to illnesses such as diarrhoea and cholera, and it is essential that local governments invest in improving access to safe water and sanitation (Lake *et al*, 2010:83). Dirty water is responsible for four-fifths of all sickness and one out of three deaths in the world today, with lack of safe drinking water being one of the clearest signs of poverty. Furthermore, the fact that no reliable data on the number of CWPDs exists − government

developmental budgets do not specifically delineate expenditure on children − allows this lack to be ignored (Lake *et al*. 2010:65; INDS, 1997:1).

5.2.3.1   Findings

The findings in this research as regards the lack of clean water and sanitation agree with the findings that emerge from the literature. On a personal level, safe hygiene practices include practices such as washing hands after going to the toilet or changing the nappies of the CWPDs, as well as emptying buckets from the night before. The researcher witnessed this lack of hygiene by observing as well as by living in the rural areas targeted in this study. In addition, necessities such as toilet paper are not always available and, if there is a bucket of water available for washing hands, there is not always soap, and several individuals use the same bucket in which to wash their hands.

However, in general, safe and clean drinking water is available in the rural areas of KwaZulu-Natal. Nevertheless, the researcher observed that the members of the community had to walk fairly long distances in order to fetch water. This is extremely difficult when the caregivers are, for example, grandmothers and the water is heavy to transport. Accordingly, these parents/caregivers are sometimes compelled to leave the CWPDs alone at home. The day, on which the researcher herself went to fetch water, the queue was long. In addition, the researcher realised how difficult it is to fill the bucket as this has to be done manually by the continual turning of the tap. The gravel roads also mean that it is extremely difficult to push a wheelbarrow, as the water is far too heavy to carry. As all members of a community wait in the same queue one large container only may be filled at a time and then one has to return to the back of the queue. The water collected in one container is not sufficient for a family to wash themselves, wash their clothes and clean their houses, as well as to use in the preparation of food. Frequently, the CWPDs were the last to be washed as they did not have to be clean for school. Accordingly, these children often did not smell fresh and it was unpleasant to be in close proximity to them. The gatekeeper, who is a qualified Community Based Rehabilitation worker, was forced to intervene and spoke to the parents/caregivers about the importance of hygiene and cleanliness for the CWPDs. Sadly, the cleaning of the CWPDs is also often deemed to be too time consuming.

Do you think CWPDs are exploited?

"Yes, they (CWPDs) are exploited because others do not bath them: Sometimes they leave them alone in the sun being dirty and untidy". This statement is in keeping with the researcher's observation of limited water and time constraints.

Water is also used very sparingly. The lack of cleanliness of CWPDs is often as a result of a lack of access to health and hygiene education. In addition, this lack of sanitation and access to clean water in the rural areas mean that the threat of waterborne diseases is on the increase. This statement is corroborated by Swanepoel and De Beer (2009:3), who agree that CWPDs, who have a weaker immune system than their typically developing peers, suffer poor health as a result of unsafe drinking water.

Toilets such as the one depicted in the photograph below are not only unhygienic but also totally wheelchair unfriendly. In addition, it is impossible to access such a toilet in the rain.

An outdoor toilet. Very unsuitable for a child in a wheelchair.

Overall, in terms of Bronfenbrenner's exosystemic and macrosystemic levels, a sound infrastructure in respect of service delivery and overall planning as regards every household having clean water is absent and, despite the dismantling of apartheid, there continued to be a

backlog in service delivery. It is, thus, essential that national and local governments improve their service delivery to the people. In addition, supplies must be given to those most in need. The photograph below depicts the general lack of service delivery. There is no service delivery in terms of the removal of refuse and the accumulation of waste materials, in particular old food and used napkins may lead to an increase in diseases.

A major problem is the litter and lack of refuse collection.

In addition to the poor houses and inadequate shelter, parents/caregivers interviewed complained of not being able to leave their homes. This inability of the community to leave their homes because of the poor roads and lack of transport hampers their ability to gain employment and this, in turn, results in a lack of resources with which to repair their homes.

5.2.4   Lack of transport and physical barriers

The physical inaccessibility of public transportation and other facilities including, *inter alia*, government offices, shopping areas and recreational facilities, is a major factor in the marginalisation and exclusion of CWPDs and markedly compromises their access to any services (CRC, 2006). Watermeyer *et al*. (2006:340) are of the opinion that if, as a result of inappropriate public or private transport, a person is not able to move from their homes to such shops, clinics, etc in the first place, then changes in these other environments are of little

value. These negative influences as pertaining to the lack of accessible roads and transport remain unaddressed in the rural areas in South Africa. South Africa is committed to the Convention of the Rights of the Child (CRC) (UNICEF) which urges its members to set out appropriate policies and procedures aimed at making, whenever possible, public transportation safe, easily accessible to CWPDs and free of charge, and, thus, taking into account the financial resources of parents or others caring for such children. However, the findings of this study will show that there is no public transport, y*et al*one free transportation, and that, on the other hand, it is a profitable business to transport CWPDs.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON THE LACK OF TRANSPORT IN RURAL AREAS AND THE EFFECT ON CWPDS

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child at home. CWPDs are often left at home and do not got out with the family due to lack of being able to transport them

This is the *Mesosystem.* Lack of transport to the community denies the child of contact with peers, church and the neighbourhood. Parental involvement in the school is also denied.

This is the *Exosystem.* Local level does little to provide transport to schools for CWPDs.

This is the **Macrosystem.** Government does not provide accessible roads, busses or any other means of transport for CWPDs thus denying the child inclusion to health and education.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

THE CWPD'S

Figure 5.3:   A perspective of the lack of transport based on Bronfenbrenner's bio-ecological model (Adapted from Bronfenbrenner, 1999).

The lack of affordable and accessible transport is emerging as a major hindrance for poorer South Africans in their accessing of state health care and education, especially in respect of those poorer South Africans living in rural areas (Langa, 2010: 1). The South African government's national policy, as well as legislation, articulates the responsibility of both

government and civil society to promote the full integration of CWPDs into society (INDS, 1997). This responsibility of integration includes the instruction to government to "take steps to reasonably accommodate the needs of [persons with disabilities]".

It is stipulated in the National Land Transport Bill, 2009 (Government Gazette, Vol. 526) that the needs of special categories of passengers must be considered in the planning and provision of public transport infrastructure, facilities and services, and that these needs should be met, as far as may be possible, by the system provided for mainstream public transport. However, this is not the case for CWPDs living in rural areas of South Africa, despite the fact that the rights of children have been enshrined in the Constitution of South Africa (1996) and reaffirmed in South Africa's Children's Bill (2003). The latter guarantees the rights of children to access to basic services and resources. However, the reality is that a lack of affordable and reliable transport is severely limiting the access of many South African children to fundamental services and resources, including health care and education. This is particularly true of children living in rural areas where access is constrained not only by geographic isolation, but also by inadequate and poor transport infrastructure and services. Travel and transport constraints for CWPDs impact on a range of rights, needs and opportunities, including access to education, health care facilities, social services, information, social networks and economic participation (Chakwizira, Nhemachena, Dube & Maponya, 2010:642).

Despite the fact that South Africa has made significant strides in the fight against poverty, there are still extensive sections of the populations for whom service delivery is lagging with the rural areas, in particular, remaining deprived of a basic minimum of infrastructure and services. The National Rural Transport Strategy (National Department of Transport, 2003) has, thus, been developed as a programme directed towards addressing the transport challenges faced by rural communities in terms of access to social and health services, and to educational facilities. This strategy revolves around the notion that transport is, potentially, a powerful vehicle in seeking poverty alleviation and economic growth with development, as well as a visible instrument for correcting spatial distortions. The inability of CWPDs to use transport in the rural areas has a far greater impact on their lives than merely an inability to travel from A to B. Throughout South Africa the existing transport and spatial systems in rural areas are failing to meet the needs of the majority of CWPDs.

5.2.4.1 Findings

It was as a result of spending time in the rural areas and walking long distances that the researcher was able to identify fully with parents/caregivers who all complained about the long distances that needed to be travelled as constituting a barrier to both accessing services and promoting inclusion of their CWPDs in the community and inclusion in mainstream schools. Access to road transport was an issue that was raised by all parents/caregivers with their expressing as their main concerns their inability to afford to use taxis on a regular basis, the negative attitudes of taxi drivers towards CWPDs, long distances to the taxi ranks and long waits, difficulties getting in and out of the taxis and taxi drivers refusing to assist with heavier children.

There is a severe lack of public transport in the rural areas with the transport that is available often being extremely limited in terms of routes travelled, running times, availability, affordability and accessibility. Alternative transport options are few and far between. The distances that have to be covered in these areas are often too great for walking with CWPDs and, whilst cycling is an option for their typically developing peers (bicycles are donated in these areas), this is not an option for CWPDs. The Department of Transport(National Land Transport Act No.5) is currently supporting the initiative of providing transport through the provision of bicycles, for example, the Shova Kalula Bicycle Partnership Programme. The latter is a government sponsored initiative providing subsidised bicycles to rural areas. These bright yellow bicycles were clearly evident in the mainstream schools. However, the lack of transport in the rural areas is exacerbated for CWPDs as they are not able to ride bicycles. Nevertheless, they do need to access schools and services and to be included in the way as their typically developing peers.

It is often extremely difficult for CWPDs merely to leave their homes. The roads/pathways are gravel and this makes it difficult for wheelchairs and for children using crutches. In addition, it is impossible for them to leave home when it is raining as it the roads/pathways are often still muddy even days after it has rained. There is often also a river to be crossed and access to a road becomes impossible when the child is too heavy to be carried on the mother's back. Many taxis do not stop for children in wheelchairs and, even if they do, taxi drivers often charge double for the wheelchair. This, in turn, places a huge financial burden on already impoverished families.

This finding is similar to the findings of Chakwizira *et al.* (2010), who reported that people in the rural areas in Mashupatsela and Lerolo which they were studying reported that they have problems, especially boarding and alighting from taxis. In addition, the members of the community complained that people do not understand their situation and have negative attitudes towards them. One member of the community reported being charged three times the normal taxi fare, while others complained that they were left on side of the road with the taxis picking up able bodied people only. It would, thus, appear that these difficulties with public transport are experienced by PWDs and CWPDs in all rural areas in South Africa.

Accordingly, the fact that these rural areas are so remote makes it both expensive and time consuming for poverty stricken caregivers with CWPDs to reach important facilities.

These observations are echoed in the answers given by the parents/caregivers to the following question.

According to you, what are the disadvantages of living in rural areas?
All nine interviewees indicated that transport was a major problem for them and for their children with answers ranging from "there is no transport" to "bad roads". The mother from Loskop voiced her concern as "lack of special schools close by". This mother was extremely distressed as she had to send her seven-year-old child to boarding school. These answers are amplified by their voicing of the other barriers which they are forced to confront. The following quote encapsulates the transportation difficulties they face − "Long distances, especially going to school, employment difficulties, not being accepted, birth certificates and then, actually getting the grant, *transport* and the *road is bad, bad*".

All the answers given were similar and revealed the desperation of the parents/caregivers at the lack of roads and the resultant lack of accessibility of resources.

Is transport to the clinics a problem for you and your child?
Six parents stated that transport to the clinics was a problem, whilst two felt that this was not a problem. One parent replied that "We do have a mobile clinic that comes on Mondays and the hospital is very close to us". As can be seen in the photographs below lack of roads is a major problem for parents and their CWPDs. Roads are uneven and wheelchair unfriendly.

It was difficult for the researcher to probe further into the answers to these questions as the

interviews were all conducted in Zulu, and were transcribed only later.

The majority of the parents found transport to the clinics a problem for their children. It must be borne in mind that the mobile clinic is for minor problems and medications only and caters for typically developing children with no specialists, such as a speech therapist, being available in the mobile clinic. Depicted in the photographs above one sees the roads to two of the homes visited with limited access to the houses ,including a river that has to be crossed.

The unexpected answer given by a child at the mainstream school gave the researcher some insight into the cost of transport.

Would you go with a CWPD to town?
"Yes, but I cannot, I do not have enough money for myself and a special child"

The findings in respect of the lack of adequate transportation for CWPDs which emerged from this study are the same as those found in the literature study.

Another issue in respect of the lack of transport in the rural areas is the fact that accessing a job on a daily basis is both extremely difficult and expensive.

Watermeyer *et al*. (2006:341) validate the fact that parents/caregivers and their CWPDs should be able to move continuously and without difficulty through all built environments. However, it is clear that there are a host of existing barriers, both physical and attitudinal, to this notional freedom of movement and that, although policies and guidelines do exist, these need updating and enforcement. Institutional funding is often not available to deliver on policies, and attitudinal barriers exacerbate the difficulties of accessing benefits.

This lack of transport has, in turn, led to high rates of unemployment in the rural areas.

5.3   THEME 2: UNEMPLOYMENT

Unemployment is both a cause and a result of the poverty situation in which people find themselves. It is a cause since, without a job a person has no income and is, thus, not able to pay for proper housing (see discussion above), food, medical care or education for themselves and their family. It is also a result because the poor health brought about by an unbalanced diet, poor housing and the lack of appropriate education − all on account of poverty − prevents a person from finding and keeping gainful employment (Swanepoel & De Beer, 2009:6).

5.3.1   Unemployment in the rural areas

As a result of social exclusion and discrimination in the labour market, persons with disabilities may be disproportionately affected by unemployment and this, in turn, leads to an increased incidence of poverty. In addition, the healthcare costs related to having a child with a disability are high and this exacerbates the poverty which these people are already experiencing. People with disabilities are often those most readily excluded from both the education system and from the labour market and they are, therefore, often destined to remain the most poverty stricken within the community.

Single mothers with a CWPD and a limited education only, find it extremely difficult to find work. In addition, the lack of childcare services mean that, even where there are employment opportunities, mothers are faced with the choice of leaving their children to go out to work, or staying with them and remaining in acute poverty (Landsdowne, 2002:20).

5.3.1.1   Findings

Spending time in the rural areas means that the high unemployment rate becomes obvious, as so many community members merely sit around all day. The researcher did observe that certain factories make use of daily labourers with community members starting to queue early in the morning in the hope that they may be employed, albeit for one day only.

The majority of parents/caregivers interviewed stated that unemployment is a major cause of their poverty and loneliness. This emerges clearly from the following replies.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON UNEMPLOYMENT IN THE RURAL AREAS AND THE IMPACT ON CWPDS

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child at home. CWPDS need full time care and their caregiver is often unable to leave them to seek employment. They frequently leave the rural areas and migrate to urban areas, which is detrimental to the child's development

This is the *Mesosystem*. Unemployment results in no money for socialisation outside the family such as no money for transport to visit family or for the caregivers to be active at the child's school and in the neigbourhood.

This is the *Exosystem*. Parents are often unable to seek employment as employers do not provide parents with time off to assist their children, stressful work situations impact on the child

This is the **Macrosystem**. Social policies that increase access to economic resources and quality housing, and nutrition are likely to enhance proximal processes in the micro and mesosystem and result in better developmental outcomes.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development.

THE CWPD'S

Figure 5.4:   Bioecological perspective on unemployment (Adapted from Bronfenbrenner, 1999).

What do you think are the major problems facing CWPDs?

One mother explained: "Employment difficulties. I am unable to work myself as I have to look after my child". Another mother was concerned about employment opportunities for her child when he grew up and she voiced her frustration – "They are exploited; especially those with mental problems. They make them work for nothing or pay them peanuts". This sentiment was echoed by a grandmother who stated that "They are given the heavy tasks to do".

Unemployment is anticipated in the futures of the CWPDs as well as for their parents who have to look after them. This lack of employment opportunities for parents/caregivers is perceived as impacting negatively on CWPDs in an unique way as their needs are not only greater but, at the same time, their parents/caregivers are unable to find employment as their children require full time care. Another mother stated that her child is regarded as incompetent and will, thus, never be a productive member of society. Many mothers were

lonely as their spouses had gone to the urban areas to seek employment − a result of the legacy of the apartheid regime.

The Disabled Children Action Group (DICAG) estimates that 98% of the mothers of children with disabilities living in rural areas are unemployed, semi-literate or functionally illiterate, single mothers. Deserted by husbands and lovers, often socially ostracised by their communities, and banished into isolation by their extended families, they tend to withdraw into a world of their own (Watermeyer *et al*. 2006:228). INDS (1997:6) supports this finding in their statement that, although the parents of CWPDs have a special and specific role to play in the development of their children, mothers (especially) of children with disabilities often face ostracism from their partners, their families and their communities. This exclusion, in turn, has a negative effect on other non-disabled siblings, the survival of the family as a unit and the meaningful development of the child with the disability. Related to these realities is the perception in many families with CWPDs that such a child is unlikely ever to find employment or to be in a position to contribute to the family income. At best, the child is kept back from attending school until their able-bodied siblings have been accommodated or, at worst, the CWPD is never accorded the opportunity to go to school to learn. As a result, such children grow up to become disempowered adults, unable to make decisions, solve problems or take the initiative. This high level of illiteracy, in turn, leads to high employment figures amongst adults with disabilities (INDS, 1997:17).

Of concern is the lack of a high school in the rural areas visited by the researcher and that CWPDs could attend. At the end of their schooling at Kwazamokuhle they are sent home, where they remain without access to either skills training or to a high school.

The parents interviewed were aware that a lack of education for their CWPDs leads to a lack of employment and that the CWPDs would, thus, be destined to remain in the trap of poverty. The parents/caregivers worry about employment opportunities for their children was evident in the answers they gave to the following question.

What do you think are the major problems facing CWPDs?
"Employment difficulties. Nobody wants to employ them." One mother stated that "Government does not help us to start a small business like poultry farming so we can earn money"; whilst the grandmother was clearly aware that there were no prospects for her grandchild when she commented that there is "No tertiary education". Two other parents

stated that 'some people regard them (CWPDs) as useless". Yet another parent realised the importance of education and stated that "Government can build a high school for CWPDs in our district".

All these answers are indicative of huge concern on the part of the parents, not only as regards their children completing a high school education, but also that this would enable them to find employment and lift themselves out of poverty.

This high unemployment rate leads to another negative influence that impact on the life of the CWPDs, namely, abuse of their disability grants which are used to support the family. This issue will be discussed below.

5.3.2   Abuse of child grants

The right to social security is guaranteed under the South African Constitution. This realisation of the right to social security for children in South Africa takes the form of support grants, foster child grant and care dependency grants. While South Africa has one of the most progressive constitutions in the world, the realisation of the socioeconomic rights of the majority of its population remains a mirage. This state of affairs has exacerbated the vulnerability of those CWPDs who come from poor families. It is, thus, against this background that an effective mechanism for the protection and care of CWPDs becomes essential with empirical research and data illustrating that the implementation of basic social services for children is imperative in order to alleviate their plight (Mirugi-Mukundi, 2009:i).

Section 27 of the South African Constitution establishes that everyone has the right to access to social security, even if they are unable to support themselves. Accordingly, the state is under a legal obligation to take 'reasonable legislative and other measures, within its available resources to 'achieve the progressive realisation' of this right. For CWPDs such assistance is not only imperative but it is often a matter of their basic survival (Mirugi-Mukundi, 2009:2). From 2009 the grant for CWPDs amounted to R1 010 per month (Hall, 2010:1). However, sadly, there are barriers to the CWPDs receiving their grants and, in addition; there is a great deal of abuse of their grants.

The establishment of the South African Social Security Agency (SASSA) as the sole agent responsible for the administration of these grants was aimed at ensuring that efficient and effective services be rendered to the beneficiaries. However, in the last decade, both the

social security system and access to social assistance grants has faced, and continues to face, several obstacles. These obstacles include, inter alia, the inefficient delivery of social grants to certain parts of the country, poor levels of service delivery, lack of knowledge about grants, unilateral control of social grants and corruption and fraud (Mirugi-Mukundi, 2009:32).

In addition, corrupt and unhelpful officials further add to incessant delays in the process of accessing these funds. In addition, parents/caregivers experience difficulties filling out the forms, forms are lost, and it is often not possible to contact parents/caregivers. These issues all add to the frustration of accessing the grants that are due to the CWPDs.

5.3.2.1   Findings

The above findings are echoed in the answer which one of the mothers gave us.

What do you think are the major problems facing CWPDs?

Mother 9 complained that "I have difficulty getting a grant". She did not, however, volunteer further information. Another mother stated that there are "No bursaries for further studies".

Some families living in the rural areas are not able to afford the cost of the transport to the government offices. In addition, many of them have nobody to look after their children during the school holidays when they need to collect their grants. One parent did not apply for the grant because the correct procedures to follow in applying were too difficult. There is also inadequate dissemination of information in the rural areas about grants. Illiteracy, particularly in the rural areas − where one caregiver could sign her name only as an X − further exacerbates the situation since some of the potential applicants are unable to fill in the forms. There are also some parents who are not even aware of the grants available − a lack of information was evident in these rural areas visited. In addition, South Africa continues to be plagued by inefficient bureaucratic procedures, inadequately trained staff, poor management, serious delays and backlogs in government departments (Mirugi-Mukundi, 2009:39).

During the interviews, a clinic sister discussed with us the fact that, as a result of the high unemployment rate, most families depend on their child's disability grant with the grant becoming the only source of income for the family. This, in turn, has a negative impact on the CWPD concerned, as the grant is then not used to purchase any type of essential assistive devices or medical supplies, correct seating or transport to school, and the child often

It was behind this closed door that the researcher, the gatekeeper and the Induna discovered the CWPDs who were "hidden" and their grants were abused. See further photographs below.

develops malnutrition as the entire grant is used to feed the family. One mother complained to us that "my child he does not have a wheelchair at home the weekends if he comes home from the school". The clinic sister also discussed with us the fact that the money allocated to CWPDs is frequently used to send the siblings to school as the CWPDs are considered useless. This, in turn, leads to exclusion, discrimination, marginalisation and exploitation. There is also a feeling that the child will not ever be able to contribute to the household income. One father felt that there was a stigma attached to receiving a "disability grant" and, thus, did not apply for one. In such cases the CWPDs bears the brunt of not receiving that to which they are rightfully entitled. However, the father in question refused to discuss the matter either with us or with the school.

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Furthermore, as in the case of the group of children we discovered "behind closed doors", the disability grants tend to be fraudulently used. Unfortunately, there are members of society who prey on the ignorance of the families of CWPDs. We discovered a "perpetrator" who went to the isolated rural homes and promised the parents he would take care of their children at a special school. In return, they handed him the children's disability grants. We found these

children locked up in a cold, damp room with no sanitation, no electricity, no stimulation and little food. The children were removed the following day, as soon as transport arrangements had been made and a docket opened with the police. However, it took some time for the social worker to track down the parents, as there was no documentation for any of the children. Unfortunately, the negative experiences they had endured in being removed from their parents and held in such a cruel manner are harrowing and the effects may be long term. Furthermore, to date, although a police docket was opened, neither the researcher nor her gatekeeper has been asked to give evidence, and there has been no follow up to the blatant abuse of these children. Once again, the system has failed the child.

As depicted in the above photograph one little boy was left on the cold floor all day (this was during winter) in the position as indicated while the other child in the wheelchair was seated in the worst way possible. Any expert on seating will confirm that being seated in such a way will cause spasticity and is, in any case, extremely uncomfortable. Once again, no stimulation whatsoever was being provided with the photograph showing that not one child had anything to do.

The lack of employment and no income other than the child's disability grant on which the entire family depends lead to a lack of essentials in the home. In this study, essentials are considered not only to be food and clothing but the other essentials that are important for CWPDs.

5.3.3   Lack of essentials

Clark and Qizilbash (2005:32) used a random selection of "ordinary people" for their study on disadvantaged regions in South Africa. Participants were asked how they themselves distinguished between poor and non-poor, with specific reference to the basic essentials required to "get by" as opposed to "live well". As a result of their work in three poor

communities in South Africa, Clark and Qizilbash developed a ranking of the 30 most essential things as reflected by the participants. The researcher used this (below) study of Clark and Qizilbash to identify, through observation and participation, the lack of essentials in her study in the rural areas.

1.	Housing/shelter	✓
2.	Food	✓
3.	Water	✓
4.	Work/jobs	✓
5.	Money/income	✓
6.	Clothes	✓
7.	Education/schools	✓
8.	Health/health care	✓
9.	Electricity/energy	✓
10.	Safety and security	✓
11.	Transport/car	✓
12.	Family and friends	some
13.	Sanitation	✓
14.	Infrastructure	✓
15.	Leisure/leisure facilities	✓
16.	Own business/enterprise	✓
17.	Religion	yes
18.	Furniture	✓
19.	Happiness and peace of mind	✓
20.	Community development	✓
21.	Love	some
22.	Freedom/independence	yes
23.	Better life	✓
24.	Oxygen	yes
25.	Respect	✓
26.	Blankets	✓
27.	Heat/temperature	n/a
28.	Land/livestock	some
29.	Sexuality	n/a
30.	Sunlight	n/a

Wright (2008) conducted a study of poverty using the Socially Perceived Necessities approach. The Indicators of Poverty and Social Exclusion (IPSE) project forms part of the National Development's Social Analysis Programme. The researcher in this study considered these Socially Perceived Necessities and, during her observations and the second phase of her spending time in the rural areas selected the following 10 topics as representing the necessities which were lacking which had emerged either from her observations or the interviews conducted.

- Someone to look after you when you are ill

- Separate bedrooms for children and adults

- Ability to pay for a funeral

- A bath or shower in the house

- A large supermarket in the area

- A car

- Somewhere for children to play safely outside of the house

- Some new, not second-hand, clothes

- Someone to look after you when you are feeling sad

- Someone to transport you in a vehicle if you need to travel in an emergency

Inability to pay for a funeral.

As regards the above observations, the 10 Indicators of Socially Perceived Needs are clearly visible throughout the rural areas and not only specifically in the homes visited.

The lack of adequate healthcare facilities in the rural areas will now be discussed.

5.4   THEME 3: INADEQUATE HEALTH CARE FACILITIES

The fact that the provision of health care facilities lags far behind what adequate health care should be may be attributed to the long distances as well as the lack of transport between the scattered villages in the rural areas. However, it is essential that the preventive primary health care facilities in these rural areas be expanded, as the curative facilities provided by large clinics and hospitals are situated at long distances from where the rural poor find themselves. In addition, the transport facilities, such as ambulance services to health centres, are inadequate.

Poverty also contributes to the squalor in which many children live and this, in turn, renders them vulnerable to disease. In addition, poverty limits their access to proper medical care and, for the CWPDs especially, this lack of heath care and early intervention has serious consequences (Swanepoel & De Beer, 2009:6).

5.4.1   Lack of adequate health care

As already mentioned, prior to 1994 South Africa was marked by extreme inequalities; with the health policies being instrumental in maintaining the economic and political power in the hands of the white population group (Chetty, 2007:4). The differences in the health status and allocation of health resources between the urban and rural communities reflected the extreme inequalities between these groups. However, such inequalities are not in keeping with the CRC (2226), which stipulates that the attainment of the highest possible standard of health as well as access to affordable quality healthcare is inherent rights for all children. Nevertheless, the CWPDs continue to be marginalised as a result of the many challenges facing them, including discrimination and the physical inaccessibility of health care facilities. Another important factor is the absence of targeted health care programmes that address the specific needs of CWPDs. It is, thus, essential that health policies be comprehensive and that they address the early detection of disabilities as well as early interventions, including psychological and physical treatment.

Landsdowne (2002:6) maintains that a significant proportion of the disabilities in the rural areas arise from preventable factors. The lowest socioeconomic families are almost two and a half times more likely than families who do not experience poverty to have a child with a disability and much of this may be attributed to a lack of maternal care. Nevertheless, MDG 5 aims at improved maternal health care in order to reduce disabilities both for the mothers and

the children. The mortality rate for children with disabilities may be as high as 80%. MDG 4 aims at reducing child mortality and specifically states that Goal 4 (a) is to reduce by two thirds the mortality rate of children under 5 years, the infant mortality rate and the proportion of 1 year old children immunised against measles. Furthermore, MDG 4 states that every child should have an equal right to life with any discrimination in service provision excluding CWPDs and, thus, denying them access to quality health and social services.

The situation is exacerbated in rural areas where service delivery such as sanitation and reuse collection is clearly lacking. This, in turn, results in an absence of screening and early identification services. This lack of identification then leads to a deficiency in terms of early interventions for CWPDs in the form of, for example, physiotherapy, occupational therapy and feeding therapy. This lack of intervention is in contradiction to the National Health Act No 61 of 2003 (Government Gazette Vol. 469) of which one of the objectives is to "regulate national health and provide uniformity in respect of health services across the nation". In addition, the CRC that states CWPDs require special services in terms of health care to allow them to achieve their fullest potential.

5.4.1.1   Findings

The findings resulted from a thorough data collection process which included interviews and questionnaires. Moreover, having already conducted an ethnographic and participatory research study, the researcher had observed that there was one clinic only in the area and that this clinic was accessible by foot only from the research participant's homes and then the parents/caregivers would need to catch a taxi. In addition, the terrain is rough and uneven, and extremely difficult to access, especially for pregnant mothers. Access to the clinic in hot weather is as difficult as when it is raining, and the gravel paths become muddy. Furthermore, the clinic does not include a labour ward, and the geographical isolation of their homes, together with no money with which to pay for pre-natal check-ups, impacts negatively on the children before they are even born. We asked one caregiver who lived in an extremely isolated area near Loskop what she thought that government could do to help. She replied as follows: "Help us with extra food and medicines when we are pregnant." This answer indicates that, even at the clinics, the mothers were not given any additional vitamins, folic acid or healthy foods necessary for a healthy pregnancy.

Whilst there is free primary health care for those mothers who do manage to reach a clinic, this free health care does not cover the tertiary needs − speech and physiotherapy − of many

of the CWPDs for whom payment for this type of treatment is out of the question. Even where services do exist, such as at Kwazamokuhle School, these services are centralised and the children have to move away from home to access the services and, in so doing, have all their needs met. However, this is the situation only once they have reached school-going age. In addition, when they go home for the holidays there are no facilities available locally.

The nearest town to the four rural areas visited by the researcher is Estcourt where the researcher was handed a pamphlet from one of the local doctors who was promising that his medicine would "make their children walk". Desperate parents/caregivers would be prepared to make the journey which, in itself costs money, and pay for the consultation, if they thought it might help their children.

We interviewed nine parents/caregivers. Although the parents/caregivers did indicate that transport to the clinics was a problem it did, nevertheless, emerge from their answers (See below) that they were happy with services they were receiving.

What is the professional health worker's attitude when you bring your child to the clinic for a check-up?

All the parents were happy with the services provided with their answers ranging from "excellent", "positive" and "good, except that it is far" to "good, except there are no rehabilitation services".

However, the answers received from the research participants in this study are contrary to the literature findings as discussed above. For example, Landsdowne (2002:6) voiced that a significant number of disabilities arise from preventable factors as discussed above, including the lack of nutritional food and no pre-natal care. All the parents appeared happy with the staff at the clinic and they indicated that they had no problems with the health services provided, except that there were no specialists. Nevertheless, it may be that many caregivers/parents lack awareness of existing options and are unable to identify problems which may arise at an early age. The researcher and her gatekeeper attribute a great deal of their acceptance to ignorance as it is obvious that the mothers living in remote areas are not aware of early screening, scans and paediatricians who diagnose problems before birth and, with an Apgar Scale, at birth. This lack of information also impacts negatively on the CWPDs and will be discussed in depth later in this chapter. The research study did not, however, investigate whether children were born at home with the assistance of a midwife or at a clinic.

The photograph below, which shows the path to one of the participant's houses, clearly indicates the difficulty a heavily pregnant woman would experience in accessing a clinic. Although a mobile clinic does visit the area, it is not able to access many of the areas.

A long and difficult gravel path to a road to wait for transport to the clinic

Poverty clearly plays a role in the standard of nutrition and, thus, poverty and disability are related. There is increasing evidence that poor nutrition in CWPDs is associated with both short-term and long-term adverse consequences such as poor immunity and a higher incidence of poor cognitive function and learning ability than in those CWPDs who do have access to healthy food (Van Kampen, Van Zijverden & Emmett, 2008:19).

5.4.2   Lack of adequate nutrition for the CWPDs

Child poverty and child hunger are some of the endemic problems that South Africa has been struggling to overcome since the dawn of democracy. According to Chirwa (2009:v), millions of children in South Africa suffer extreme forms of poverty as well as its associated evils, including malnourishment, stunted growth and nutrition deficiency diseases. However, despite the prevalence of poverty and malnutrition there has been no litigation in South Africa on the right to food, unlike the litigation on other rights such as the rights to housing, water and social security. There is also no case law directly concerning the socio-economic rights of children. In fact, the rights to food and basic nutrition have been implemented

somewhat unsystematically in South Africa through a hodgepodge of policies and, indirectly, by legislation (Chirwa, 2009: abstract). Nevertheless, the elimination of hunger and malnutrition is technically feasible and the means to do so are available. The challenge lies in generating the requisite political will, developing realistic policies and taking concerted action, both nationally and internationally (http://www.who.int/nutrition/index.html).

Malnutrition may, either directly, cause impairment or else increase susceptibility to debilitating diseases. Malnourished mothers are at risk of bearing low birth weight babies, and these babies are, in turn, are at a higher risk of contracting disabling diseases than typically developing babies. As already discussed, adverse environmental conditions, including inadequate shelter, the lack of clean water and poor, or no, sanitation facilities, all compound the risk of infection (Watermeyer *et al*., 2006:210).

Moreover, CWPDs are at an increased risk of under nutrition as a result of a myriad of emotional, physical and social stresses that may include financial factors, chronic use of medications (ARVS) and the complicated feeding problems common in CWPDs (Tada, Baer, Robinson & Ichiho, 1998:76). Good nutrition is especially important for children who struggle with chronic health conditions. Many of their able-bodied peers attend schools where there are feedings schemes but, for some CWPDs who remain at home, hunger is a daily reality. Such a child has no chance of developing properly and is, consequently, doomed to a bleak future of illiteracy, poverty and destitution. With underdeveloped mental faculties, it is not possible for CWPDs to make much progress with the education which is critical to the fight for an independent existence and the freedom that they have already been denied. The CRC (2006) recommends that state parties (Government health sectors, social welfare departments, etc) provide adequate post-natal health services and also develop campaigns to inform parents and others caring for the child about basic health care and nutrition. However, these recommendations had clearly not been promulgated in the areas the researcher visited.

5.4.2.1   Findings

The researcher observed that, of the caregivers/parents visited, one only worked. This may be as a result of the fact that the parents of CWPDs are unable to obtain employment as CWPDs need full time care. However, the result of the parents/caregivers not working is that there is often less money available with which to purchase nutritional food.

It would appear that the parents of CWPDs had received no guidance on how to feed their children with disabilities. This was noted by the researcher and gatekeeper who both observed the homes had no adaptive seating, specialised feeding cups or adapted spoons for their children. Observation in a study such as this may provide unexpected findings and, in fact, one observation that took the researcher by surprise was the fact that there is no speech therapist at Kwazamokuhle School. In addition, not only is there no feeding assistance at this school, but children who are not able to feed themselves are not admitted to the boarding school as the boarding school is understaffed and, thus, does not have sufficient manpower to feed children. The education department is clearly to blame as it is inconceivable that a specialised school would not have a post allocation for a speech therapist. Accordingly, the education department is, in fact, exacerbating the exclusion of the CWPDs, as the children who are unable to feed themselves have no opportunity for education.

Furthermore, observations yielded insights into on how little food families manage to survive. The time spent in these areas meant that meals for both the family and the researcher consisted of 'mielie pap', 'marog', and chicken giblets, necks and feet. In the time the researcher spent in the areas no fresh fruit or vegetables were served to the children. The only bread given to the children comprised white rolls and, on occasion, the luxury of a red vienna. Any extra money which families had they 'splurged' on cream soda soft drinks. In other words, the food not only lacked in nutrition but there was widespread ignorance as to what actually constitutes a healthy diet. In addition, the families do not have access to healthy foods, which are expensive.

The children from the families interviewed all attended Kwazamokuhle boarding school

where they do receive nutritious meals during term time. This may also be a reason for the following assertion made by a teacher at this school to the researcher: 'some of the parents do not even want to fetch their children in the holidays as they know that they cannot provide food at home." Having visited all nine homes, this is a feasible possibility. There were no refrigerators or cupboards stocked with food in these homes. Fried cabbage was often served as a meal. It was not deemed necessary to ask the parents/caregivers about the lack of food in their homes as the evidence was clear to the 'naked eye'.

The researcher's observations are in keeping with The Alliance for Children's Entitlement to Social Security (ACESS 2006), which estimates that nearly 66% (12 million) of all children in South Africa live in dire poverty on less than R1 200 per month. According to UNICEF, this situation has not improved in the last 10 years (Chirwa, 2009:3). These findings are in line with the study conducted by Clacherty, Matshai & Sait (2004:24), who reported that hunger was an everyday reality for many of the children who had participated in their study.

The hunger endured by children is in direct contradiction to Article 20 of the African Children's Charter that posits that the primary responsibility for children's upbringing and development rests with the parents (Gose, 2002). This is in keeping with Bronfenbrenner's microsystemic level. However, this Charter also provides that the state shall assist parents and, in case of need, provide material assistance and support programmes, particularly with regard to nutrition, health, education and housing − see Bronfenbrenner's mesosystemic, exosystemic and macrosystemic levels.

The Integrated Nutrition Programme, lauded as the solution to child hunger at its launch in 1994, has focused mainly on feeding children at school, while thousands of children younger than two years continue to die of under nutrition, partly as a result of the 'failure to thrive' syndrome seen at clinics. Many deaths are the result of nutritional defects (Children's Rights Centre, 2006). Criticisms of the National School Nutrition Programme include the inappropriateness of the foods distributed, both in nutritional terms and in its potential to stimulate community job opportunities (Lake *et al*. 2010:67).

Furthermore, the domino effect is felt as an unbalanced diet and prolonged illness lead to physical weakness. Physical weakness, in turn, leads to increased vulnerability to other diseases such as tuberculosis, malaria and HIV/AIDS which then break down the natural immune systems of the caregivers and the CWPDs.

5.4.3 HIV/Aids

The impact of HIV/AIDS on the CWPDs is in keeping with current statistics. An estimated 5,7 million children were living with HIV/AIDS in South Africa in 2009, more than in any other country. HIV prevalence among those aged two and over is highest in KwaZulu-Natal, with 15,8% at the upper end of the scale (United Nations General Assembly on HIV/AIDS UNGASS, 2010). The estimated overall HIV prevalence rate is approximately 10,5% while, for adults, an estimated 17% of the population is HIV positive. These figures estimate that, in 2010, approximately 1,6 million people aged 15 and older − approximately 183 000 − will need ART. The total number of new HIV infections for 2010 is estimated at 410 000 and, of these, an estimated 40 000 will be among children (Statistics South Africa, P0302, 2001:3).

HIV/Aids has also been described as a disease of poverty (Van Kampen *et al.*, 2008:30). As is evident from the mounting literature on the subject, as well as public debate on the issue, the fact that poverty and disease are inextricably linked is widely accepted (Tladi, 2006:369). Research has tended to extend this link to HIV/AIDS. Poor community members in the rural areas are susceptible to HIV infection for the following reasons:

- Poverty and its associated factors, such as low education, reduce the chances of the poor possessing sufficient knowledge of the means of preventing HIV infection.
- Poor woman are less likely to use condoms or to negotiate condom use as a result of both their low education levels and their economic dependence on their partners (Tladi, 2006: 37).
- According to Barnett and Whiteside (2002:1), there is an undoubted relationship between poverty and the development of epidemics of communicable disease and, at the same time, epidemic disease, like any illness, has the potential to increase poverty. AIDS deepens poverty and increases inequalities at every level − household, community, regional and sectoral.

In the rural areas, poverty and HIV/AIDS may affect the CWPDs in that orphans who are taken in by extended family are less likely to enjoy proper schooling. The death of a prime age adult in a household often reduces a child's school attendance as such households may be less able to pay for schooling (especially in the case of CWPDs as transport with a wheelchair is twice as expensive). In addition, sick adults may have reduced their expectations of the returns of investing in their children's education as they would not expect to live long enough to recoup the investment. When a child is taken into another household after the death of

his/her parent(s), the obstacles in terms of the activities pertaining to daily living − being dressed − that CWPDs face on a daily basis, become even greater as the child is not their own (Barnett & Whiteside, 2002:16). Few families want to take on CWPDs.

The standard of education CWPDs receives may be low. This may, in part, be because of the under-resourcing of public education; but it is also often a result of the AIDS epidemic. AIDS increases teacher deaths and it may be difficult to replace these teachers, particularly in deprived and rural communities (Barnett & Whiteside, 2002:16).

Prevalence of HIV in the South African Population, 2008
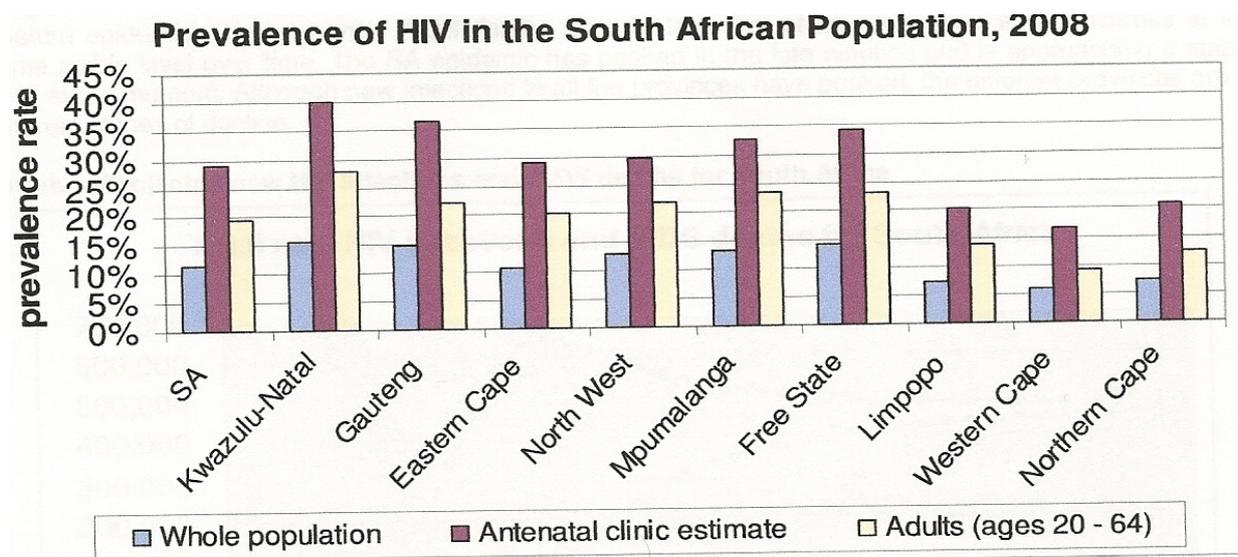
Figure 5.5:   Prevalence of HIV in 2008

The AIDS pandemic is the world's most deadly, undeclared war and, thus far, South Africa has borne its brunt, because South Africa is believed to have more people with HIV/AIDS than any other country (http://www.avert.org.around the world.htm). Neither words nor statistics are able to capture adequately the human tragedy of CWPDs grieving for dying or dead parents, stigmatised by society through their association with HIV/AIDS, plunged into economic crisis and insecurity by their parents' death and struggling without the extra services or support systems in impoverished communities in KwaZulu-Natal. These CWPDs endure overwhelming and largely unmitigated losses, living as they do in rural communities already weakened by underdevelopment, poverty and the AIDS epidemic itself.

5.4.3.1   Bronfenbrenner and HIV/AIDS
Bronfenbrenner's Ecological Theory may have an impact on understanding the way in which people in a community conduct themselves sexually. Using his model we are able to see how HIV/AIDS affects the child's development across all of his/her systems.

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BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON HIV/AIDS

This is the *Microsystem* and refers to the activities and relationships with significant others experienced by the developing child such as family & peers . The child orphaned by HIV/AIDS no longer has the love, guidance and support of parents, and are frequently orphaned, or left with extended family.

This is the *Mesosystem.* A CWPDs who is left orphaned has less chance of having a healthy mesosystemic development such as interaction between school and peers and the community, this is exacerbated by the geographic isolation in the rural areas.

This is the *Exosystem.* In this system local government needs to provide educational training and awareness, and workshops about HIV/AIDS. Clinics and social support services are needed.

This is the **Macrosystem.** Government needs to ensure that the rights of children who are affected by HIV/AIDS and secure health and education are available to them.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development. The HIV/AIDS pandemic has changed entire communities and societies killing millions.

THE CWPD'S

Figure 5.6:   Bronfenbrenner's perspective on HIV/Aids (Adapted from Bronfenbrenner, 1999).

Microsystem

In the microsystem, the child is affected by his immediate environment. This may mean either living with parents who are HIV positive, or losing one or both parents, as well as friends, who are infected. In addition, many teachers in the rural areas have been affected by HIV and there is, thus, a shortage of qualified teachers in these areas. If the parents are unemployed as result of the virus, food and other factors necessary for the child's well-being may be affected. The tragic fact is also that it is often the children themselves who are infected. Families, whether one parent families or grandparents, provide the best environment for bringing up children and, if adequately supported, they would be best able to provide the care that CWPDs orphaned by AIDS require. It is, however, essential that support encompass improved access to the basic services as outlined in the exo and macrosystemic levels. The loss of a parent not only has an immense impact on children but, for most families, probably also means financial hardship. One survey on the impact of HIV on households found that "80% of the sample would lose more than half their per capita income with the death of the highest income earner", suggesting a lingering and debilitating shock at the microsystemic level (http://www.avert.org/aidssouthafrica.htm, 2010:3).

Mesosystem

In the mesosystem, Bronfenbrenner proposed that development during childhood would be enhanced if the different settings in which the child interacts were strongly linked. In the mesosystem this encompasses connections between microsystem, such as home and school. A child's academic progress depends not only on the activities that take place in the classrooms but it is also promoted by both parental involvement in school life and the extent to which academic learning is carried over into the home. If one or both parents are suffering from HIV/AIDS it may not be possible for them to interact with the school, recreation activities and neighbours, as they should. In addition, children from poverty stricken areas often do not have the necessary support and leisure support (going to church or into town) that they need. Families that are socially isolated because of the stigma of being HIV positive and, thus, experience higher levels of stress than parents who are uninfected, may resort to violence, child abuse or neglect.

On this mesosystemic level orphans may exert pressure on the older relatives who become their primary carers; they may have to relocate from their familiar neighbourhood; and siblings may be split apart, all of which may harm their development (http://www.avert.org/aidssouthafrica.htm, 2010:3)

Exosystem

The exosystem influences behaviour in the child's macro and microsystems, although the child does not have direct contact or influence in terms of this exosystemic level. This may be found in formal organisations such as the parent's workplace or health and welfare services within the community. For example, flexible work schedules and paid leave for illnesses associated with HIV/AIDS make it easier for the parents to seek medical care without being penalised. In a study conducted by Steinberg, Johnson, Schierhout and Ndegwa (in Thladi, 2006:370), the households reported that, on average, the sick person was chronically ill for a year before dying. Considering the number of paid leave days to which employees are entitled, such an ongoing illness is guaranteed to result in a loss of income, thus reducing the household income. The possibility, in the future, of being able to attend school, on the other hand, further reduces the chances of alleviating household poverty as both the education and skills necessary for gaining employment are forfeited. Furthermore, it is essential that this exosystemic level be characterised by adequate health services provided by government. A lack of education about HIV/AIDS is also attributed to the exosystem. As discussed above,

there are still many stigmas associated with HIV/AIDS and there is widespread ignorance as to its cause. Bronfenbrenner confirms the negative impact of a breakdown in the exosystem activities.

On the exosystemic level the researcher and the gatekeeper visited he local HIV/AIDS clinic. It was an excellent clinic − clean, well run and well organised with qualified nursing sisters to tend to the community members. The staff at the clinic advises parents on aspects such as

safe hygiene, safe sex, breast feeding, immunisation and other health related matters.

Free condoms are available, although the staff indicated that many men refuse to use them. It also emerged from the interviews that the parents/caregivers felt that there was a 'stigma' attached to be seen at the clinic.

Macrosystem

The macrosystem comprises cultural values, laws and customs as well as resources. The priority that the macrosystem accords to the needs of children affects the support which the children receive at the inner levels of the environment. If there are support services and AIDS awareness is a priority within the community, then there will be more health services and anti-retroviral medicines will be available at the local rural clinics. It is essential that government make this awareness of HIV/AIDS and treatment a priority and also that government mobilise political will and re-allocate national resources as follows:

- Invest in poor communities.

- Allocate resources more fairly, that is, provide adequate resources to the 'hidden' rural areas and, especially, to the CWPDs who, because of their disabilities, are not easily either homed, fostered or taken into homes.

- Increase investment in basic social services, especially education.

- Involve all sectors.

- Coordinate action centrally (UNICEF, 1999:27).

Accurate information on the numbers of children orphaned, where they are, the circumstances of their lives and the nature of their needs, is vital. As an advocacy tool, such information may also help raise awareness about the social impact of HIV/AIDS and promote the realisation of children's rights. On a macrosystemic level strategic action on the part of the government should involve the review and reform of laws and policies dealing with children and, especially, CWPDs.

According to Bronfenbrenner, the environment is not a static force that affects children in a predictable manner but, instead, it is ever-changing. Important life events, such as losing a family member to the HIV pandemic, will have a massive impact on the child.

The above explanation provides a clear understanding of HIV/AIDS in the context of Bronfenbrenner's ecological model. However, unless HIV/AIDS is addressed across micro-systems, the problems that CWPDs face will not be alleviated.

HIV/AIDS and other communicable diseases are, in and of themselves, disabling. Efforts to halt these epidemics should be directly targeted at CWPDs as CWPDs are at an increased risk for contracting these diseases because of the vulnerabilities stemming from both their isolation and their exclusion (Groce, 2005).

In addition, CWPDs who are orphans run greater risks of being malnourished and stunted than their typically developing peers as they will frequently no longer have the special care that they need on a daily basis – special care such as assisted feeding and drinking that takes time and exercising in order to prevent and reduce spasticity of the muscles. This special care may include the fact of being denied an education because they are not able to walk to school as their siblings do and their caregivers are too weak either to carry or to push them to the

Table 5.2:   Population figures in KwaZulu-Natal

Maternal orphans under 15 years, KwaZulu-Natal

Year	Total orphans	Total AIDS orphans	Total non-AIDS orphans
1991	77 770	73	77 697
1992	78 601	188	78 412
1993	79 553	452	79 102
1994	80 724	1 013	79 710
1995	82 280	2 132	80 148
1996	84 558	4 228	80 329
1997	88 084	7 924	80 160
1998	93 603	14 042	79 561
1999	102 108	23 590	78 518
2000	114 732	37 683	77 049
2001	132 440	57 375	75 065
2002	156 048	83 501	72 547
2003	186 196	116 537	69 659
2004	223 023	156 412	66 611
2005	265 861	202 277	63 584
2006	313 039	252 370	60 669
2007	361 398	303 682	57 717
2008	408 367	353 445	54 922
2009	451 525	399 028	52 496
2010	487 920	437 651	50 269
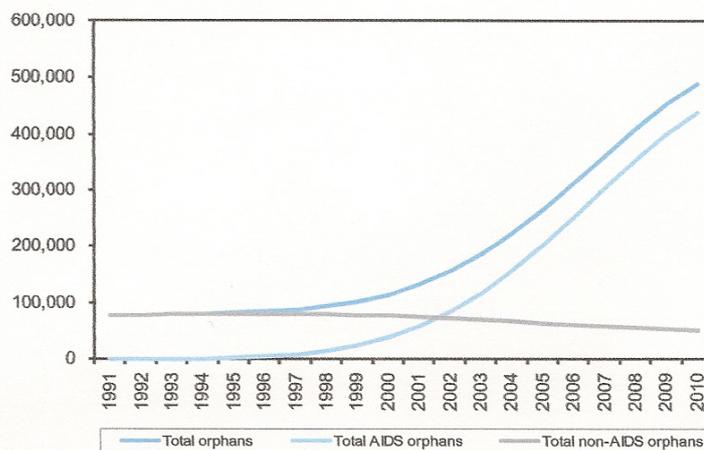
Population pyramid in 2000 and 2010, KwaZulu-Natal

Age	2000 Male	2000 Female	2010 Male	2010 Female
0-4	590 195	581 566	556 662	547 619
5-9	523 884	516 914	557 830	549 897
10-14	502 177	497 508	561 037	554 803
15-19	476 899	477 840	518 447	514 415
20-24	443 089	456 042	491 718	483 103
25-29	393 655	425 824	449 674	409 087
30-34	306 740	355 545	366 341	322 524
35-39	260 916	311 422	266 460	271 568
40-44	228 972	274 046	184 783	224 550
45-49	192 190	223 953	154 325	208 700
50-54	157 771	188 314	137 688	203 928
55-59	115 572	145 085	118 931	184 173
60-64	89 033	117 830	100 772	160 671
65-69	60 013	85 412	73 444	119 217
70-74	40 946	63 833	52 533	87 829
75-79	22 474	38 187	29 624	54 327
80-84	10 910	20 469	15 095	31 721
>=85	4 976	11 719	7 182	18 499
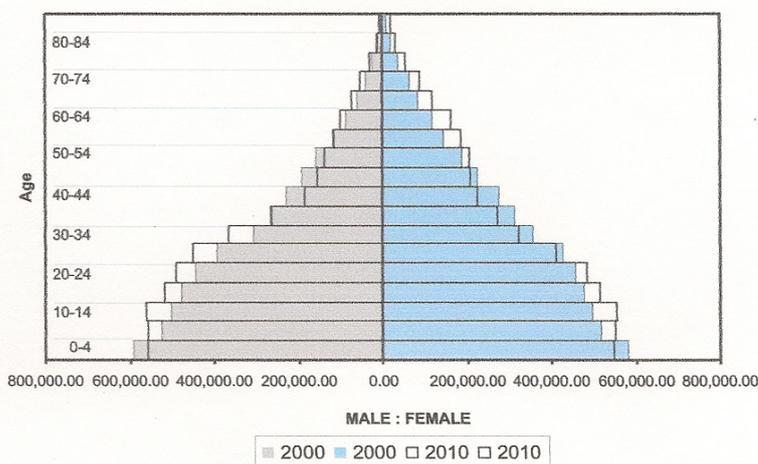
main roads to transport. Extended families are often not able to afford to educate all the children in the household, particularly a CWPDs who may already be perceived as a burden and not worthy of education.

5.4.3.2   Findings

It is extremely difficult, even in an ethnographic, advocacy/participatory study to report the findings relating to HIV. Although the researcher visited the homes of all the research participants and the mothers reported that their husbands had died and, in one case, the grandmother informed us that the mother had died the researcher deemed it not to be ethical to ask if they had died as a result of AIDS. This also applied to children such as Ntombeni who had lost both her mother and her stepmother. One may only assume that these deaths are as a result of the AIDS pandemic.

However, the drawing below of a child indicates that her mother is pregnant, her dad has died, and her mom is not happy. The teacher confirmed that the father had been HIV positive.

'It's just me and my mom.' As a result of the sensitivity surrounding the negative impact of HIV/AIDS the researcher relied heavily on the literature review to confirm what was,

seemingly, evident. Whilst the researcher did attend family gatherings to mourn the passing of young parents, the reason why they had died was never probed.

5.4.4 Lack of early intervention

Almost all current discussions of childhood disability and policies mention the importance of early intervention and prevention. Early interventions include services such as screening, assessment, referral, and treatments that are designed to lessen the effects of disability. Prevention happens when early intervention services reduce the occurrence of additional disabling conditions or when effective strategies are delivered to CWPDs (Aron & Loprest, 2007:73).

Very often, disabilities are detected fairly late in a child's life and this deprives the child of effective treatment. Failure to provide adequate and timely health care (whether as a result of a lack of parental knowledge or poor access to health facilities) may intensify the outcomes of disease with the result that remediable impairments become permanent. However, early identification requires a high degree of awareness on the part of health professionals, parents, teachers and any other professionals working with children. These people should be able to identify the earliest signs of disability and then make the appropriate referrals for diagnosis and management. Accordingly, the CRC recommends that state parties establish systems of early identification and early intervention as part of their health services together with procedures for following the progress of those children who have been identified with disabilities at an early age. In addition, the CRC recommends that these services be both community and home based (micro-exosystemic levels) and also easy to access. The Committee further recommends that links be established between the early intervention services and schools in order to facilitate a smooth transition to formal schooling.

The World Health Organisation (2002) defines health as a state of physical, mental and social well-being which implies, for each individual, the ability and opportunity to function optimally within his/her individual context. By international consensus, children have a right to be helped to achieve such optimal functioning. This right was codified at the United Nations Convention on the Rights of the Child. Under this charter, each child has the right to survival, namely, an inherent right to life, a name, an identity and quality medical care as well as the right to receive special care for special needs. The South African government ratified this charter as far back as 1995 (South African Law Commission). It, thus, follows that, in cases in which children suffer from sub-optimal physical, emotional or social health as a

consequence of disease, disability and/or a lack of developmental opportunities, both the state and society have an obligation to intervene (Wittenberg, 2010:91).

A well-organised, responsive health system provides the framework of community services for individual care. However, a community is the sum of individuals and it is essential that the individual health needs of each child be satisfied. In other words, in the spirit of *batho pele,* each CWPD requires early identification and early intervention. However, without an excellent individual service, an optimal state of community child health is not possible (Wittenberg, 2010:91).

It was evident to the researcher in this study that the state of community child health in the rural areas is far from optimal. Despite the fact that early recognition (screening for physical or developmental delays) and early intervention are inseparable components of comprehensive health care, nevertheless, the early recognition of a health problem is of no benefit unless it is followed by adequate intervention.

The latter was confirmed by research conducted by Laughton (Wittenberg, 2010:91) and co-workers who showed the extent to which the developmental scores of CWPDs from disadvantaged environments lag behind the norm over a period of follow-up. This, perhaps, illustrates the negative consequences of a lack of early developmental intervention for such children (Wittenberg, 2010:91).

Upon identification, it is essential that the systems in place be capable of providing early intervention, including treatment and rehabilitation. This includes providing all the necessary assistive devices that enable CWPDs to achieve their full functional capacity in terms of mobility. It should, however, also be emphasised that these services should be offered free of cost, whenever possible and that the process of accessing such services should be efficient and simple, thus avoiding long delays and red tape (CRC, 2006: C).

5.4.4.1   Findings

It became obvious through both observation and the findings of the gatekeeper, who is a qualified CBR worker that these recommendations of early intervention, treatment and rehabilitation were not being adhered to in the rural areas visited. The lack of both early intervention and follow-up are glaringly obvious in these rural areas. In addition, the researcher's training helped her to recognise, during her visits to the homes of the children who participated in the study, that there were no assistive devices in any of these homes.

There was no special seating, no adapted feeding devices, and no tables at which the CWPDs could sit that would help them to maximise their ability to use their upper bodies and hands. Children diagnosed with a disability were usually sent home after birth, (as may be seen in the answers below) and, apart from the clinic, there were no therapists within reach who could offer the children any type of therapy. This problem was exacerbated by the lack of transport and inaccessible roads, as discussed above. At one home we visited it was clear that, although the child we had interviewed attended boarding school, there were four younger children at home, one of whom was clearly developmentally delayed in all areas. As the mother and father were both present, the gatekeeper inquired what was wrong with the child and the reason why he was not at school. As far as the parents were concerned 'He is not right here (pointing to their heads)' but neither the mother nor the father had had this child diagnosed at a clinic.

This lack of early intervention services was echoed by all the parents/caregivers interviewed.

According to you, what are the disadvantages of living in a rural area?
The answers ranged from 'No rehabilitation resources' to 'Lack of specialists in the local clinics'. One mother whose child had a physical disability as well as a hearing disability stated that she thought it would nice to 'Provide assistive devices like wheelchairs or hearing aids', as her son did not have either a hearing aid or a wheelchair.

These answers reveal the desperation at the lack of intervention for their children at a crucial stage in their lives.

One parent explained in the interview that, when they had complained that there was no orthopaedic specialist in Estcourt, the hospital had arranged for them to go to Cape Town. When they had collected sufficient money they travelled to Cape Town only to be told to come back in a month as the hospital was not able to see the child. This story was confirmed by the physiotherapist at Kwazamokuhle School.

In order to gain some understanding of whether, apart from the physical support they needed for their children, the parents/caregivers received any emotional support we then asked the parents the following question.

Are you aware of any organisations for CWPDs in your area?

Seven parents/caregivers answered with a straightforward "No". The parent/caregiver from Loskop did answer, "Only from Kwazamokuhle School". These answers clearly indicate the lack of any early intervention for their children as well as the absence of any organisations that may have assisted them at this crucial time in their children's development. Furthermore, this lack of early intervention compromises the possibility of the CWPDs ever developing to their full potential, and this, in turn, leads to social exclusion and, in later years, eliminates any possibility of finding meaningful employment and, thus, lifting themselves out of the vicious cycle of poverty. This is the harsh reality for our CWPDs and it needs to be rectified.

Thus, despite government policy, it is very evident that policy and practice are not coming together in the rural areas, regardless of the fact that South Africa is committed to the Salamanca Statement (Walton, Nel, Hugo & Muller, 2009:1). The Salamanca Statement (Priority Area 53) maintains that the success of the inclusive school depends, to a marked extent, on the early identification and stimulation of the CWPDs. It is, thus, essential that early childhood care and programmes for children up to 6 years be developed and/or re-orientated in order to promote physical, intellectual and social development, and school readiness. These programmes have a major economic value for the individual, the family and the society in preventing the aggravation of disabling conditions. In addition, it is essential that programmes at this level recognise the principle of inclusion and be developed in a comprehensive way by combining pre-school activities and early childhood health care.

Almost every description of programmes and services aimed at CWPDs starts with an acknowledgement of the difficulties which families have to confront in navigating the complex system of accessing assistance and support in the rural areas. The parents/caregivers must understand not only the often complex and changing needs of the CWPD, but also where services are available, where and how to access these services, and who pays for them. Sadly, the inabilities of the parents/caregivers in the areas visited in terms of how to advocate for the child's current and future needs were all too obvious. The ability to meet the numerous and varied needs of CWPDs and their families begins with their ability to access services and benefits and it is here that Bronfenbrenner's exosystem may assist the CWPDs in their development. It is essential that clinics, hospitals and CBR workers be provided in these rural areas. In addition, disability grants should also be easily accessible (Aron & Loprest, 2007:75).

This has a knock-on effect because the parents/caregivers are desperate for assistance with their children. This, in turn, results in deep feelings of loneliness for them as they have nobody to whom they may turn for help. In addition, the lack of early intervention as well as the fact that there is no early childhood development schools for CWPDs means that the CWPDs and their parents/caregivers are ignored. Both the CWPDs and their parents/caregivers experience the first few years of the CWPDs' lives as living in isolation.

5.5   THEME 4: ISOLATION

Isolation, powerlessness and physical weakness render both parents/caregivers and CWPDs vulnerable − vulnerability in the physical sense to disease and in the psychological sense to abuse and the destruction of self-esteem. *Isolation* is typically illustrated by a lack of proper education, remoteness and being apart from the wider world. The isolation of the poor in rural areas exacerbates their poverty as social services often do not reach those living in remote areas. *Vulnerability* refers to poverty as a result of the lack of assets needed for decent living. *Powerlessness* contributes to poverty through limiting or preventing access to resources. In addition, there is also often a lack of legal redress for abuses and this, in turn, enhances the weakness of the poor in terms of negotiations (Gumba, 2010:abstract).

5.5.1   Loneliness, isolation and vulnerability.

Bronfenbrenner's multidimensional ecological approach to poverty is further explored by Robert Chambers (1983) who also referred to the notion of poverty as multidimensional referring to the clusters of disadvantage that are so typical in the rural areas. As discussed above, Clause 11 of the Children's Act 38 of 2005 defines the state's obligations towards CWPDs. This is an important piece of legislation which is in line, not only with our country's constitution and bill of rights, but also internationally. In addition, it aims to unite South Africa with the rest of the world and to bring our disability strategy and assistance up to the level of the WHO standards, as well as affirming our assent to the United Nations Convention on the rights of the child. The exclusion of CWPDs in South Africa has now been addressed by the Children's Act.

According to Bronfenbrenner's Model it is not only government and the families of these special children who have a role to play in their lives, but is also the responsibility of community members to ensure that their rights are both protected and upheld. All children,

whether healthy or living with a disability, have a basic and fundamental right to: (Department of Education, 1997).

- Acceptance and love, as well as the opportunity to develop both their social skills and relationships and not to be kept lonely, isolated and vulnerable.
- A home with proper care and in which the child's potential may be realised and participation in social, cultural, religious and educational facilities enabled.
- Be surrounded by people who have patience with those who do not understand their disabilities. This type of understanding will lead to acceptance and, thus, render the CWPDs less vulnerable, more accepted and, therefore, less lonely.

Isolation refers to physical and social isolation or exclusion. People may be physically isolated by the rural locations in which they live – see discussion on geographic isolation. However, isolation may also refer to a household that is remote and on the edge of a community, and which may lack access to either markets or information (Chambers, 1983). However, isolation is exacerbated for the CWPDs in rural areas who are excluded from accessing those services that are essential to their needs. This isolation may also include exclusion from accessing information and education, thus leading to illiteracy and ignorance. This, in turn, may lead to a lack of employment opportunities.

The issue of vulnerability is pertinent to this study. According to Chambers (1983), a household becomes poorer if it has to deal with unforeseen circumstances, such as the birth of CWPDs. This increasing poverty may be exacerbated by natural disasters, such as crop failure and, in this study, by the high cost of funerals as a result of the HIV/AIDS pandemic.

Many of the parents/caregivers of CWPDs suffer from loneliness. This loneliness is often the result of both general poverty and also the geographical isolation of living in a remote rural area.

This loneliness on the part of the parents/caregivers of CWPDS was clearly evident when we visited all the homes in the study as. See discussion on geographic isolation (see Chapter 5 Theme 4. However, isolation may also refer to a household that is remote and on the edge of a community, and which may lack access to either markets or information (Chambers, 1983). However, isolation is exacerbated for the CWPDs in rural areas who are excluded from accessing those services that are essential to their needs. This isolation may also include

exclusion from accessing information and education, thus leading to illiteracy and ignorance. This, in turn, may lead to a lack of employment opportunities.

The parents/caregivers were all on time and waiting for us. Their loneliness was very obvious in the answers they gave during their interviews. However, in addition to the loneliness, the lack of family support was yet another factor that surfaced. One mother stated that 'I feel stressed, because of lack of support, I feel so neglected'. The interviews provided the following answers that indicated the loneliness and isolation experienced by the parents/caregivers.

What was the attitude of your spouse towards you and your child?
The answers to this question varied from the expression of total support on the part of the first parent who became extremely emotional and cried that "He supported him a lot and loved him. Unfortunately he passed away", to expressions of abandonment. Parent/caregiver 3 stated that "He left me during pregnancy, he is not part of this child's life" while parent/caregiver 5 expressed simple acceptance with the words "He left".

Caregiver 3 – a grandmother (mother had died) – stated that 'The father does not accept that the child is disabled, he abandoned the child and quit since then".

These mothers and the grandmother are clearly lonely − single-headed households and lacking both emotional and financial support.

On the other end of the continuum we received the following answers.

Parent/caregiver 4: "He accepted and supported and he helps, he can take transport and water for us." (This answer also emphasises the difficulty involved in accessing transport and the lack of available water − see discussion above.)

Parent/caregiver 7 echoed this acceptance, replying: "Positive and supportive", whilst parent/caregiver six answered that "He accepted her easily".

Parent 8 responded that 'It is positive; he loves him so much he even protects him".

Parent/caregiver 9: "We accepted the situation as is and very much supportive in everything concerning the child and me".

This question was asked in order to ascertain whether the mothers interviewed had a support system. The responses were mixed as some fathers had left while others were very supportive

As illustrated in the drawings below, the children drew pictures which depicted their being excluded from family outings although this may have been as a result of the fact that transport is a problem if children with disabilities are included in an outing with the rest of

the family. It may also have been that their parents chose for them to remain behind because of the logistics of taking them. The drawing below clearly indicates a child and mommy that

are left behind.
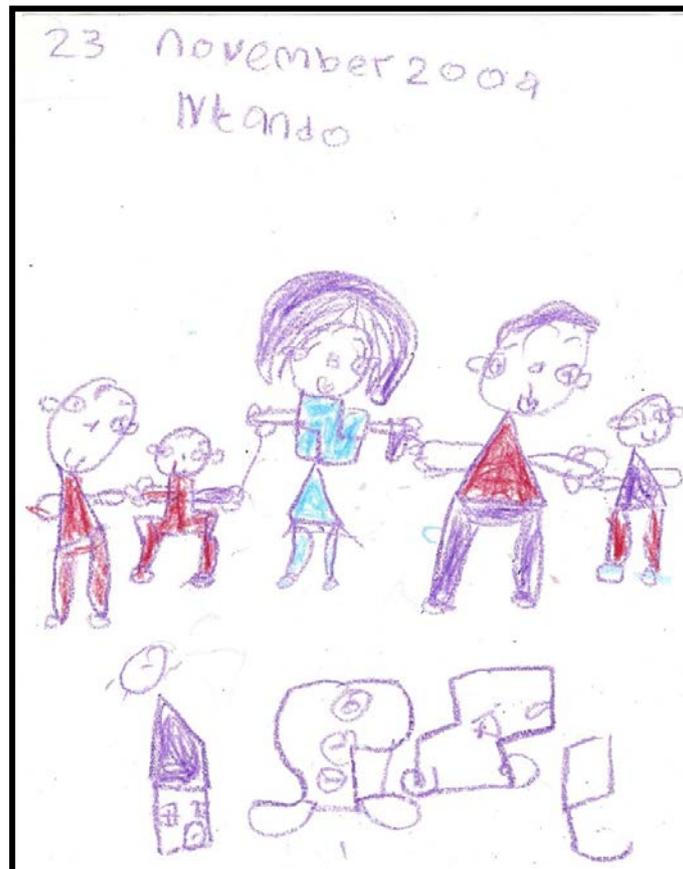
However, as emerged from the interviews there are some families who are supportive and loving and the children come from happy families, as can be seen by the drawing above.

What are the attitudes of your friends towards your child?

Sadly, we received the following answers to the above question. Four of the parents replied that they "do not have any friends"; while another four simply answered "Fine". However, parent/caregiver 9 happily answered that **"**Friends love him so, even caring and even concern".

These answers indicate a mixed response, with four mothers indicating that they had no support to the one mother who indicated that she did, indeed, have support. Nevertheless, four out of the nine mothers expressing loneliness is a high percentage within a small sample group. The researcher experienced extreme difficulty in imagining the daily reality of living in such poverty, in isolation and with no friends. These parents/caregivers are, clearly, blatantly excluded from the community.

5.5.2 The effects of poverty on the socio-emotional development of CWPDs

Development does not occur within a vacuum but is, rather, a process embedded within a context. Bronfenbrenner (1999) is of the opinion that parent/child interactions on the microsystemic level do not always account for the relation between poverty and the socio-emotional functioning of CWPDs. Indeed, poverty itself may result in children experiencing socioeconomic problems with the poverty impeding peer relations, and also being the cause of children either having to attend inferior schools and often, being exposed to unsupportive school environments. Proximal processes on a microsystemic level take place both between parent and child and within the context of peer, school learning and recreational facilities with these proximal processes either facilitating or impeding development. In addition, poverty may affect the socio-emotional development of children in both the mesosystems (linkages between home and school) and in the exosystems (parents' social support groups and communities). Increased support within the social support networks and communities of parents may decrease parental stress within the microsystem at home and, thus, improve parenting practices. In addition, social policies at the macrosystemic level may increase access to economic resources, quality housing, better neighbourhoods, schools, nutrition and health care and may, thus, enhance the proximal processes in the more immediate systems levels and result in better developmental outcomes. Chronosystem, historical and life events, and individual change across the life span may also exercise a significant influence on child development (Eamon, 2001).

5.5.2.1 Findings

Observations within the homes in the rural areas place CWPDs at risk in terms of poor socio-emotional development. All the CWPDs in this study were sent to boarding school at an extremely young age, and healthy development as Bronfenbrenner believed cannot occur on the microsystemic level. It, thus, follows that, on a mesosystemic level, there is no interaction between CWPDs and their parents and their neighbours. This was echoed in the children's answers to the following question:

Do you want to go and visit friends at their houses?
Seven of the nine children answered "No", one answered "Yes", while one was not sure. These answers indicate that interactions were not taking place on a mesosystemic level.

It was evident that the CWPDs interviewed regarded the boarding schools they attended as 'home' with all the children indicating that they were extremely happy at school and that they felt very safe there.

5.5.3 Lack of recreational facilities

One of the cruellest legacies of apartheid is the lack of sport and recreational facilities in the rural areas. However, despite the Reconstruction and Development Programme (RDP) clearly indicating the importance of sporting and recreational facilities for *all* South Africans (RDP, 1994: 3.5.2), for the majority of South Africa's CWPDs, this gross neglect in providing facilities is still continuing. The RDP goes on to state that the removal of obstacles that preclude specific sections of the community (CWPDs) from participation is crucial.

Article 31 of the CRC (2006) stipulates the right of the child to recreation and cultural activities appropriate to the age of the child. This article should be interpreted to include both the mental, psychological as well as the physical ages and capabilities of the child. Play has long been recognised as the best source of the child's learning various skills, including social skills. The full inclusion of CWPDs in the community will be realised only when CWPDs are given the opportunity, place and time to play with other children (children with disabilities and children with no disabilities). In other words, training in respect of recreation, leisure and play should be provided for all school-aged CWPDs, with equal opportunities for their participation.

In addition, it is essential that both competitive and non-competitive sports activities be so designed so as to include CWPDs, whenever possible. Nevertheless, the physical demands of the sport do often mean that CWPDs need to be given the opportunity to participate in exclusive games and activities so as to enable them to compete fairly and safely. It must, however, be emphasised that, when such exclusive events do take place, it is essential that the media play its role responsibly by giving the same attention to such events as it does to the sports for children with no disabilities (CRC, 2006: G).

In the rural areas visited by the researcher there was a lack of safe, supervised, affordable and accessible recreational facilities, not only for CWPDs, but for all the children living in these areas with this, in turn, exacerbating the exclusion of CWPDs from general free play. It was possible to observe typically developing children playing at the river and in the roads, climbing trees, and running and pushing a tyre (popular game), while their peers with

disabilities were merely watching or else they had been left at home. Typically developing children use their imagination and are creative when playing, for example, the popular game which involves collecting frogs, drawing a circle and then putting the frogs inside of the circle. Whoever's frog jumped out the circle first is the winner.

Low slides with sides, smaller climbing frames and small see-saws are all accessible to CWPDs if they are low enough for their parents to lift the CWPDs up. The photograph above depicts a typical recreational facility for *all* children in Thailand. The reason for the photographs being used from Thailand is that as South Africans we can follow the example of the Thais and cater for *all* children in the construction of much needed playgrounds.

an old, but rusted, rocking car that CWPDs would be able to use.

Yet again, CWPDs feel the impact of the lack of recreational and sporting facilities more than their typically developing peers. Bafana Bafana South Africa's soccer team is becoming involved with sport and the nurturing of talent in the rural areas. However, soccer fields generally provide for able-bodied children but not CWPDs. In addition, the RDP does not make mention of sport development for CWPDs in its programme (RDP, 1994: Section 3).

There were no parks, libraries or community centres in any of the areas visited by the researcher. According to Bronfenbrenner, interaction between families and peers and other community members takes place on the mesosystemic level and this lack of facilities results in the healthy social development of CWPDs being placed in jeopardy.

The poor, especially the rural poor, have limited access to information, services, labour organisations and opportunities as well as to opportunities to make their voices heard to leaders and policy makers. In other words, poverty renders them both voiceless and powerless (Swanepoel & De Beer, 2009:7) with the powerlessness being a consequence of being in a weak, negotiating position in terms of those in control, and ignorant of the law because they have no access to appropriate information.

5.5.4 Lack of access to appropriate information and the mass media

Access to information and to means of communication, including information and communication technologies and systems, enables children with disabilities both to live independently and to participate fully in all aspects of life. It is essential that CWPDs and their caregivers have access to information concerning their disabilities so as to educate them properly about their disabilities, including the causes, management and prognosis. This knowledge is extremely valuable as not only would it enable them to adjust to their disabilities and to live better lives, but it would also allow them to be more involved in making informed decisions about their own care.

In addition, persons with disabilities generally have poor access to HIV/AIDS information and services with those CWPDs in the rural areas who do not attend school missing out on school based education programmes. This situation is exacerbated by low literacy rates amongst the caregivers and also the difficulty in accessing the mass media. Although access to HIV testing is available in the rural areas this is, nevertheless, limited, mainly as a result of social barriers and prejudice (see discussion above) with this limited access leading to the high rate of mother to child transmission.

Community-based rehabilitation has been advocated internationally for more than 20 years as the core strategy for the improvement of the quality of life of CWPDs. In addition, CWPDs should also be provided with the appropriate technology and other services, and/or languages which would enable them to have access to all forms of media, including television (7 of the 9 homes visited did have TV, despite no electricity), radio and printed material as well as the new information and communication technologies and systems, such as the Internet. This lack of communication and access to technology is clearly lacking in all rural areas visited.

5.5.5 Birth registration

According to the CRC (2006), CWPDs are disproportionately vulnerable to non-registration at birth. Without birth registration they are not recognised by law and do not exist in terms of government statistics. Hence, non-registration has profound consequences in terms of their enjoying human rights, including citizenship and access to social and health services and to education. In addition, CWPDs who are not registered at birth are at a greater risk of neglect, institutionalisation and even death than those children who are registered and may be accounted for. In terms of Article 7 of the CRC, recommends that states parties adopt all the

appropriate measures necessary to ensure the registration of CWPDs at birth. Such measures should include developing and implementing an effective system of birth registration, introducing mobile registration offices and, for those children not yet registered, providing registration units at schools.

5.5.5.1 Findings

All the children who participated in the study were in possession of their birth certificates as they had needed them in order to attend Kwazamokuhle School. However, there were parents who did admit to us that not all the children had been registered at birth but that these children had only been registered either before they went to school or when the parents had been told that their child had a disability and that they needed a birth certificate in order to apply for a grant. They had cited inaccessibility in terms of transport and understanding the procedures involved as a major problem in the registering of their children.

5.5.6 Violence, neglect and abuse as negative influences in the rural areas of South Africa

"Maltreatment of children with disabilities may be committed by only a few, but the responsibility to protect them belongs to us all" (Mitchell & Buchele-Ash, 2001:239).

This section will explore the deleterious impact of violence, abuse and neglect on CWPDs in the rural communities. All children, including CWPDS, have the right to a safe environment which offers support and promotes their dignity and development. This section will also focus on the impact of violence on the community and on the CWPDs as described by Bronfenbrenner in his ecological model.

This section will, based on a literature review, analyse the way in which violence against CWPDs may be defined, the kinds of violence to which these children are subjected, and the contributory factors/causes of this violence. In addition, issues relating to the disclosure of and responses to violence as well as the prevention of violence will be highlighted. The literature reviewed includes philosophical examinations which attempt to explain the causes of violence, studies investigating the characteristics of both the perpetrators and the victims of violence for the purposes of identification and treatment, case studies, statistical information, analyses of factors which contribute to violence and discussions on the effectiveness of the responses to violence in rural South Africa (Ticoll, 1994:6).

According to CRC (2006), children with disabilities are more vulnerable than typically developing children to all forms of abuse, be it mental, physical or sexual, and in all settings, including the family, schools, and both private and public institutions and the community. In other words, CWPDs are often subjected to mental and physical violence and sexual abuse and, in addition, they are also particularly vulnerable to neglect and negligent treatment since they often represent an extra physical and financial burden on the parents. Their particular vulnerability, as set out in the CRC (2006), may be rooted, *inter alia*, in the following:

- Their inability to move, to dress, to go to the toilet and to bath independently increases their vulnerability to intrusive personal care or abuse.
- Should they have communication impairments, they may be ignored, disbelieved or misunderstood should they ever complain about abuse.
- Parents or others caregivers may be under considerable pressure or stress because of the financial and emotional issues involved in caring for their disabled child. Studies indicate that those under stress are more likely to commit abuse.
- Children with disabilities are often wrongly perceived as being non-sexual and lacking an understanding of their own bodies and, therefore, they may be targets of abusive people, particularly those who base abuse on sexuality.

The protection of children with physical disabilities from violence, exploitation and abuse is an integral component of protecting their rights to survival, growth and development.

The relationship between power and violence is complex and is, in part, influenced by the ways in which violence is defined. Despite the fact that violence is a feature of all societies, the nature of violence and the magnitude of the problem differ across contexts. In addition, social norms influence what people consider as constituting violence and it is for this reason that definitions of violence tend to vary across different societies and communities (Duncan *et al*., 2007:190).

For the purposes of greater clarity, it is essential that the terms *violence* and *neglect* be qualified by other terms that identify the act that is being committed. These terms include:

- Physical violence that includes, but is not limited to, striking, hitting, beating, pushing, shoving, shaking, slapping, kicking, pinching, burning, physical restraints, force feeding and physical punishment.

- Sexual violence that includes sexual contact, unwanted touching and all types of sexual assault, such as rape, sodomy, coerced nudity and sexually explicit photographing.

- Emotional and/or psychological violence that includes inflicting anguish, emotional pain, and distress as a result of verbal assaults, insults, threats, intimidation, humiliation, bullying, teasing and/or imposed physical or social isolation. Emotional abuse also refers to "the failure to provide a developmentally appropriate, supportive environment ... so that the child can develop a stable, full range of emotional and social competencies" (Duncan *et al*., 2007:199).

- Neglect that includes the refusal or failure on the part of a caregiver to fulfil any part of his/her obligation or duty to the child. Neglect typically refers to the failure or refusal to provide such necessities as food, water, clothing, shelter, personal hygiene, medicines and the other essentials of life.

- Abandonment, which refers to the desertion of the child by the caregiver. Abandonment may differ in degree of severity because it may eventually result in life-threatening situations, leading to death.

There are few studies on the incidence and prevalence of child abuse in South Africa with the resultant lack of reliable information impacting negatively on the planning for the provision of services to persons with disabilities. Moreover, existing studies have defined child abuse in different ways and also used different methods of collecting data on child abuse, thus rendering the comparison of results difficult (Duncan *et al*., 2007:200).

The INDS emphasises the attainment of a good and equitable quality of life for disabled children in South Africa. Its main objectives reflect two main pillars. The first pillar refers to the systematic integration of persons with disabilities into all policies, plans, programmes and strategies aimed at enhancing the quality of life of all disabled persons at all levels and within all sectors and institutions of government. The second pillar refers is a coordinated, multi-sectoral, interdisciplinary and integrated approach in the designing and implementation of programmes and interventions that have an effect on all citizens. It is essential that these two pillars be both reliable and informed by up-to-date information on the status and prevalence of disability in the country (Statistics South Africa, 2004/5:6).

In the wake of South Africa's democratic government and with the need to understand the prevalence of disability in the country, certain useful statistics from both the United Nations Development Programme (UNDP) and the Central Statistical Service (CSS) succeeded in

providing some insight into the problem. Nevertheless, there is still little known about the nature, determinants and prevalence of disability in South Africa. The data collected in Census 2001 provided an opportunity to ascertain the number of disabled persons, their demographic and socioeconomic characteristics and their access to basic services in the country (Statistics South Africa, 2004/5:6).

As is the case in many sub-Saharan African countries, South Africa is now beginning to recognise the rehabilitation needs and civil rights of persons with disabilities, the impact of disability activity limitations and participation restrictions, as well as the resulting disadvantages which persons with disabilities experience in terms of the national indicators of health, education and economic prosperity.

Community-based practitioners working with cases of neglect are overwhelmed by the enormity of the problem, high case loads and a lack of resources. Current estimates by POWA (People opposing Woman Abuse) indicate that, in South Africa, there is a child is abused every eight minutes, one raped every 24 minutes and one assaulted every 14 minutes. As in the case of abused women, most perpetrators of violence against children are known to the children (Duncan *et al*., 2007:201).

Violent acts against children are increasing all the time and, whether in the home, in the communities or in society at large, children are being exposed on a daily basis to these increasing levels of violence and abuse.

Children exposed to violence often experienced severe changes in their behaviour, including sleep disturbance, irritability, withdrawal and academic failure. It has been argued that, depending on the development of the child, exposure to violence will produce different outcomes. There are, however, no easy answers as to how violent behaviour develops and it would appear that there is a myriad of factors that may contribute to the development of violent behaviour. These include, inter alia, biological propensities, ineffectual parenting, poverty and cultural milieu. To date there has not been one universal theory that is able to account for the interaction between these various factors. Nevertheless, Bronfenbrenner's ecological system approach poses a possible model for attempting to explain the way in which the various levels within the child and across the environment may interact and lead to violent behaviour. Abuse occurs not only on an individual level (micro level) between the

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abuser and the abused, but is also found at the service provider (meso) and the environmental (macro) levels.

Bronfenbrenner and violence

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON VIOLENCE

This is the *Microsystem.* It is here where the effects of violence in the home are most felt. Poor emotional regulation in parents can be linked to violence, which in turn is associated with negative peer interaction. Parental control is critical in the effort to develop social skills.

This is the *Mesosystem.* The mesosystem consists of linkages in the microsystem. CWPDs frequently do not have opportunities to interact with peers when they are bullied and excluded. Linkages between home and community, and school and peers are frequently absent when CWPDs experience violece.

This is the *Exosystem.* Strong social networks where community members assist in supervising CWPDs can lower incidences of violent behaviour, as well as developing policies of inclusion

This is the **Macrosystem.** This is overall failure of the Government in many of its commitments such as improved policing in rural areas where the absence of police is felt.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development and can contribute to the decline in poverty.

THE CWPD'S

Figure 5.7:   Bioecological perspective on violence (Adapted from Bronfenbrenner, 1999)

In terms of both the **microsystem** and the **mesosystems**, the innermost layers of the system refer to the activity of the interaction patterns within the child's immediate environment.

The family

It may logically be assumed that violent behaviour would be learned from a source with the greatest impact, namely, the family. This phenomenon, which is known as the intergenerational transmission of violence, has been the subject of research for many years with most researchers agreeing that children who witness violent assault are more likely, themselves, to perpetrate violent acts on others as well (Rappleyea, 2009:26).

According to Cohen and Knizter (2004), the following three elements are crucial both to a child's development and to ultimate safety within the microsystem:

- Young children with physical disabilities and their caretakers need to be safe.
- Young children with physical disabilities need to experience warm, supportive, nurturing relationships with their parents and other caregivers.
- Young children and their families need to have their basic needs met.

According to this model, in order to understand the child's development, it is essential to understand that the interactions of the child's environment are bi-directional, that is, adults influence the child's behaviour and this influence has a lasting impact on the child. If a child witnesses his father constantly abusing his mother this may have a lasting impact on the child and the child may come to perceive this abusiveness as acceptable. Such attitudes and impressions may pass from one generation to another. In addition, CWPDs may be abused by siblings, neighbours and at school. Within these systems, what happens within one system influences another system. Consequently, if violent behaviour occurs within more than one setting, violence becomes a consistent part of the child's repertoire. An understanding of these systems may play a major role in understanding the development of violent behaviour.

Peers and the school connection

There is an extremely thin line between neighbourhood characteristics, the school environment, and peer relationships. In the study by Rappleyea (2009) he shed light on those factors that were common to those schools that experienced high rates of assaultive behaviour on the part of their learners. These factors, which are characteristic of many rural schools, include the following:

- Large school and high learner/teacher ratio
- Low operating budget
- Inconsistent rule structures

The influence of peers both at home and at school also plays a role in the perpetuation of violence. Nevertheless, recent evidence supports the notion that even negative peer influences may, at least, be partially absorbed by other supportive and protective factors both at home and within the community (Rappleyea, 2009:24).

The next system to be discussed is the **exosystem.** The exosystem involves those social settings that do not actually contain the children but still affect their experiences in their immediate setting. These social settings include police groups, social development and active centres for criminal justice and outreach programmes that further the child's human rights

through access to justice. Indirectly, if the parents' employer is not understanding and does not allow the parents time off from work when this is justified, these parents become stressed and this may lead to abusive acts and resentment. In addition, it may also lead to lack of supervision of their children.

Research in Britain has shown that families who are affected by unemployment, overcrowding, and poor social networks manifest an increased incidence of child maltreatment (Social Policy Research Centre2002: -15). Strong socialisation influences may take place within the community (Rappleyea, 2009:23) with neighbourhood disadvantage being one of the strongest correlates to adolescent violence. Conversely, strong social networks in terms of which community members assist in supervising the youth demonstrate dramatically low incidences of crime and violent behaviour. On the other hand, generally disadvantaged neighbourhoods have higher rates of crime. Furthermore, studies suggest that neighbourhoods with weak social controls have a higher incidence of violence. This is especially true is rural areas. In addition, the incidence of violence is three times more likely to occur in low income neighbourhoods (Appleyea, 2009:24). It is important that, at this exosystem level, young children and families encounter both service systems that are both welcoming and culturally respectful and service providers with the cultural knowledge, skills and attitudes to be able to help them (Cohen & Knizter, 2004:ii).

The **macrosystem** comprises the fourth subsystem. The macro level of abuse or violence takes place when there is a lack of community involvement, a lack of education on the part of the general community on what constitutes abuse, as well as a lack of effective legislation to protect CWPDs. In terms of Bronfenbrenner's 'macrosystem', several researchers maintain that the cultural environment has a profound impact on the development of violent behaviour (Appleyea, 2009:17). Indeed, culture may be an intimate web of shared experiences, proximity, and socially constructed values. If schools emphasise safe spaces for children, then these safe spaces will benefit the children. It is in respect of this macrosystem that the Bill of Rights and the Constitution, if implemented, will protect the children of South Africa and it is in respect of this system that Human Rights Commission Act 54 of 94 was promulgated.

If teachers are to teach and learners are to learn then a safe learning environment is essential. Everyone within a school is entitled to a reasonable measure of security with regard to both their persons and their belongings. Broadly speaking, in terms of Bronfenbrenner's model, all

South Africans are responsible for the well-being of South Africa's children. However, despite the fact that the roles of parents and the State appear to be clear, duty bearers and others often violate children's rights, and the services are, all too often, inadequate.

Nevertheless, the researcher in this study did not observe or hear of any violent happening during her stay in the rural areas.

In order to establish whether the CWPDs were the targets of violent acts we interviewed those closest to them (their family) with the parents/caregivers being asked the following question.

Do you feel afraid that a violent act might be committed against your child?
Seven of the parents/caregivers replied in the affirmative – they were, thus, worried that a violent act may be committed against their children whilst two of the caregivers replied in the negative. Seven of the nine parents indicating that they feared a violent act may be committed against their children is a high proportion and indicates they are aware of the vulnerabilities of their children. However, the parents also indicated that they had access to the police and that, if necessary, the law would take its course. As be seen in the answers quoted below they also indicated that the community leader would offer assistance'

Do you feel that, if a violent act were committed against your child, you have the necessary support?
"Yes. I will report it to the police." (2 x)

"Yes. Report it to the community leader."

"I have the support from my family. I will move her to my mother's place."

"Yes. Let the law take its course."

"Yes, police, courts and community leaders."

"Yes. I can report the case, talk to the family and community leaders."

These seven answers indicate that the parents do fear that violent acts may possibly be committed against their children and that this is a problem. It was both interesting and pleasing to hear their belief in the strong support they felt they would receive from both community leaders and the local police. This is, however, in contrast to the literature findings

that the rural communities generally have no access to the police and that violent acts would be ignored. This support for the community on the part of both the community leaders and the police is an excellent example of the involvement of the entire community at the micro- and mesosystem levels with the strong police force in the area representing the exosystemic level and the laws and policies made by government to protect CWPDs representing the macrosystemic level. This is also in keeping with Mitchell and Buchele-Ash view that the entire community needs to be involved in the protection of the child (2000:239).

The researcher interviewed the social worker at the Estcourt Police Station about any violent acts committed against CWPDs. She reported that one case only had been reported to her in the preceding year. It must be noted that the social worker at the police station is extremely accessible to the community members.

The majority of CWPDs interviewed did not perceive violence in the community as a major threat and, on the contrary, they were more concerned about being teased, laughed at and excluded.

Of the CWPDs interviewed, one only (Tombi not her real name) indicated that her father and her brother beat her, but she also indicated that they 'dealt' with anyone who teased her. The researcher and her gatekeeper were of the opinion that this lack of violence may be as a result of the fact that most of the children interviewed were still young. It is for this reason that the researcher felt it was not possible for her to ignore the literature findings and she, thus, deemed it necessary that violence be included as a negative influence on the CWPDs. The fact that one child had had her arm broken by her peers at a mainstream school and one child was sexually abused is sufficient to confirm that violence against CWPDs does exist. The researcher also bore it in mind that the sample used had been small sample (nine children) and that three of the nine had been abused or violated in some way. The fact that, during the term the CWPDs are at Kwazamokuhle School means that they are safe, at least during term time.

Only one child, who had, as confirmed by his teacher, been sexually abused, indicated this in *his* drawing (below) of the family.

5.6 THEME 5: LACK OF ACCESS TO SCHOOLS, EXCLUSION AND NEGATIVE ATTITUDES TOWARDS CWPDS

Poverty and all its dimensions that impact negatively on the CWPDs have been explored in depth. However, as debilitating as poverty is for the CWPDs, negative attitudes are equally, if not more, debilitating. Poverty, disability and inequality are multidimensional issues that continue to require intervention.

BRONFENBRENNER'S BIOECOLOGICAL PERSPECTIVE ON NEGATIVE ATTITUDES TOWARDS CWPDS AND THEIR EXCLUSION

This is the *Microsystem.* It refers to the immediate realtionships with the child's family, parents and siblings. Parents who accept their CWPDs and have a positive attitude towards their child and include them in all family activities have a healthy developmental outcome.

This is the *Mesosystem.* The family who include their CWPDs in all activities and involve them in the community and neighbourhood and are involved in the school promote a positive developmental outcome for their children.

This is the *Exosystem.* Local government who provide opportunities for CWPDs to be included in the community and in schools promote acceptance and inclusion.

This is the **Macrosystem.** Government must ensure that policy and practice to meet and ensure that CWPDs do not experience exclusion at mainstream schools as they currently do.

This is the *Chronosystem* and involves temporal changes in ecological systems or within individuals, producing new conditions that affect development. At present SA is following international equality of all PWD and CWPDs.

THE CWPD'S

Figure 5.8:   A bioecological perspective on negative attitudes towards CWPDs and their exclusion (Adapted from Bronfenbrenner, 1999).

5.6.1   Negative attitudes

The aim of this theme of negative attitudes is to offer a distinctly South African agenda for the understanding of the negative attitudes towards CWPDs within the black communities in rural South Africa. It is essential that an understanding of disability from a black, rural perspective both reflect and meet the local needs, local knowledge and local experience (Watermeyer *et al.*, 2006:10) as this will systematise how CWPDs in the rural areas of South Africa remain excluded in terms of both mainstream education and social activities. Despite the fact that, as discussed in chapter 3, South Africa has embraced inclusion this chapter will show that the CWPDs in the rural areas of KwaZulu-Natal are excluded and in peril and that the goal of both educational and social inclusion is far from being realised. This section will present the findings of the researcher on the exclusion of both the CWPDs and their families. Furthermore, it will show that the resources that are needed to promote inclusion must be

matched with political will, and that it is essential that constitutional pressure continue to be exerted on the government to force government to fulfil its obligations.

The daily reality of life for CWPDs and their families is frequently one of discrimination and exclusion. The discrimination they endure may be either direct or indirect. Direct discrimination takes place when a child is deliberately treated differently from a typically developing peer. Although indirect discrimination may be unintentional, its effects include the negative attitudes and inequality experienced by CWPDs.

Figure 5.9 Below: How negative beliefs result in negative attitudes

<u>**Situation**</u>

Meeting a child with a disability

<u>**Beliefs**</u>

Caused by witchcraft

Parent violated traditional standards and/or values
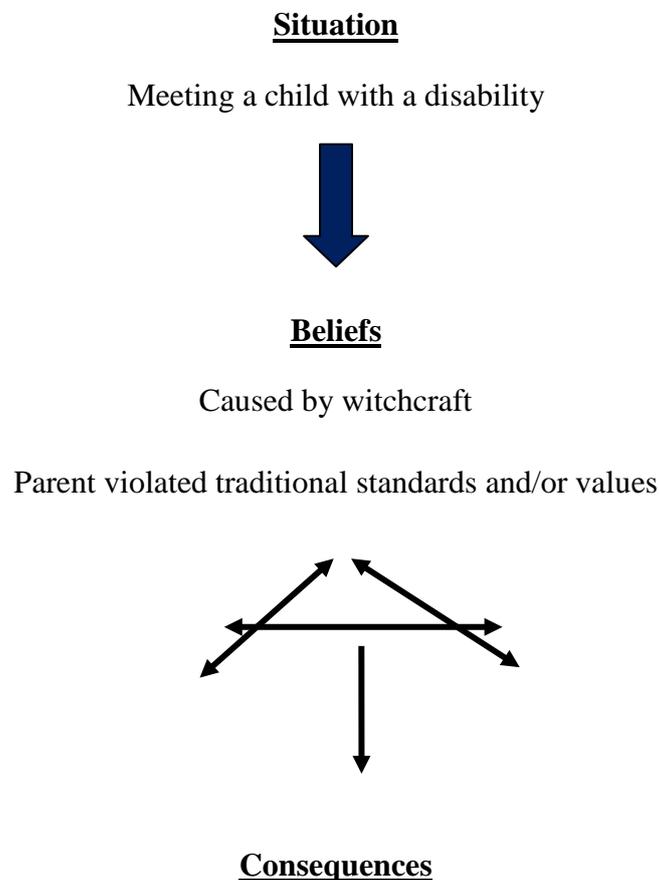
<u>**Consequences**</u>

Short term:
CWPDs in the rural areas are hidden.

Long term:
CWPDs do not participate in mainstream, formal education and, consequently, their development in several areas is impeded:

This figure (5.8.1) illustrates how 'DISABILITY' deteriorates into 'INABILITY' when the disability is not understood or accepted

Disability in South Africa, particularly in the rural areas, continues to be surrounded by stigma and prejudice. Having a child with a disability is still associated with punishment, curses and failure with the parents of CWPDs often experiencing ostracism. The birth of CWPDs doubles the likelihood of abandonment. This was evident in one interview conducted when the father had abandoned the family rather than remain with CWPDs. In rural areas, it is often the wife who is blamed for the impairment. Furthermore, this abandonment of CWPDs is not frowned on and, indeed, it is often condoned by local communities (Landsdowne, 2002:8). However, Anderson's findings (2004:4) contradict the above and Anderson is of the opinion that African folklore often promotes attitudes of tolerance and respect. Nevertheless, disabilities are often feared by the community as disability may be associated with supernatural forces, such as the god's anger at a parent for wrongdoing. In 1996 Hops conducted research into negative attitudes towards CWPDs (Grol, 2000:7) and his summary of these negative attitudes is still relevant in terms of understanding these negative attitudes that still do exist in the rural areas.

It emerged from informal conversations that certain community members believed that an offended individual could be cursed by a witch doctor (*Sangoma*) and that this curse caused a baby to be born disabled. This finding is confirmed by Anderson (2004:5).

In view of the fact that the *sangomas* are often used to treat CWPDs, the researcher decided to interview three *sangomas* in order to gain an insight into their knowledge of disability and their perceptions.

Interviews with traditional healers (*sangomas*) (3 were interviewed)

What do you think of when you think of disability?
Sangoma no. 1 was about 90 years old − She was not very sure of how old she was. She replied "It is very painful and depressing thing that one with a lot of unanswered questions. It is a *curse* that needs traditional or cultural practices or to perform ancestors' rituals". *Sangoma* no. 2 was more enlightened and answered "They are accepted, even by some of my clients". The final *Sangoma* we interviewed confirmed our conviction that belief in witchcraft does still exist. As portrayed by her answer her attitude was extremely negative − "They are

not recognised because everybody thinks that they do not have a future and are not productive".

These answers ranged from partial acceptance to non acceptance. This finding is in keeping with Kisanji (in Anderson, 2004:4), who states that, while there is an element of respect, some adults and CWPDs are still feared.

What do you think are the causes of disability?
> I believe in being bewitched during pregnancy or may be the cause of depression or being involved in a car accident during pregnancy. I also believe in hormonal changes during pregnancy or any medical history during pregnancy, including failing of ligaments and so forth, or is an inborn thing.

> I believe in evil spirits during fertilisation to both parents and have a bad impact to the unborn baby. I also believe that it is a punishment from the ancestors and God.

> Punishment and, from my experiences, witchcraft"

These three answers all indicate a belief in witchcraft.

The next question was designed to ascertain whether the sangomas believed that, after a parent has taken CWPDs to the *Sangoma* and a ritual has been performed, the child may become better.

The oldest of the *sangomas* answered "Yes! Yes!" She became extremely excited about this and more excited about the prospect that we understood the true cure for disabilities. She insisted on performing a ritual on the researcher to take away all aches and pains.

The second S*angoma'*s answer in the affirmative underlined the firm belief that had been evident in her first two answers, namely, that the cause of disability was, indeed, due to the ancestors and evil spirits. Finally, the more enlightened S*angoma* explained to us that the cause of the disability was important and replied, "Yes, but only sometimes". She explained that, if the disability was not related to the ancestors, then the parents should take the child to the hospital.

These interviews yielded the information that negative attitudes and perceptions, as well as discrimination, stigmatisation and marginalisation, still exist. Nevertheless, members of the community are still open to accepting CWPDs and there are both disability awareness campaigns and posters explaining disabilities visible in the rural areas at schools and clinics. This may have contributed to a change in the negative perceptions, as reported in Baloyi's research study in 1997 (14 years ago), on Black Community Attitudes, is to the researcher's findings of greater tolerance, understanding and acceptance.

The findings from this research study are in keeping with the findings of Anderson (2004:2) to the effect that recent decades have witnessed a considerable improvement in the way in which CWPDs are viewed. Concerns for social justice, disability awareness and the promotion of equality are all promoting a more "enlightened" attitude towards CWPDs. However, as was evident from the answers elicited from the parents/caregivers, community leader and *sangomas*, superstition does still exist. McConkey and O'Toole (1995) are in agreement with this assertion and comment that CWPDs are still victims of superstition.

Nevertheless, it is essential that the efforts to create an educationally and socially inclusive society continue. Members of the OAU (Organisation of African Unity) have adopted the African Charter on the Rights and Welfare of the Child (Kaime, 2009) which affirm the right of CWPDs (Article 3) to protective services under conditions which would guarantee their dignity, and encourage self-reliance and active participation in the community. This charter seeks to ensure opportunities that are designed to promote the fullest possible social integration of CWPDs.

The community leader, who is both highly respected and influential in the area, was interviewed in order to gain an insight into his understanding of CWPDs.

According to your view, what are the advantages of placing CWPDs in a mainstream school?
"For integration purposes, it is good. In a special school they have enough resources and accessible buildings and assistive devices for CWPDs."

Describe the community's attitudes towards CWPDs?
"Initially, parents used to hide their children but now things have changed, because Kwazamokuhle has changed community attitudes towards CWPDs and now they accept them."

What do you think are the causes of disability?

"Lack of health information during pregnancy, taking alcohol and car accidents."

Do you think that the disabled are bewitched?

"That belief is still there in some cases."

Do you think disability is a punishment or curse?

"Yes."

Are the parents of CWPDs bewitched?

"Yes."

Are the parents witches?

"Yes, some still have that belief, if not all of them"

Do you involve CWPDs in community activities?

"Yes, there is a community team that consists of CWPDs and non-disabled ones."

Do you think CWPDs have special rights?

"No, they have equal rights."

These answers proffered by the community leader may be sympathetic but, nevertheless, they do indicate his view that CWPDs may be either bewitched or cursed. However, the leader did also indicate clearly that the attitudes towards CWPDs have certainly improved.

According to the literature most people in the rural communities of South Africa believe in the existence of witchcraft and in its power. Parents/caregivers were questioned on their attitudes towards CWPDs in order to determine whether they believed that disabilities are still associated with witchcraft. In other words, these questions were intended to assess whether the parents/caregivers believed in witchcraft. It was interesting to determine what the parents believed and whether their children had been exposed to western traditional medicine or to that of the traditional healers.

Once the community has accepted that disability is socially constructed, the questions then arise as to the value which contemporary society accords to disability and to the way in which CWPDs are perceived (Sloth-Nielson, 2008:302). The CRC Committee (2006, Para 31) has noted that some cultures still view children with any form of disability as a bad omen and that they may "tarnish the family pedigree".

The following set of questions was asked to the parents/caregivers.

Do you think the disabled are bewitched?

No, it's God's will, I have no enemies who could have bewitched me, I was not cursed and did nothing wrong" This sentiment was echoed by seven of the parents/caregivers with one mother only replying in the affirmative.

Do you think as parents of CWPDs you are bewitched? And Do you think disabilities are a punishment or curse?

Five of the parents/caregivers answered in the negative whilst one mother blamed herself for her child's disability − "Yes, I went to visit my boyfriend during his mother's death when I was pregnant, I then gave birth to a child with a disability". Two of the parents/caregivers answered in the affirmative.

Four parents/caregivers firmly believed that disability is a punishment or curse.

As regards the aetiologies of physical disabilities, Baloyi (1997) postulates that the major aetiologies are ascribed to taboos and witchcraft. Kisanji (1995), however, cautions that certain literature on disability in developing countries may overemphasise the presence of negative attitudes towards CWPDs. He asserts that the general pattern of overt community reaction has been one of sympathy and acceptance with the community fulfilling basic needs such as shelter, food and clothing at the extended family level, and also allowing CWPDs to participate in community institutions and activities.

Nevertheless, he notes that attitudes towards CWPDs in African communities do vary, according to the type, cause and severity of the disability. In view of the spiritual meaning attached to the birth of a child in the traditional African belief system, a mother may be blamed when a child is born with disabilities. A significant disproportionate number of children with disabilities live in single parent families because of fathers abandoning their families when a child with disabilities is born (Sloth-Nielson, 2008:302). This finding was echoed in this research study as one father had abandoned the mother.

Attitudes affect the way in which we think about CWPDs and act towards them and they have implications which are both noticeable and important. Overcoming negative attitudes is a challenge in every country around the world, from the most developed to the developing, and this includes South Africa.

All negative influences are debilitating but, in addition, negative attitudes and exclusion are damaging in all respects, as such attitudes not only exclude the child from both community life and educational facilities, but also condemn the child to a life in which he/she is not able to improve his/her own living conditions and status. Exclusion is unique to the CWPDs as, despite the fact that all children may experience the effects of poverty and lack of resources, it is the CWPDs only who experience stigmatisation, marginalisation and exclusion in the context of and belief in witchcraft.
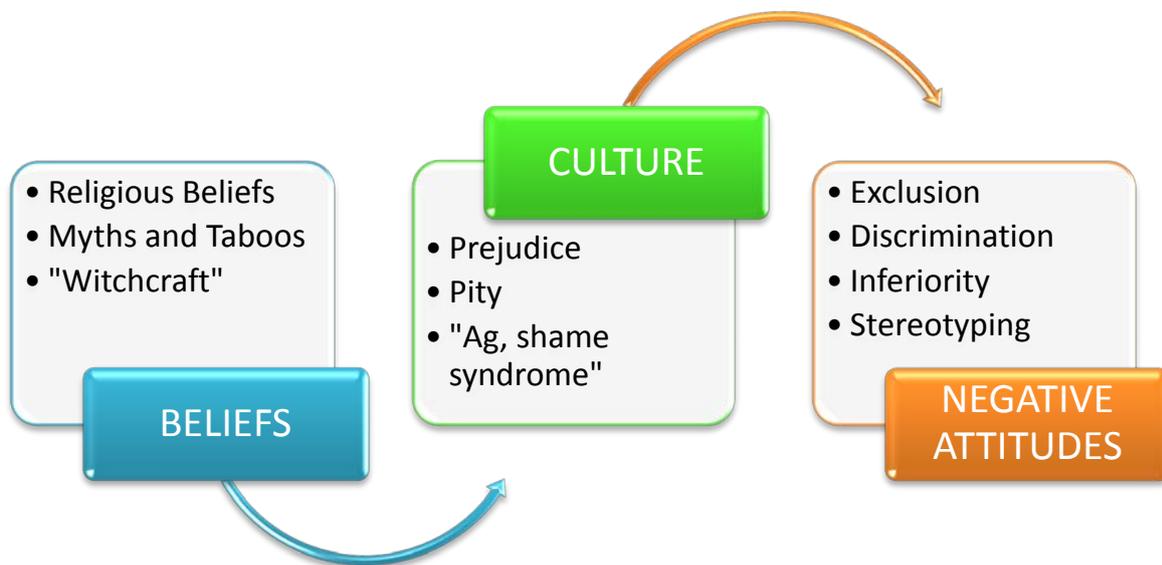
Figure 5.9:   The effects of beliefs and culture on negative attitudes towards CWPDs

Bronfenbrenner(1999) emphasises the necessity of the child's being involved in the family and school, neighbours and peers as well as necessity of the parents' being involved. In addition, he stresses that both the micro- and the mesosystem are crucial to the overall development of all children and their acceptance in the community. CWPDs face their disabilities everyday on a microsystemic level and on a macrosystemic level − from non-acceptance on the part of their peers and families to physical barriers in buildings and systemic barriers in employment and civic programmes. Nevertheless, the most difficult barriers to overcome are the attitudinal barriers towards the CWPDs. Whether from ignorance, misunderstanding or hate, these attitudes prevent children with disabilities from achieving their full potential. The most pervasive negative attitude involves focusing on the child's disability rather than on the individual child's abilities.

Firstly, all the CWPDs who were interviewed were already being educated apart from their typically developing peers as the CWPDs were at a special school. In addition, the fact that this special school was a boarding school meant that the CWPDs had no contact with typically developing peers unless they were taken home over weekends. No CWPDs were seen at any clinics, in the roads or even in the shops. It was, thus, as though CWPDs do not exist. Also, none of the mainstream schools in the areas visited catered for CWPDs. Nevertheless, as is indicated in the following answers, the parents did not want their children in mainstream schools.

Do you wish your child to be separated from mainstream schooling?
"Yes"

"No, because she was not coping and the teachers advised us to take her to Kwazamokuhle School. Since then she is progressing a lot."

"Yes, because is a special school. They have all the resources and understanding and his progress report is good."

"Yes, I am happy about Kwazamokuhle because at this school they have all the facilities for CWPDs and they understand our children's disability and they have specialists and they even have a nurse."

"Yes, because mainstream schools do not have enough facilities and children are overcrowded."

"I want him to be in at a special school. They take good care of him and nobody will laugh at him."

"Yes, Yes."

"Yes, because they are discriminated and labelled. I like him to remain in the special school like Kwazamokuhle."

"There is no reason for them to be there (in a mainstream school) because they are discriminated and labelled. As a result, they will end up not having an interest in schooling."

None of the parents wanted their children to attend a mainstream school, mainly as a result of their previous experiences at mainstream schools as regards resources and a lack of

understanding on the part of both the teachers and peers of their children's disabilities. The parents all felt that their children needed special care, in general, and also within the school situation. Clearly, the parents realised that educational exclusion was the best for their children as their experiences of inclusion in the rural areas had been disastrous. However, it is a debatable question as to whether parents should be able to choose what they feel is best for their children. The parents were also concerned that was no high school in the area for the CWPDs to attend.

One parent summed up specialised schools for us in one sentence.

"They get special treatment and they improve in all facets of life. They even gain confidence since they are the same."

The following questions were asked of parents/caregivers in order to ascertain the perceptions of the community towards the CWPDs.

How would you describe CWPDs?
Mother 1 commented that they are "Emotionally abused because of physical limitations", while mother two stated that the CWPD is, "A child who has challenges in life". This last sentiment was echoed by mother 3 who referred to the CWPD as "A child living a different and difficult life. The grandmother was of the opinion that a CWPD is "A child who needs a lot of support, not overprotection". Mothers 7 and 9 answered respectively "It is an unhealthy child, physically and mentally" and he is "A child with a lot of problems"

One mother's answer was heartbreaking − "My heart is still aching so hard it still feels like it is bleeding blood. There are so many problems for us all."

All these answers refer to the medical model discussed earlier with the parents clearly perceiving the CWPD as both the problem and as experiencing problems. In addition, they all foresaw a bleak life ahead for their children. Mother 4 indicated the lack of support her child is receiving as she wanted her child to be independent.

The researcher interviewed parents/caregivers in depth as regards teasing, exclusion and neglect.

How are CWPDs treated in your area?
'some are not accepted."

"Children are laughing at them and others are teasing them."

"They laugh at her, especially her age group, they isolate them."

'some people ill-treat them and some treat them nicely."

"They laugh at them and they are not accepted as part of their community. They even label them according to their disabilities. They have no value at all."

How could people in your area help to improve the lives of CWPDS and include them in all facets of the community?
Mother 1 − "They should treat them with dignity and respect."

Grandmother − "By loving and respecting them."

Mother 3 − "By accepting them because they are the same as us, they are God's creatures as well."

Mother 9 − "They need to involve them in everything they are doing to make them feel that they are important."

The researcher had anticipated answers referring to offers of financial aid or else offering to include the CWPDs in a community event. However, the answers clearly indicated a positive and accepting attitude towards their children − in essence, what the parents/caregivers wanted.

Furthermore, all the answers are typical of what Bronfenbrenner advocates on a mesosystemic level, namely, that being part of the community, schools, the neighbourhood and the parents and is crucial in terms of the need for interaction on the mesosystemic level.

Initially, we had wanted to interview all nine of the children whose parents/caregivers we had interviewed but it was not possible to interview all of them as one was cognitively delayed and one had gone to a clinic for the day. However, the other seven children were interviewed with the interviews taking place at the school, with the social worker present and the gatekeeper conducting the interviews in Zulu. Both the researcher and the gatekeeper deemed it sufficient to interview just these seven children as saturation was reached. In addition, the interviews were extremely time–consuming, as the interviewer had to establish a rapport with the children and, also, the interviews were all conducted individually with the gatekeeper

translating the content to the researcher throughout the interviews in order to ascertain whether the researcher wanted to ask any extra questions.

As a result of the fact that the questions had to be adapted to the children and also the radically differing circumstances of each child a few answers only will be discussed. Flexibility is an essential part of qualitative research and we were, indeed, forced to make some last minute adjustments. All the interviews were extremely relaxed with both the interviewer and the gatekeeper introducing themselves, explaining to the children the reason why they were there and discussing their families or dogs (we had already visited their homes). This informal chatting with the children also gave us an understanding of the children's cognitive abilities and level of understanding in terms of the questions and answers.

Two questions only were asked of each child in order to ascertain whether they had been confronted by negative attitudes and whether they wanted to remain at a specialised school. All the names are pseudonyms.

- Have you experienced any violence or teasing away from this school?
- Do you want to stay at Kwazamokuhle School?

Twin girls (12 years old)

This question was posed to the two girls who are mildly cerebral palsied and had been in a mainstream school. They revealed that they had been in a mainstream pilot school(a school that was supposed to have support from the Department in including CWPDs) for three years. During this time they had continually been taunted that they had AIDS and that that was the reason why they looked as they did, they had had food thrown at them and had not been allowed to assist in helping in the preparation of the feeding scheme at the school as they had volunteered to do. They had reported the incidences to both the educators and the school principal and, finally, their grandmother had spoken to the principal, but all to no avail. When one of the girls had had her arm broken they had transferred to Kwazamokuhle School.

They were clearly aware that both adults and children are cruel and prone to teasing them. They also revealed their fear of being raped − an extremely frightening and sad aspect with which to have to live at their ages.

Despite the fact that, as they need very little physical assistance and no adaptation of physical resources, they could have coped at their mainstream school, they are happy at their new school.

LINDE (boy of 10 years)

Although Linde does have best friends he revealed that he does get beaten in the community by his peers and that they swear at him. This makes him sad although he does tell his father about it. He is happy at Kwazamokuhle School because nobody teases him – this echoed the words of one parent who had divulged that all the children are the same (all with a disability).

TOMBI (girl of 15 in Grade 5)

Tombi's story was extremely sad as both her mother and her stepmother had died. Accordingly, her only caregivers are her father and brother, who are both abusive to her. Her father has also refused to apply for a disability grant to assist her. She is happy at the boarding school because she feels safe there. She also revealed that she is teased in the community although, when she tells her father, he "deals" with them. At the time of the interviews we were approaching the July holidays, when she would have to go home, and the staff at the school revealed to me that she had started to show signs of depression and anxiety.

THANDI (girl of 11years)

Thandi has mild cerebral palsy. Nevertheless, she is an amazingly intelligent child who revealed to us many negative influences that we had not even anticipated. However, she has friends and is happy at school as she is not teased − her other friends have disabilities so they are all equal − and they are very well looked after at school. She was extremely eloquent and had a vivacious personality.

She revealed to us that she was HIV positive and that she was extremely upset, both because she would have to rely on medication for life and also because of the stigma attached to being HIV. She was also extremely angry about the fact that her mother had died. Therefore, in addition to her physical disability, Thandi has to contend with AIDS. Her goal in life is to be able to give motivational talks about HIV/AIDS and the necessity of being tested and taking the medication in order to live a normal life. She, thus, perceived her HIV status, and not her disability, as a major problem in her life.

Both the gatekeeper and I were awestruck by the intelligence of this child who despite coming from a poverty-stricken home where there is no radio, television, computer or access to books had such knowledge. She is well taken care of at Kwazamokuhle School and wants to stay at the school. However, the fact is that a child with her level of intelligence and who requires minimum assistance should be in a mainstream school where she is not teased. The cruelty of both exclusion and negative attitudes, which emerged so clearly in this interview, saddened us all.

The interviews with the other children indicated that, at some stage, these children had all been teased but that they were happy in the safe school environment at Kwazamokuhle School. They all indicated they did not want to go to mainstream schools and became stressed when asked whether they would like to attend the same school as their siblings and other peers.

The answers of these children corroborate the findings of Clacherty *et al*. (2004:6), which also indicate the stress, unhappiness and vulnerability of CWPDs. All the CWPDs in this study have been abused or teased at some stage in their lives and they all echoed their parents' sentiments about wanting to remain at Kwazamokuhle School.

5.6.2   Attitudes of mainstream teachers towards CWPDs

Having interviewed the mothers/caregivers and the CWPDs regarding mainstream schools the researcher decided to visit a mainstream school to investigate the attitudes of the teachers there.

The attitudes of the teachers at mainstream schools and their willingness to participate in the implementation of inclusive education as regards CWPDs would clearly play a part in determining whether the implementation of an inclusion policy would be successful or not. The attitudes and values of teachers would play a central role in the successful implementation of inclusion. The way in which the teachers perceive competence in inclusive education and the values they hold with respect to CWPDs form their attitudes towards inclusive education (Sidogi, 2001:84). It was, therefore, deemed necessary to understand these attitudes and perceptions.

Questionnaires were given to these teachers to complete although no interviews were conducted with them. The aim of the first question was to ascertain whether the teachers had some understanding of the concept of inclusive education.

What does inclusive education imply?

It means mixing learners who are physically challenged and those who are not.

Mixing all the learners in one school, despite their challenges.

There must be no learner who can be discriminated because of their capabilities. All learners need to be taught according to their understanding.

It means combining learners from all walks of life in one special/classroom, teaching them without having to discriminate because of physical or mental ability.

It emerged that each of the teachers who filled in the questionnaire understood fully what inclusive education was about. It was, therefore, not unexpected that their answers to the following question also revealed a degree of understanding.

Do you think it is possible for inclusive education to work in your school? Why?

"Never. It will take time, there should be renovations/building of another block will cater for such learners, e.g. toilets, floor space, etc."

"Never, due to the floor space which is not favourable because of the number of children. Also the condition of the site is not good, even for those normal ones here, some classes are not in a good position for certain conditions."

"No, the inclusive education towards us will not be successful because of our environment and also because of the useless resources at our school."

"No, the classes are too large i.e. enrolment per class."

"No. Most of the teachers do not have enough training and knowledge of inclusive education. Most of the educators in this school do not have an idea how to treat a child with a disability."

"No. It cannot unless a total rebuild of the school can take place to accommodate all the challenges and extension of classrooms."

All the answers were both similar and understandable. In addition, they were logical and clearly revealed that it would not be possible for the school, as it is at present, to accommodate CWPDs. The researcher herself would have given a similar answer.

The next question was aimed at ascertaining the attitudes towards inclusion in general.

What are the attitudes of teachers, in general, towards implementing inclusive education?

"It is up to the government to motivate teachers (macrosystemic level), and not to include these learners without prior consultation. It's enough, we are not babysitters."

"I think the department must motivate the teachers who study this course with this inclusive education."

"If there is no training, surely it will have negative attitudes. Inclusive education needs a teacher with passion and to be patient with these learners."

"The department should include the lesson in the upcoming students so as to familiarise or raise interest in them to teach all learners with difficulties."

"I, for one, would love to have it in my school, but circumstances beyond my control do not allow it."

Once again, the teachers were both realistic and honest. As a teacher who is qualified to teach CWPDs the researcher is able to understand the position of the teacher who has had no training and no experience and who has no assistance in their already overcrowded classes.

These answers are still in accordance with the findings of the study conducted by Clacherty *et al.* (2004:15) six years earlier. In their study one teacher describes her own sense of inadequacy and lack of skills with CWPDs. In addition, Clacherty *et al.* (2004:15) also refer to the need for appropriate curricula.

"I am one of the teachers from a mainstream school. I was teaching one of the boys there. I could not understand that boy. I was beating him to hell. He would defy me. I used to say he was stubborn, disruptive and naughty. That is until I got training in remedial education. When we did work on remedial education I began to understand him. By this time he was already gone in my school. So teachers cannot understand these children" (Clacherty *et al.*, 2004 15).

As stated in the Expanded Commentary on The Dakar Framework for Action, Par. 33: (2000) "In order to attract and retain children from marginalized and excluded groups, education systems should respond flexibly. Education systems must be fully inclusive, actively seeking out children who are not enrolled, and responding flexibly to the circumstances and needs of the learners ... ."

It is, thus, essential that curricula be relevant to the learners and sufficiently flexible to respond to the needs of all children. However, in order to achieve this flexibility, teachers must move from curricula focused to child-focused teaching methods. This would, in turn, require both teacher training and flexible rules concerning the curriculum. At present in South Africa there is no fixed curriculum and OBE has been discontinued. Therefore, once again, the CWPDs are adversely affected because they are still not being catered for.

Furthermore, if one takes into account the answers of the teachers from the mainstream school, there was not only a definite lack in their training but they are eager to receive training. However, government is not providing this training in the rural areas although there are no qualified teachers in these areas – yet another factor which impacts negatively on the CWPDs. According to Miles (2000: 2) South Africa is not the only country in which the rural areas lack qualified teachers. Nevertheless, teacher training and ongoing support and training are crucial if any changes are to be introduced in rural education. From the findings of this study it is evident that teachers are not receptive to inclusion as they are not trained. Mike Collins, Head of Education in Britain, agrees and argues that "When teachers do not know how best to support a child with a disability the whole class is affected, and the child is unable to develop their capacities to the full" (BBC News, 16 May 2006).

In her study, Materechera (2009) recommends that it is essential that policy makers consider the hindrances before either implementing or agreeing to the implementation of inclusive education. For example, teacher training for inclusive education should be considered during both pre service and in-service training sessions, regardless of whether the teachers will make use of the knowledge or not. In addition, support in the form of professionals, teaching aids, school administration, workshops and financial support should be made available to those schools that have included learners experiencing barriers to learning.

5.6.3   Attitudes of typically developing peers towards CWPDs

Once there was a clear understanding of the way in which the teachers felt, the researcher then asked typically developing children how they felt about CWPDs attending their school.

Before asking the questions, the researcher gave a talk to the children on the topic of disability, explaining the concept and answering all their questions. The children were then interviewed individually so that their answers were not influenced by what their friends had said. All the children interviewed were in Grade 7 and they all understood English well. It

was decided by the researcher to discuss disability with this group before interviewing them so that their answers reflected an understanding of the involvement of playing with CWPDs, which it did as is evident by the child who answered that he would not play running games with them as running is his favourite game.

Should CWPDs be able to come to your school or should they to go to a special school?
The answers were mixed with some children indicating that inclusion should take place while others indicated they CWPDS should remain separated. Nevertheless, the answers showed insight and an understanding of the concept of disability. The following answers were all in favour of inclusion.

"They should be allowed to come here. They are children just like us. We must learn not to tease them and make fun of them."

"They are better at special schools. They will be treated better."

"Here, because we teach respect at this school."

"Here, we will form a group and protect them."

"They should stay at a special school, they have more problems and other children will bully them."

'same age, same nation, they must come here."

"They should stay at special schools, they have special teachers that can help them do things."

"They should stay at a special school; here they will be laughed at."

"Yes, they are welcome and it would be fair, but they do need a special school."

"They must come here − this school is close for some children. Some stay at home because they cannot come here. Special schools are far."

Three children were not in favour of inclusion with the remainder being a mix of undecided and not really sure.

One child answered that "No, they cannot talk, and we will not understand what they are saying".

The researcher returned to the school the following day and showed this little girl a Picture Communication Symbol Board (it is a low tech communication board which is easy for most children to use and understand) and explained to her how CWPDs could communicate with pictures so that everyone in the class would understand them.

The researcher explained how the CWPDs may point to the pictures indicating "I need Help" or "I need to go to the toilet" or "I am hungry".

The girl was fascinated and replied that "OK, if we can understand them, its then fair for them to come to this school".

It is clear that, as regards the particular vulnerabilities experienced by CWPDs and as discussed in this chapter, these vulnerabilities are not determined by the levels of disability only, but also by the levels of exclusion. The findings of this research study are in keeping with the findings of Philpott (2004:272) that, despite key achievements in terms of the legal framework protecting the rights of CWPDs, many of these children still do not have access to the services they require. These services include early rehabilitation, access to transport and inclusion at all schools. Clearly, inclusion is still not taking place in 2011and there are schools that either do not accept them or do have the necessary physical barriers removed to accommodate CWPDS, the qualified teachers needed and support from the Education Department and classes that are not overcrowded.

From the above discussion it is clear that the development of an inclusive educational environment for CWPDs is neither a simple nor a straightforward process. In addition, it would appear that there are more questions than ever regarding the efficacy of inclusion in the rural areas. The barriers that CWPDs are forced to confront within the South African context have led the researcher to question the feasibility of the inclusion of CWPDs in rural South Africa.

There is clearly a great deal that still needs to be achieved in rural areas before inclusion becomes feasible. "If attempts were made to place children in regular classrooms where these requirements were not met, those who advocate inclusion would consider that both the theory and practice of the concepts were being abused (Pottas, 2005:29). This sentiment was echoed

by the BBC on Tuesday, 16 May 2006, 14:10 during a discussion of inclusive education when it was stated that "You might call it a form of abuse, in a sense that those children are in a situation that's totally inappropriate for them".

The researcher cites that the above quotation as a valid statement. In addition, in view of the fact that an inclusive community, both socially and educationally, is not feasible in the rural areas, the researcher has devised guidelines in terms of which this situation may be rectified and, wherever possible, the impact of the negative influences facing CWPDs in these areas countered.

5.6.4   Lack of parental involvement in education

Bronfenbrenner (1999) clearly emphasises the importance of parental involvement in the developing child's education and goes on to stress the relevance of the mesosystemic level of healthy interaction between the parents and the school. Parental involvement in children's schooling has been, repeatedly, shown to be positively and significantly correlated with a number of positive child outcomes. These findings are in keeping with the Hoover-Dempsey and Sandler Model which also stresses the importance of parental involvement in a child's schooling (Lavenda, 2011: abstract). This model argues that continued research into parental involvement in a child's schooling may improve the child's chances of succeeding at school (Hoover-Dempsey & Sandler, 1997:3).

5.6.4.1   Findings

In terms of the parents/caregivers interviewed in this study there was no apparent parental involvement although not by choice but rather by distances. However, their children were all at Kwazamokuhle School which is a boarding school. Nevertheless, the parents are at an immediate disadvantage as they are so totally uninvolved due to the school being a boarding school and it being expensive to visit their children They also know that their children are being well looked after. However, this was not, necessarily by choice but as a result of factors such as the distance to the school and a lack of available finances to visit their children. In terms of Bronfenbrenner's mesosystemic level these parents are further disadvantaged as they are unable to be involved in any other of their children's daily activities or with their children schooling. The involvement of the home is crucial to the microsystemic level. This lack of ability on the part of the parents to be involved in their children's schooling is in conflict with the approach of Hoover-Dempsey and Sandler (Lavenda, 2011) who maintain that, if the parents want to be involved in the school, it is more likely to have a positive impact on their

children. However, in the rural areas this involvement is impossible and the CWPDs interviewed in this study, as well as their families, are at an immediate disadvantage as the CWPDs attend a boarding school, whereas their typically developing peers are day scholars at a school that is close to their home and they have contact with their parents, siblings and neighbours on a daily basis. The CWPDs are effectively removed from the microsystemic level.

5.6.5   Lack of self-esteem and self-reliance

Self-esteem refers to both the way in which children feel about themselves and also how they expect to be accepted and valued by others who are important to them. In view of the fact that it is important for CWPDs, in particular, to feel accepted and included, a healthy sense of self is crucial for determining how they will approach life and interact with their typically developing peers. Self-esteem also represents an individual's need to belong and to feel loved unconditionally. In addition, self-esteem has many aspects and develops within the context of a child's evolving sense of identity and ever-changing life tasks and, in the case of CWPDS, the challenges they face with their disabilities. It is a lifelong developmental process of which the roots are established in early childhood (www.notMYkid).

According to the CRC (2006), it is crucial that the education of CWPDs include the strengthening of positive self-awareness and that it ensures that the child feels he/she is respected by others as a human being, without any limitation of dignity. It is, thus, essential that these children be able to observe that others respect them as well as their human rights and freedoms. Peer support enhancing self-esteem of CWPDs should also be more widely recognised and promoted. In addition, education should provide the child with empowering experiences of control, achievement, and success to the maximum extent possible for each child.

A range of questions were posed to typically developing children in order to determine their perceptions of CWPDs:

Do you laugh when you see CWPDs?
Eighteen of the participants stated that they would not tease CWPDs with one participant noting that they would "protect them". Four of the participants maintained that, while they would not tease them, "others would" However, five participants mentioned that they would tease with one participant stating that that he/she would "bully them". When probed as to the

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reason why they would tease them the answers varied from "They look funny", "They cannot play games and are useless" and "They cannot run".

These answers indicate that CWPDs do get laughed at, something which would make it impossible for them to build up a positive self image. The sense of self of CWPDs is not fostered when they are laughed at and this may make them fear attempting integration at a later stage. It is natural that they would not have either confidence or a positive self-esteem. These feelings were confirmed by the following question.

Do you feel sorry for CWPDs?
"Yes, they are alone."

Nevertheless, despite the majority of the children stating that they did not tease or bully CWPDS, some of the children did admit to the teasing and bullying which, ultimately, damages the potential for CWPDs to grow up with confidence.

This teasing and bullying is further backed up by the comments from the parents of the CWPDs.

How could people in your area help to improve the lives of CWPDs and include CWPDs in all areas of the community?
The following answers to this question revealed that the parents were, on the whole, concerned and anxious about their children facing exclusion from the community.

Parent/caregiver 2 felt strongly that her child was not accepted. She indicated, however, that she was willing to play an active part and bring an end to exclusion if she had an opportunity to do so − "I can educate parents and the community to love and *accept* CWPDs". The researcher's heart ached at this answer as she was clearly so desperate for her child to be included in life. Parent/caregiver 5's answer echoed this sentiment of acceptance − "By accepting them because they are the same as us, they are God's creatures as well".

Parent/caregivers 8 and 9 respectively answered that they needed support "By loving and supporting them" and that the community should "Help to understand disability; they laugh at her, especially her age group. They isolate her". In essence, parent/caregiver 9 simply wanted *inclusion* in the community.

These answers underline the importance of Mobility for Independence's (international non-profit organisation) emphasis on the fact that mobility is critical to the self-esteem and self-reliance of CWPDs. The goals of this organisation include raising the necessary funds to help CWPDS to acquire safe and reliable transportation and mobility so that they may be included in the community (http://mobility for independence, 2011:1). Sadly, these funds are not available to the children in the rural areas of South Africa.

5.6.6   Poverty and the lack of education children for CWPDs in rural areas.

According to the CRC, CWPDs have the same right to education as all other children and, as stipulated in the Convention on the Rights of the Child, they should enjoy this right without any discrimination and on the basis of equal opportunity. It is within this context that the Committee of the CRC makes reference to the United Nations' Millennium Declaration and. in particular, to Millennium Goal No. 2 which relates to universal primary education in terms of which by 2015 all children will be able to complete a full course of primary schooling. South Africa is committed to the MDGs(Millennium Developmental Goals, 2010).

The impact of poverty as witnessed by the researcher on education is clearly evident in the deprived rural areas. Section 29(1)(a) of the South African Constitution states that "everyone has the right to a basic education" while section 29(1)(b) states that "everyone has the right to further education" and that it is incumbent on the state to make such education "progressively available and accessible"

In terms of Article 11(3)(a) of the South African Charter on the Rights and Welfare of the Child, "[s]tate parties to the present charter shall take all appropriate measures with a view to achieving the full realization of this right and shall, in particular, provide free and compulsory basic education".

Article 28 of the UN Convention on the Rights of the Child recognises "the right of the child to education" and also obliges the State to "make primary education compulsory and available free to all". In other words, education is a central socioeconomic right that provides the foundation for lifelong learning and economic opportunities.

At the mesosystemic level barriers include the slow implementation of the recommendations of White Paper 6 by both the provincial departments and the districts which are, as a result of decentralisation, moving at different paces and effecting change in different ways. Barriers at

the district level include inadequate human resources and financial constraints (Ladbrook, 2009:11).

At the macrosystemic level national level decisions are made regarding policy making and the funding of education. It is, in fact, at national level that the decentralisation of power was considered necessary as a project for democracy (Ladbrook, 2009:11).

Accordingly, dealing with the CWPDs in the rural communities is more than merely a healthcare issue for government. It is essential that CWPDs be included society and they have access to education. One in every ten children has a disability with only 2 to 3% of these children having access to education. In South Africa, 33,8% of CWDs will have received no education or schooling at all by the time they reach the age of 20 (Siena & Jackson, 2009:1). This statistic is confirmed by the empirical evidence that indicates that CWPDs have less access to education than other typically developing children. According to UNESCO, of the 75 million primary school children who are out of school, one third of this figure represents children with disabilities. It is, thus, only with the inclusion of children with disabilities that universal primary education will be attainable by 2015 (UNESCO, 2010:1).

Rural poverty and quality education in the rural areas are the greatest challenges facing South Africa. Rural schools continue to be marginalised as inequality in the education system persists, particularly for the CWPDs. However, unlike rural education in the rest of the world, the situation in South Africa is the result of a specific political dispensation, namely, apartheid. Today, more than a decade after the abolition of apartheid, this legacy of this policy continues to benefit some while disadvantaging others, particularly the CWPDs in rural areas. In South Africa there are more rural schools than urban schools. Nevertheless, despite the fact that rural schools are poor in comparison to urban schools, they are systematically ignored. Rural schools are often inferior because they are the product of disadvantaged communities with government's failure to provide schools that meet the needs of typically developing children clearly visible in the schools which the researcher visited in the rural areas. Most of these schools do not even have a media centre.

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Overcrowded classes for wheelchairs and lack of accessibility for wheelchairs into these classes.

Overcrowded tables and- Poor terrain
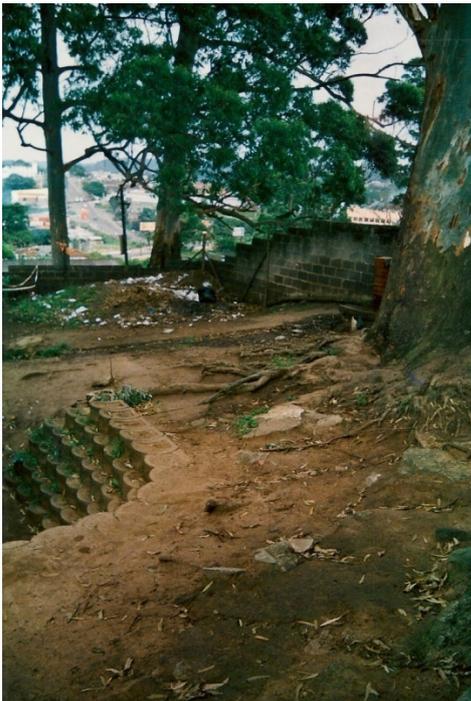
and inaccessible entrances to a class.

Since the changeover from South Africa's apartheid system of government (heavily influenced by South Africa's elite Afrikaner leaders and the secret Afrikaner society, the *Broederbond)* in 1994 to a democratic system of government, much has been expected of the post apartheid government in terms of the greater equalisation of opportunities in all aspects

of life. However, for the poor and rural black families who comprise the majority of South African citizens by tens of millions, this has not been the case. The reason for this situation is probably to be found in the fact that the roots of separate and unequal education are extremely deeply embedded in South African society (Meek & Meek, 2009:506). As for education in the rural areas, poverty is a fact of life for 66,3% of those who have had no schooling and 59,9% of those who have not completed primary schooling (Armstrong *et al.,* 2009:2).

Inaccessible toilets and a toilet at a Special School.(with handrails, and adapted taps).

Photograph depicting the differences between a toilet in a special needs school and a toilet in a mainstream school. A toilet in a school for children with special needs − note the hand rails, wide doors and taps, all of which are adapted for CWPDs.

Nevertheless, this statistic is not peculiar to South Africa. More than half of the world's population is to be found in rural areas which are characterised by hunger, illiteracy and low school achievement (UNESCO, 2000). However, the provision of education to the large numbers of people in the rural areas is crucial for the realisation of sustainable development. In addition, in view of the fact that so many people in the world and, particularly, in Africa, live in rural areas, education for this group of people deserves special attention. Nevertheless,

it is essential that their education not simply be moulded on the urban model but rather that it take into account the specific characteristics of each rural setting (Seroto, 2003:1).

The dilemma of education in the rural areas in relation to the social, economic and political structures is clearly evident in South Africa. In September 1997, the Interim Unit for Education and Management Development and the Centre for Education Policy, Evaluation and Management, in association with the National Department of Education, hosted a four day conference in White River, Mpumalanga. The theme of this conference was "Developing quality schools in rural areas" with papers dealing with issues such as "Multiple inequalities and challenges facing South African rural schools" being presented (Seroto, 2003:1). The conference reached the conclusion that the state of rural schooling in South Africa was not being adequately addressed and that it needs attention.

On 3 September 2002, the Food and Agricultural Organization (FAO) of the United Nations, together with the United Nations Scientific and Cultural Organization (UNESCO), in support of education for rural people, launched a partnership at the World Summit on Sustainable Development held in Johannesburg, South Africa (Johannesburg Summit, 2002. The objectives of this partnership included the following:

- Building an awareness of the importance of education for rural people as a crucial step to achieving the millennium goals of eradicating extreme poverty and hunger and achieving universal primary education for CWPDs.
- Overcoming the urban-rural gap.
- Increasing access to basic education for rural people.
- Improving the quality of basic education in rural areas.
- Fostering the national capacity to plan and implement basic education plans aimed at addressing the learning needs of rural people (UNESCO, 2002).

A "poor quality" school refers to a school in which the basic necessities are lacking, thus rendering accessibility more difficult for CWPDs (Jonsson & Wiman, 2001). In such a school there are too few desks, textbooks or classrooms for all the children with facilities for CWPDs not even a consideration. The teachers do not have the necessary qualifications for teaching children with special needs and, apart from attitudinal barriers; the physical barriers in such schools are clearly visible even before the CWPDs have left home.

To a large extent, the rural areas have been neglected in developmental policies. The researcher intends to highlight the government's inability to act on its policies with not enough being done to improve the plight of the CWPDs in rural areas. This became clear to the researcher during Phase 1 of the study. Even after the ANC has assumed power the strategies outlined in *The Policy Framework for Education and Training* have not been adequately implemented. Nevertheless, the South African government has attempted to become increasingly mindful of, and has showed an interest in, education by publishing several related documents. These include:

- The Reconstruction and Development Programme (RDP)

- Rural Development Strategy of the Government of National Unity; Notice No. 1153 of 1995 which aimed at re-addressing educational backlogs in rural areas.

- In 1995 the government published a document entitled Education White Paper 5 on Early Childhood Education. This document pointed out that 40% of families live in abject poverty, with rural Black families being the most affected.

- The Education White Paper No.2 on Organisation, Governance and Funding of Schools (1996)

- According to the Constitution of the Republic of South Africa of 1996 "everyone has the right to a basic education" with rural learners being included in this Bill of Rights.

- The South African Schools Act, Act No.84 1996 was also enacted by the government. This piece of legislation reflected steps the South African government intended to take to redress the imbalances in schooling.

- In 2001 White Paper No.6 made provision for CWPDs in rural areas.

- In 2002 the Education Department introduced a Revised National Curriculum Statement in which the then minister of education, Kadar Asmal, admitted that the curriculum was not addressing some of the challenges in rural areas (Seroto, 2003:11).

Although it would appear that the ANC Government is attempting to address the rural education problem in South Africa, nevertheless, there are few visible results. A media report stated that, with regard to the state of rural education in the democratic era. "The ANC Government has promised to provide equal schooling for *all* South Africans but, eight years into democracy (now 17 years), is struggling to extend basic schooling to the formally neglected, rural Bantustans regions" (Seroto, 2004: 6). It is clearly evident from the literature reviews and from observations that the constitutional right of children to education is not

being realised and, in addition, their rights within education or through education are also limited. Poorly trained teachers who receive few incentives to live in the areas in which they teach, as well as startlingly limited facilities and resources to assist them in their task, compromise the rights of children within education. Early Childhood Programmes for CWPDs are virtually nonexistent. In addition, a lack of educational opportunities outside of schools, or offered through schools for adults and out of school youth, form part of this wider picture of educational deprivation. Not surprisingly, both the literacy levels of adults and the educational attainments of children in rural areas are amongst the lowest in the country (Gwitimah & Khupe, 2008: 1-30).

Furthermore, CWPDs are less likely than their siblings to attend school, to go on outings, or to experience situations in which they are required to solve problems or to contribute to household chores. As a result they grow to be disempowered adults who are unable to take decisions, solve problems or take the initiative. This, in turn, contributes to the high unemployment figures amongst adults with disabilities and, so, the domino effect continues (White Paper on South Africa's Integrated National Disability Strategy, 2007:6).

Conclusion

Education in the rural areas in South African is clearly in crisis. In addition, it is not meeting its goals in terms of providing the broad access to quality education that would enable the equitable sharing of opportunities. In other words, the constitutional requirements of equality are not being met (Pendlebury, Lake & Smith, 2008/2009:1).

Education is a central socioeconomic right that provides the foundation for lifelong learning and economic opportunities. All citizens should enjoy equality in terms of this right, but this equality of opportunity is clearly absent in the rural areas.

Chapter 6 will provide a framework that will attempt to address the negative influences impacting on facing CWPDs. This framework will be based on Bronfenbrenner's Model and will involve the community.

At this juncture it would seem appropriate to quote the following words of the famous anthropologist, Margaret Mead (1901–1978): "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." (www. brainy quotes.com/Margaret _mead.html.

Chapter 6

SUMMARY, FRAMEWORK TO REDUCE THE IMPACT OF NEGATIVE INFLUENCES, STRENGTHS AND LIMITATIONS, AND THE CONCLUSION TO THIS STUDY

"Every child had the right to the best possible start in life" (UNICEF, 2006).

6.1   INTRODUCTION

This study set out to explore and describe the impact of negative influences facing CWPDs in the rural areas. The study originated from the researcher's desire to make a positive contribution to the reduction of these influences in South Africa as a developing democracy.

Efforts to ameliorate or lessen the impact of negative influences on CWPDs and their families in the rural areas have not been successful. Although South Africa is recognised as having progressive and comprehensive policies in place to ensure the rights of CWPDs, it is also acknowledged that the lack of a specific budget for CWPDs in rural areas means that their needs have been neglected, resulting in the many negative influences identified by this research and discussed in chapter 5. The wellbeing of CWPDs is crucial to any society, as children represent the future and it is important for CWPDs to lead happy and healthy lives. Consequently, the context in which many such children live remains undesirable and places them at both at an educational and a social disadvantage.

In this thesis, "context" refers to the circumstances or conditions in which such children reside. Accordingly, Bronfenbrenner conceptualised human development as a process that occurs within a set of defined nested contexts. This was discussed in depth in Chapter 3 and formed the basis of the theoretical framework for this study. This theoretical framework of child development focuses on the neighbourhood and community contexts of development, in addition to the more proximal, social contexts such as the family, all of which influence a child's developmental outcomes directly and indirectly. All aspects of the framework take account of the context within which child development occurs.

This research concentrated on what Bronfenbrenner refers to as the microsystem and mesosystem. He proposed that a child's development will be enhanced if two settings in which they are involved are strongly linked. Thus, even if children are placed in a very good specialised setting, but it is away from their families, this is in direct conflict with Bronfenbrenner's Bioecological Model and the theoretical framework of this research.

The framework of solutions outlined in this chapter will thus be embedded in the context of Bronfenbrenner's model of child development. Critical to the framework will be the impact of the community (mesosystem) and family (the microsystem) variables on positive child wellbeing. In this regard, the solutions will take on an ecological approach in assisting to reduce the impact of negative influences facing CWPDs. The framework of these solutions will be outlined in section 6.4.

6.2   SUMMARY OF CHAPTERS

Disability was discussed at length in chapter 2, where the correlation between disability and poverty was highlighted as a key issue; in addition, definitions of poverty within the South African rural context were discussed.

Chapter 3 concentrated on disabilities and the shift that has occurred in society from viewing CWPDs as a medical model to seeing it as a social model, in terms of which the environment should accommodate the needs of the child. In addition, the concept of social and educational inclusion was explored. This chapter also discussed Bronfenbrenner's Bioecological Model in detail, as well as the way it relates to this research study. This model views the child as being at the centre of the model and maintains that children are affected by the settings in which they live.

Chapter 4 gave an in-depth account of the research design and the methodology used to conduct this study. The nature of qualitative research was discussed and the various data collection methods used in the research were highlighted. This was followed by an account of how the researcher planned to analyse and interpret the findings. Being a qualitative study, an explanation was given on how validity and trustworthiness were ensured in the research, as well as discussing the ethical guidelines that were followed in this study, as it was of an extremely sensitive nature.

Chapter 5 provided a detailed analysis and interpretation of the data collected during the study. As the negative influences affecting CWPDs were identified, it became evident that these could be attributed to the chronic poverty experienced in the areas investigated by the study. These findings should be seen as presenting an opportunity to create a framework for reducing the negative influences, as well as the extent of educational exclusion at a mainstream school, by applying Bronfenbrenner's Model as a point of departure.

Table 6.1: Summary of chapter 5: The impact of negative influences facing CWPDs

NEGATIVE INFLUENCE (cause)	IMPACT(effect)
Lack of adequate shelter	One child left with severe burns, lack of safety; poor living conditions; caregivers/parents sick and unable to maintain their homes
Lack of electricity	Lack of hot cooked meals Cold when sleeping Illegal connections – constant fire risk
Lack of sanitation and fresh water	Children cannot go to toilet independently Children not always clean Waterborne diseases such as diarrhoea
Lack of transport and the presence of physical barriers	Social exclusion on outings Inadequate access to health services
Unemployment in the rural areas	Unemployment exacerbates the poverty; parents take care of CWPDs instead of working and therefore basic items are unaffordable.
Abuse of grants	CWPDs lack necessities as the family is living on the child's grant Father refuses to accept grant so child has very few material items
Lack of essentials	Lack of radio, warm clothes Lack of independence and self-respect
Lack of adequate health care	CWPDs lack the support they need as babies and thus do not develop to their full potential
Lack of adequate nutrition	Very little nutritious food in holidays and no treats
HIV/AIDS	Single-headed households, CWPDs left in care of grandparents CWPDs are themselves infected
Lack of early intervention and adaptations	Effects of disability have not been lessened and essential adaptive equipment is not assisting them in becoming independent
Loneliness, isolation and vulnerability	Not all CWPDs are accepted and loved and are therefore vulnerable, lonely and isolated. Children do not feel part of a peer group
Socio-emotional development of the child	Lack of social support networks, little interaction on the micro- and mesosystemic levels
Lack of recreational facilities	No parks to interact, no libraries, no stimulation
Lack of access to appropriate information and the mass media	CWPDs cannot live independently Parents lack access to information to help them manage their children better
Lack of birth registration	CWPDs not accounted for in statistics and government has not planned for them Children are denied access to their grants until registered
Violence against CWPDs	All the children had been exposed to some form of teasing and bullying. Remain vulnerable to abuse
Neglect and abuse of CWPDs	CWPDs remain socially neglected CWPDs remain open to abuse.
Lack of access to schools	No access to mainstream schooling therefore children sent to boarding school thus eliminating healthy development on micro- and mesosystemic levels.

Social exclusion	Very evident in most of the children
Negative attitudes of typically developing peers towards CWPDs	Sending CWPDs to boarding school – schools have no understanding of disability
Attitudes of mainstream teachers	Teachers have negative attitudes mainly due to lack of training and understanding
Lack of parental involvement	Essential in daily life on the mesosystemic level – does not exist
Lack of self-esteem and self-reliance	CWPDs still laughed at – sense of self is not developed
Poverty and lack of education for CWPDs	They do enjoy the right to a quality education but at the expense of healthy family development

6.3   OVERVIEW OF THE OBJECTIVES

Data collected in this qualitative ethnographic study have been integrated and will be discussed in response to the following research questions which were stated in chapter 1. The main research question that directed the focus of this study was exploratory in nature:

- What is the impact of negative influences on the lives of CWPDs?

These findings were discussed in detail in chapter 5.

The two sub-questions that were asked to clarify the research question were the following:

- What theoretical framework can assist the researcher to investigate these negative influences?
- What best can be done to reduce the impact that these negative influences have on the lives of CWPDs?

The theoretical framework that was best suited to investigate the impact of these negative influences was Bronfenbrenner's Bioecological Model, which concentrates on the micro- and mesosystemic levels. This model was explored in chapter 3.

The answer to the second sub-question was obtained by collecting rich data by means of questionnaires, interviews, observations, children's drawings and photographs. This chapter (chapter 6) will provide possible recommendations based on the micro and mesosystemic level.

Finally, this chapter will provide concluding statements, some ideas, the limitations of the research and several recommendations for further research.

6.4   BEN-DAVID'S FRAMEWORK FOR REDUCING THE IMPACT OF NEGATIVE INFLUENCES FACING CWPDS (BASED ON BRONFENBRENNER'S BIOECOLOGICAL MODEL)

IN THE MICROSYSTEM THE CHILD IS IN THE CENTRE

PEERS

PARE

Figure 6.1:   The child is the centre of Bronfenbrenner's model of child development and cannot be displaced

6.4.1   Introduction to the framework

Educational exclusion from mainstream schools for CWPDs remains a topic of both interest and debate. The theoretical framework underpinning this research study is that of Bronfenbrenner's Model, which is opposed to the removal of children from the centre of the microsystem and, for example, sending them to boarding school.

In chapter 5, one of the most important findings of this research was the lack of ECD and early intervention. In her investigation, the researcher had not expected to find that ECD and the early intervention would be so lacking for CWPDs. Therefore, the lack ECD and early intervention will feature prominently in this framework, owing to the extremely negative effects this has on the lives of CWPDs. Early experiences have a profound effect on the later

developmental outcomes of CWPDs. At no other time in a person's life does one learn and develop as fast and intensely as in the early years. UNICEF (2007) states that the care and attention CWPDs receive in the first eight years of life – particularly during the first three years – are critical and influence the child for life. Play is an important part of children's development and parents/caregivers and teachers determine the level of development of infants and children though interaction and play. Consequently, their involvement is crucial for early learning – this is in keeping with Bronfenbrenner's Bioecological Model.

According to the researcher's findings in the rural areas visited, there is at present no centre where CWPDs and their parents can interact. In addition, there is no possibility at present for many of the parents/caregivers to gain employment as they have to take care of their children. Hence, it is critical to develop a framework within which CWPDs could reach their full potential and their parents/caregivers could acquire the skills needed to earn money to escape the "poverty deprivation trap", as discussed in depth in chapter 5.

The researcher's development of this framework is both timely and innovative, given the fact that action has to be taken and, as the findings suggest, there is strong support and enthusiasm for such a framework. This research also suggests that the causes of educational exclusion from mainstream schools and the lack of early intervention are multiple; therefore this framework will adopt a multidimensional approach.

This research study was designed to identify the impact of the negative influences facing CWPDs in rural areas using Bronfenbrenner's Bioecological Model as the theoretical framework. It therefore follows that the impact of these negative influences needs to be addressed within this model.

While conducting interviews with the parents/caregivers, clinic sisters and CBR workers it became evident that parents/caregivers with CWPDs want their children to do well. Although parents want to interact with their children, they do not have the skills or the opportunities to do so. Such close interactions have been identified by Bronfenbrenner and Ceci, who argue that "proximal processes" are the engines of development and that by engaging in these activities and interactions children come to make sense of their world (Tudge *et al.* 2009:3). These proximal processes are enduring forms of interaction in the immediate environment and examples include parents/caregivers playing with their children, learning new skills (especially important in CWPDs), making plans, performing complex tasks such as tasks of

everyday living – tying shoelaces, doing up buttons – that CWPDs so desperately need assistance with, as well as acquiring new knowledge and know-how (Bronfenbrenner & Morris, 1998:996). The nested structures of the ecological environment proposed by Bronfenbrenner's process–person–context–time model provide a useful framework that can be used in reducing the impact of negative influences facing CWPDs by making recommendations and selecting appropriate interventions. The stressful life events (of having a CWPD) and the chronic strains caused by the poverty that these families live in appear to affect the child's physical and socio-emotional functioning by eroding parental coping behaviours and resulting in parenting practices that are uninvolved, inconsistent, emotionally unresponsive and harsh (Eamon, 2001:263).

The lack of a setting in the areas visited where CWPDs can learn new skills and be prepared for mainstream schooling and interact at the same time with their parents/caregivers is evident. The findings in chapter 5 indicate that CWPDs in rural areas lack early intervention and education and therefore this is included in the framework. The skills CWPDs need in order to attend a mainstream school, as well as and parental involvement, are crucial when looking at the objectives of this framework.

6.4.2 Objectives of the framework

The main objective of the framework is to keep the CWPDs at the centre of their development; other objectives in the recommendations of this framework are levelled at four groups:

- Early intervention for CWPDs
- Preparation of CWPDs for mainstream schooling
- The parents/caregivers – empowering them to act as facilitators, as well as to generate income
- Prepare the mainstream school and teachers to accept CWPDs so that they do not need to be sent away to specialised schools.

Parents/caregivers start intervention with their CWPDs from birth to three years, from three to seven years the CWPDs receive ongoing intervention they attend mainstream schools where they can make their needs known, teachers interact with parents/caregivers

Parents

Infants Birth to three years

Ben-David's centre for promoting inclusion

Mainstream teachers and schools

CWPDs 3-7 years

The centre is ongoing with all involved passing knowledge onto the next level and next group

Figure 6.2:   The ongoing cycle of intervention for CWPDs in rural areas

For the CWPDs in this study, education is provided by Kwazamokuhle School. For some of the children attending this school and who participated in this study, such recommendations might come too late; however, the children who were interviewed can still be used as input as they have experienced being sent away from home, and they can act as "spokespersons" for many other CWPDs still faced being sent to boarding school. For the younger children interviewed there is still a chance for inclusion in a mainstream school. The twins interviewed are ideal spokespeople for what happens when schools, teachers and typically developing peers are not prepared for CWPDs. These children bore the brunt of being bullied, teased and finally excommunicated when they were sent away from home to boarding school, even though they were able cope in a mainstream school both physically and cognitively. The HIV-positive 12-year-old girl who was interviewed is confident and outspoken and resents the accusations that her disability is as a result of AIDS. She indicated she would like to grow up and make others aware of what AIDS is about and how her mother's carelessness has left her in the care of her granny and that she is very angry about being HIV positive. Although

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any direct intervention that might result from this research may not benefit these children, they tell very important stories that all community members can learn from.

Parents and community, promote self empowerment by building on the recommendations offered in this framework and their CWPDs have a chance to reach their full potential and attend a mainstream without having to leave the microsystem.

Parents continue to remain at home alone with no support, no generation of income and CWPDs spend their early childhood at home unstimulated, and unable to reach their full potential

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Figure 6.3:   Community support for parents. The figure above indicates the advantage (the upside) of getting a community centre going and the downside of no involvement in the centre.

Research and practice consistently show that providing quality early childhood care and education is inextricably linked to positive child development. Research has also recognised that the value of early educational support programmes can only be measured by their impact of the child, the family and the community, and in this research study, the reduction of negative influences facing CWPDs and their families. Parents and the community need to respond to the needs of CWPDs

The implementation of the recommendations made by the researcher is envisioned to take approximately two years from inception to being up and running (see timeframe). Although there will be risk factors, such as a possible lack of funding and sustainability, the researcher nevertheless believes that these recommendations are too beneficial to the child, parents/caregivers and community not to be committed to ensure the centre envisaged will a success.

The researcher acknowledges that it will require community commitment and hard work as a team. It should be noted that various stakeholders have indicated their willingness to participate and their need for assistance and have signed forms in support (see Appendix 8). As with all new 'visions', it will be a challenge, but there are existing resources available and these will be used as the foundation. The researcher firmly believes that with passion such a framework will succeed. Although it is a new concept, there are no other solutions and opportunities offered to CWPDs or their parents/caregivers at present where both can benefit simultaneously. Without an attempt by committed parents, CWPDs will be unable to develop to their full potential and will continue to spend their childhood alone and unstimulated at home and then be taken from their homes to be sent to a specialised stetting. This scenario is in direct contrast to Bronfenbrenner's Model.

6.4.3 Structure of the framework

The structure of the framework refers to the overall motivations and recommendations for each target group.

The framework is based on Bronfenbrenner's Model, which includes only the micro and mesosystemic level. In line with Bronfenbrenner's Model (1979), Palisano, Kang, Chiarello, Orlin, Oeffinger and Maggs (2009:2) and Berns (2010), the researcher proposes that, for CWPDs, social and educational participation involves interaction with others *within* the context of the home, school and community. As the researcher intends to strengthen the poorly developed microsystemic and mesosystemic levels in these areas, it is not deemed necessary, feasible or practical to include the exosystemic and macrosystemic levels. Accordingly, the structure of the framework comprises three main headings:

- Target group
- Motivation
- Recommendations

The first step in this framework is to look at the existing resources that are available.
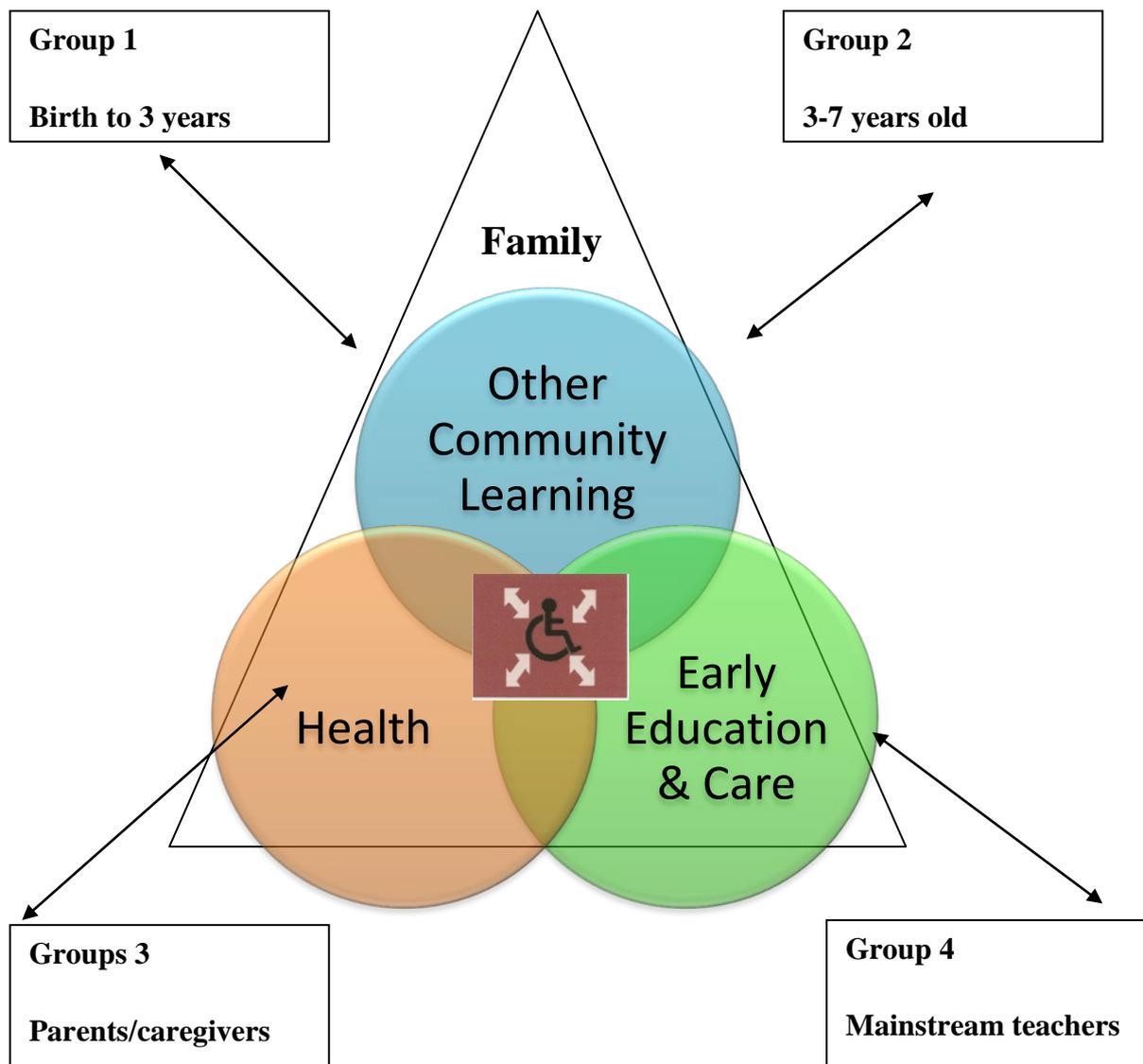
Figure 6.4:   The child is the centre of Bronfenbrenner's Bioecological Model

The child is in the centre as is in the micro- and mesosystemic levels of Bronfenbrenner's Bioecological Model both involved and supported by education and care, health and other community living. Involvement is bi-directional between CWPDs and the various groups involved.

6.4.3.1   Existing resources

Building on existing community networks in the rural areas is seen as an integral part of supporting CWPDs and their parents/caregivers. There are networks, organisations and centres in the rural areas that should be accessed wherever possible and some of these are discussed in this section.

In Bhekuzulu, for example, there is a non-profit community centre, which provides knowledge and ground for planting vegetables. The community are able to get these

vegetables at no charge and, in exchange, they care for the garden. This centre was keen to include CWPDs and their parents and promote inclusion as part of their centre. Consequently, the director signed the form included in Appendix 2.

In addition, Kwazamokuhle School is an outstanding school and needs to be used as a support and resource centre. The principal of the school was keen not only to assist but also to become very involved in the suggestions and solutions offered.

The Disability Action Research Team (DART) is an excellent team with experience in setting up and maintaining such centres. They are based in KwaZulu-Natal. This is one of their activities to which they are truly committed.

Training Resources for Early Education (TREE) is a first-rate centre from which to obtain assistance. TREE's mission is to promote and support quality, holistic ECD in marginalised areas. Moreover, TREE also impacts on woman's education. TREE is accredited with the Education and Training Development Product and provides onsite support and monitoring, access to low cost resources and educational equipment in this regard. TREE believes that *all* children must be given the chance to reach their full potential which is crucial to the suggestions and solutions offered here. TREE is a non-profit organisation.

African Solutions for African People (ASAP) assists organisations, centres or community development projects aimed at woman and vulnerable children. A key aspect of ASAP is that it provides capacity-building interventions that help to develop their organisations, improve their services, attain their goals and assist with sustainability. Furthermore, ASAP has demonstrated that grassroots organisations and their social networks of woman are capable of scaling up and replicating effective models of care for vulnerable children. The suggestions/solutions offered in this research study can be used in any of the provinces.

Once this assisted empowerment takes place at individual, family and community levels, the community will work together and achieve the set goals (Kgole, 2009: 85). Hard team work is needed. To succeed there must be a sense of urgency by all stakeholders, "a feeling that you know that something you care about is very wrong and must be made right" and stakeholders must believe that these changes are achievable. Furthermore, they must believe that there will be 'pain' and 'gain' in this change. This might appear to be a tall order, but with commitment it can work. It is important to remember in this framework that with short-term success, such as seeing an improvement in their children, or having their loneliness

alleviated and not being isolated, these stakeholders will jointly agree that the "risk/reward" ratio makes the framework the more beneficial option (Gambone & Connell, 2004:20).

Hard team work by all stakeholders is needed to make the framework a success in the rural areas

1. Parents/caregivers are the first group that need to be committed to making the framework viable

2. Fundraisers and NGO's are crucial in this framework

3. The community, mainstream schools, and other stakeholders need to be committed in the hard work required to ensure success.

Figure 6.5:   Team work

6.4.3.2   Funding

The researcher found that there are many black economic empowerment (BEE) groups that are willing to promote health, education and welfare in these areas. These groups acknowledge that financial assistance for this group of children at an early stage is crucial, and that this investment is reaped when the children finally become adults and have had an education that results in them becoming productive members of the community and breaking the vicious cycle of poverty. The following are a few of the groups that provide training for African groups and would need to be approached:

- African Institute of Corporate Citizenship
- Standard Bank Sustainability
- Africa turning golden

- All for Africa

- Africa.com

- African economic forum

- The foundation for the development of Africa

- Southern African Grantmaker's Association (SAGA)

- Ufadhili

In terms of government assistance, section 145(1) of the Children's Bill states that the MEC may, from funds appropriated by the relevant provincial legislature for this purpose, provide for:

- Facilities and services for prevention and early intervention (feeding therapy, and physio therapy for example and psychological support) services to families, caregivers and children; and

- The subsidisation of facilities and services by non-governmental bodies and other organs of state for prevention and early intervention services to families, parents/caregivers and children.

In view of the funds that are available, a person/persons would need to be appointed who would approach the various organisations.

6.4.3.3   Realistic outcomes of the framework

The goals of the framework are both short term and long term. In the short term they are to provide CWPDs with an opportunity to reach their full potential as soon as possible; for the parents of CWPDs to interact with their children; to assist in facilitating CWPDs transition to a mainstream school, and finally, to offer them support.

The long-term goals of the framework are to empower the parents/caregivers to become economically self-sufficient. The acquisition of the skills needed to become productive and to contribute to the community are longer term goals that those of developing and sustaining good family and social relationships. Finally, the training of teachers with regard to making adaptations for their learners in the class can be seen as a long-term goal.
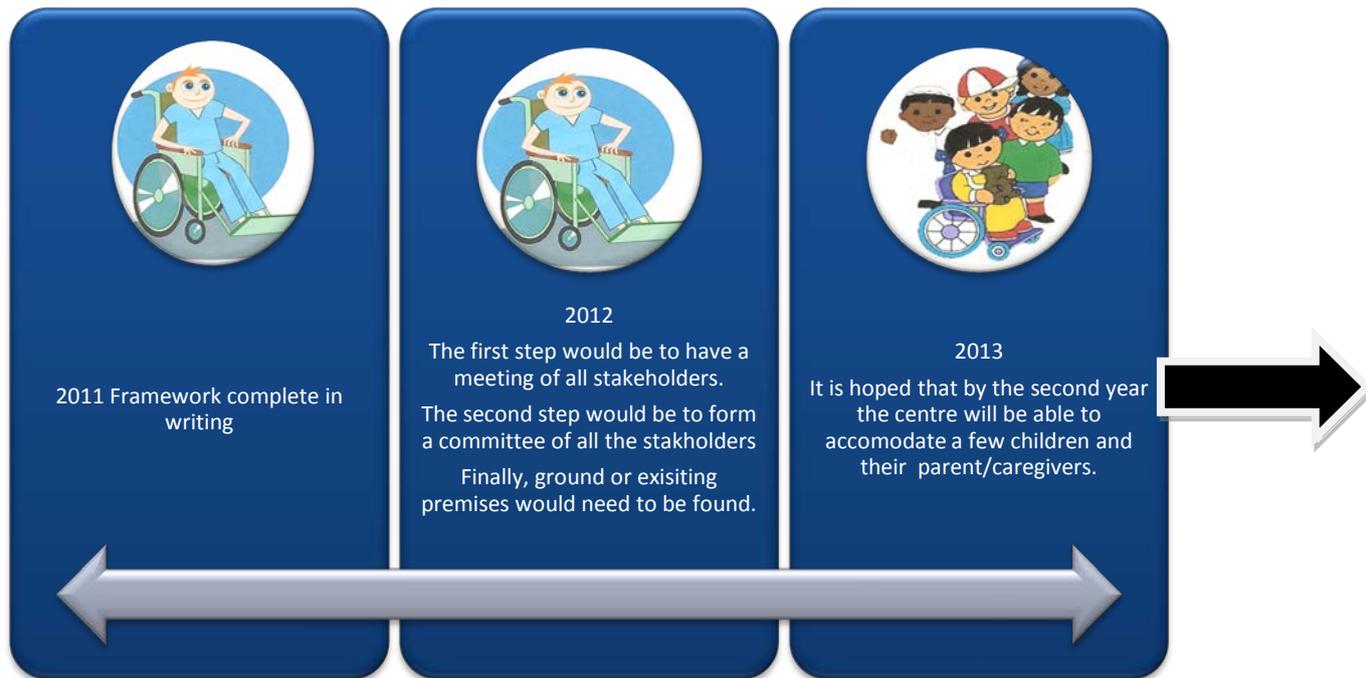
Figure 6.6: Timeline of framework

6.4.3.4 How will the framework function?

The first step would be to arrange a meeting of the various stakeholders such as parents, Sangomas, Teachers, The Ward Councillor etc. What makes this study unique in South Africa is that decades after the apartheid era this framework is directed at the community and will belong to the rural community and the stakeholders who have always been excluded. These will now include the N*kosi, Induna* and S*angomas*, members of the community who are held in high regard. Their input will thus be regarded as crucial in this framework. The researcher recommends that this takes place at Kwazamokuhle School, as all the stakeholders know where it is situated and the principal indicated that she could host the meeting. Once all stakeholders are present, a committee or board of trustees should be appointed. The second major challenge would be to find premises, or land where the centre can be built. As there are various options that have been suggested already, the committee will have to follow up on available options. Having found the site location, the committee has to look at costs either for building or doing renovations and then approach various organisations to ascertain which groups could assist. The groundwork will be the most time consuming as only once premises are secure can the centre get up and running.

It is envisioned that this centre will not be very large. As accurate statistics are not available as to the number of CWPDs in the areas, the researcher is aware of only some of the children

who remain in need. If the framework benefits five to six CWPDs the researcher would consider it feasible for a start.

6.5 TARGET GROUPS IDENTIFIED FOR THIS FRAMEWORK

6.5.1 Group 1: Birth to three years

6.5.1.1 Early intervention

Motivation

Early intervention consists of services that CWPDs and their families could access that would lessen the effects of their condition. Early intervention could be remedial or preventative in nature – remediating existing developmental problems or preventing their occurrence. Early intervention needs to begin as close to birth as possible. There are four reasons for intervention for CWPDs:

- To enhance the child's development
- To provide support and assistance to the family
- To maximise the child's and family's benefit to society
- Early intervention services also have a significant impact on the parents and siblings (microsystemic level) of an infant with physical disabilities, as these families in the rural areas feel disappointed and experience social isolation, added stress, frustration and helplessness.

The provision of such services would alleviate these problems.

Recommendations

CBR workers, nurses and social workers are needed for this age group. All three of these groups already have a presence in the rural areas but are not always easy to access. The motivation here is for all three services to be available at one location. Physio and speech therapy is essential, and for these services funds will be needed. Therapy students doing community service could possibly assist. Leaflets such as that included in Appendix 11 could be handed out. Stimulating toys to help infants reach their goals will also be needed.

6.5.1.2 Nutritional support

Motivation

Alleviate malnutrition and educate parents on what constitutes healthy food, and what types of food are recommended for infants with feeding difficulties. Malnutrition resulting from

feeding difficulties is preventable. Feeding therapy is not necessarily ongoing, and often one training session can be sufficient. Therapy students from the universities could be encouraged to do their community service with these infants, as these students are required to do community service.

Recommendations

There are local clinic sisters who can assist with training. There is also a mobile clinic in the rural areas, which could be used.

6.5.1.3   Promotion of infant wellbeing

Motivation

Prevention of illness, secondary disabilities and injuries in early childhood is particularly important, as this is the stage at which much potential damage can be averted.

Recommendations

Clinic sisters should monitor the children and notify the parents for referral should this be necessary. Immunisation can also be given by the mobile clinic, consequently ensuring that all children are immunised against measles.

6.5.2   Group 2: Three to seven years

The underlying assumptions in the followings suggestions/solutions of the framework is that early intervention and childhood education can prepare the CWPDs for attending a mainstream school by strengthening all areas required for coping in a mainstream environment thus making it possible for the child to remain at home during their formative years.   It is also assumed by the researcher that the Centre would have prepared the mainstream school for the arrival of CWPDs.

Figure 6.7:   The framework is ideal for small groups of CWPDs who can receive individual and intensive training (adjusting a table to accommodate the wheelchair by a physiotherapist). The relevance of this photo is the "vision" of what a class will look like in the centre, small and equipped for CWPDs.

6.5.2.1   Provision and adaptation of equipment

Motivation

Adaptations are critical in helping CWPDs to participate in routines and activities in a mainstream environment. Such adaptations maximise their functionality and prevent exclusion. By attending physiotherapy, occupational therapy and speech therapy with their children the parents will be able to carry over and work at what they have observed. This is what Bronfenbrenner referred to as *proximal processes,* where interaction occurs on a regular basis over extended periods of *time.*

Adaptations make it possible for children to participate and learn. CWPDs should be given opportunities to learn that develop their full potential. A child using a wheelchair needs to have a table that accommodates the size of the wheelchair or alternatively a lap tray. Hand weights assist children by reducing tremors and promoting better hand control. The purpose of an adaptation is to assist children to compensate for intellectual, physical or behavioural changes. They also allow children to use their current skills while promoting the acquisition

of new skills. The adaptations discussed below can make the difference between a child being merely present in the class and a child being actively involved (mainstreaming vs. inclusion)

Recommendations

Firstly, the most important recommendation for functioning in the classroom is that of correct seating. Specialised seating that supports and strengthens upper trunk control and allows for maximum use of hand function is a priority. Secondly, mobility training is essential. Provision must be made, for example, for the child to learn to use a walker. CWPDs must learn to ask mainstream teachers and peers to keep a path clear for them, promoting independence. Children who need wheelchairs should be taught to manoeuvre them with confidence, agility and ease. If they are unable to do so they must be encouraged to ask a peer to help "push" them.

Prone boards that assist the child with standing and strengthening their muscles at the same time should be used. As children do not spend long periods of time in them one prone board per group is sufficient.

Special devices like slanted boards can help CWPDs to participate in learning activities. Rubber mats that prevent their work from crumpling, as well as taping their work to the table, are essential. An occupational therapist can train the teacher and parent/caregiver in the use of these devices. In turn, the parents/caregivers will be able to train mainstream teachers and other parents. A weekly or two-weekly session with an occupational therapist is recommended. The same applies to the physiotherapist who can also assist parents/caregivers. Developing adaptations and accommodations for a child with special needs is a continuous process that also involves the child.

Finally, stable furniture is needed in which the children can be well positioned.

Figure 6.8:   Simple constructions such as these 'stairs' allow CWPDs to practice going up and down stairs, rather than face stairs for the first time when they arrive at the school

6.5.2.2   Provision of augmentative and alternative communication where necessary (AAC)

Motivation

Children who have very little or no speech should still be able to express themselves by means of gestures or communication boards such as PCS. This means that no child will be excluded. Teachers should also ensure children can answer questions to stories, using instructions such as 'show me ...". This encourages participation by all children and parents/caregivers. At the mesosystemic level of Bronfenbrenner's model, the proximal processes of acquiring and learning new skills with their children over "time" is an ideal intervention. Parents/caregivers subsequently become familiar with using these communication boards and can show other family members, mainstream teachers and new parents/caregivers how to do so. A speech therapist or teacher who has knowledge of AAC is crucial in this regard. The AAC Centre in Pretoria will be able to advise the centre as to whom to approach. Ongoing training is not necessary. High technology interventions are not recommended as these are costly and need high maintenance and, importantly, need electricity to operate. A communication system must be portable and therefore usable in all situations, making PCS an ideal choice.

PCS can also be used to play lotto, snap and memory games. They can also be used in teaching children themes and emotions. One system can thus be used in a multitude of ways keeping costs to a minimum and at the same time familiarising all children with the communication system used by their typically developing peers.

Recommendations

Stories are ideal as they teach vocabulary, increase concentration spans and promote participation in questions and answers. Teachers and parents/caregivers can learn to use communication boards. Cutting out pictures from magazines to assist with communication is also an inexpensive option. Parents/caregivers who have been trained can, in turn, train new parents. In addition, parents/caregivers who are familiar with the system can train both children and teachers at the mainstream schools in the four areas in this study. Communication is as essential as any other intervention as it promotes inclusion.

6.5.2.3   Promoting cognitive development

Motivation

CWPDs frequently function below their chronological age. It is essential that these children are given the maximum opportunity to make up for their physical disability wherever possible and to give them the opportunity to function on the same cognitive level as their peers. None of the homes visited by the researcher had any books, games or toys that the parents could use to interact with their children.

Recommendations

Educational puzzles, books and games should be provided, as they promote the development of literacy through the reading of stories and other literacy acquisition activities, as well as stimulation through memory games such as remembering items missing, cards in a sequence and finding the other half.

6.5.2.4   Encouraging language acquisition

Motivation

Before formal learning can take place, children need to develop listening skills in order to be able to execute multi-sequential instructions. Language acquisition is important so that children can express their emotions, especially CWPDs who need to indicate aspects such as feeling lonely and scared. Children with a good language foundation will find it easier to solve problems when they are placed in a mainstream school.

Recommendations

These activities do not require a great deal of funding, and can be taught to the parents/caregivers through demonstration and training. Asking children to play games where they have to repeat the instruction they have just heard or the names of food and so on are fun and require interaction. The singing of songs is effective, as songs for children are often of a repetitive nature. Open ended questions should be encouraged with answers that do not require a "yes" or "no", such as "tell me how you feel" – not "do you feel sad?"

Parents/caregivers need to know how to structure their conversations with their children. Stimulating children's imagination and language using toy phones or cut-out mobile phones pasted on cardboard is inexpensive, creative and imaginative – parents/caregivers need this knowledge, which they can once again pass on.

6.5.2.5   Developing gross and fine motor skills

Motivation

The development of gross motor skills teaches the CWPDs to make optimum use of their larger muscles. In the context of this research study, with its main objective of inclusion in mainstream schools, CWPDs need to know how to use walkers with confidence and to be able to manoeuvre their own wheelchairs where possible. Upper body strength development involves climbing onto their chairs and getting off, all skills that make them as independent as possible.

The development of fine motor skills teaches children to become more independent, including tying their shoelaces, and doing up buckles, buttons and zips. These are all skills that CWPDs require for maximum independence if they are to be placed in mainstream schools. Cutting, holding a pen and colouring in are school readiness activities that need to be developed. These activities are ongoing and do require great funding. Learning how to turn the pages in a book, pick up small items, and manage utensils for eating lessens their dependency on others. Once again Bronfenbrenner's Model is ideal as parents are interacting with their children both inside and outside the home.

Figure 6.9:   Teaching of fine motor skills even to a child who does not have a developed hand enables CWPDs to cope with tasks such as drawing.

Recommendations

Threading beads, reading board books, and playing with pegboards, sand and mud and mastering the tying of shoelaces on existing shoes and shoe buckles. A wide range of drawing materials such as thick wax crayons, shorter wax crayons, soft oil pastels and finger grips on pencil crayons allows the child experimentation and repetition. Dough play is sensopathic and includes the development of fine motor skills.

6.5.2.6   Developing the five senses

Motivation

It is essential that children are aware of their five senses and that they use these to their maximum potential. Hearing, for example, promotes listening to instructions and responding appropriately, whereas touch encourages CWPDs to use their hands to the maximum potential.

Recommendations

The learning of the five senses is integrated into all activities on a daily basis. This can also be incorporated into themes such as 'My body'. The curriculum goal is to enhance the children's and knowledge about how they experience the world through their senses-and to

promote acceptance about differences. They need to be aware that their senses keep them safe and teach them things.

6.5.2.7   Opportunities to become reliant in self-care

Motivation

Becoming as independent as possible is crucial for all aspects of inclusion, and includes mastering such activities as undoing a belt. These activities practised over a three-year period will enable children to reach their potential. Instead of sitting at home, parents/caregivers are taught what to do to maximise their children's potential.

Recommendations

Children need to be taught and encouraged to do as much for themselves as possible, such as going to wash their hands rather than bringing a cloth to the child; also fetching their own lunch, getting onto their chairs.

In summary, there are many other recommendations that can be made in this age group, however, that is not the purpose of this framework. This framework is intended to provide the reader with some insight into the infinite number of activities that can be done with CWPDs.

Many of these activities can be done using waste materials such as shoeboxes for building and plastic bottles for making bird feeders. It is about being innovative and sharing. Moreover, in such a framework, TREE is excellent at promoting these activities, and Kwazamokuhle School will provide a wealth of information to parents/caregivers.

6.5.3   Group 3: Parents/caregivers

6.5.3.1   Training parents/caregivers as facilitators

Motivation

The training of parents/caregivers is the main thread that runs through this framework – that is, the involvement of parents on the different levels of the Bioecological Model. By training the parents/caregivers on how to work with and assist CWPDs it is hoped that they can assist other children with disabilities who are mainstreamed and, in turn, train their parents/caregivers. It is also hoped that parents/caregivers will go into mainstream schools not only to act as facilitators for their children but also to train mainstream teachers and assist them in adapting the environment.

Recommendations

Parents should interact with their children daily. According to this framework, the different professionals will assist both the CWPDs and their parents/caregivers. With time and when they feel comfortable with their children, they can start to demonstrate and transfer their skills to new parents and other members of the community.

6.5.3.2   Developing parent/caregiver skills

Motivation

As the parents are part of the micro- and mesosystems, they need to be included in any planning that takes place. When parents/caregivers are stressed it has an impact on the children. The poverty these parents live in undoubtedly causes stress, which is exacerbated by the limited opportunities for employment. These parents/caregivers need to be provided with opportunities for self empowerment.

The researcher, as a teacher in a specialised school, has noted that there is a gap in the market for items such as the sponge inserts for wheelchairs that are covered in durable materials that must be made the exact size for each and every child. Parents/caregivers can be taught the skills of making these inserts by occupational therapists. This niche provides a great opportunity for a business, as all CWPDs need equipment that meets their individual needs.

Recommendations

In the interviews with the parents/caregivers, what emerged was their 'dream' of earning an income. When asked what they would like to produce, these people were clearly resourceful. Accordingly, answers ranged from learning how to weave to having some land on which they could have a poultry farm. Whilst a poultry farm might not be practical, skills such as bead making and weaving are easy skills to learn, and members of the community could teach them these skills. There is, for example, a weaving centre in the area visited. It is simply a matter of looking at existing resources and using them where possible. The researcher also strongly believes that when there is such eagerness and excitement about a possible opportunity, it should be offered to them. Huff and Johnson (1998) corroborate with this and state, "[t]o empower people is to help them find strengths and worth within themselves".

6.5.3.3   Supporting parents/caregivers

Motivation

There are both social workers and CBR workers in the areas visited. They need to be able to come to a central point in order to meet with parents/caregivers. Parents need to be given training and support in coming to terms with having CWPDs. More support is needed when the mother is ostracised and accused of witchcraft, for example. Many of these parents/caregivers face long, lonely days with no social contact and no friends. They are sent home with a difficult baby and have no idea where to turn. Many mothers are not aware of disability grants, and consequently need to be made aware of the various support services that are available.

Recommendations

The Department of Social Welfare needs to be approached and arrangements made for the social workers in the areas, as well as the CBR workers, to come to the setting where the parents and children are located. This would be an example of making use of existing resources. Bringing parents/caregivers together with others in similar circumstances would encourage them to share their feelings and this would alleviate their feelings of isolation, loneliness, disappointment and fear.

6.5.3.4   Training parents/caregivers in home support

Motivation

The motivation to train parents/caregivers in home support echoes the training in various skills that enables parents/caregivers to assist their children, for example feeding, communication and seating.

Recommendations

Parents need to be supported in assisting their children in the home situation and encouraging siblings and other family members to interact, communicate and assist with the CWPDs' daily care.

6.5.3.5   Promoting positive parental attitudes towards their CWPDS

Motivation

Parental attitudes refer to the beliefs and attitudes that parents hold for the future development of their children. Attitudes held and expressed by parents/caregivers strongly influence the opinions of others towards disability. This is very important when children attend mainstream school for the first time, where caregivers need to promote a positive image to staff and peers. Parental involvement includes support and expressions of interest in

the inclusion of children in the mainstream schools and in society (Bennett & Hay, 2007:383).

Recommendations

With the support of CBR workers, social workers and other parents, parental involvement will be built through communication in informal and non-threatening environments.

6.5.4 Group 4: Teachers in mainstream schools

6.5.4.1 Preparing mainstream teachers and schools

Motivation

CWPDs once they are ready only need to be integrated into mainstream classrooms as soon as possible. This early integration affords children the opportunity to experience the same education as their peers and allows them to become socially, emotionally and intellectually integrated. The most important aspect of this framework is to prepare the CWPDs for mainstream schooling. The interviews in this research study indicated that mainstream teachers need to be trained in how to deal with CWPDs. At present if inclusive education is to be truly effective there is an urgent need for teachers to become more knowledgeable of how best to handle CWPDs. In terms of this framework it will be the parents/caregivers who will inform them. According to the literature, one of the major implications of developing a policy of inclusive education is training teachers to work with CWPDs. It is for this reason that parental involvement is essential on the mesosystemic level. Furthermore, it is disturbing to realise that, despite all government's policies, teachers in mainstream schools still lack the appropriate training.

The objective in this framework is for parents/caregivers not only to train teachers but for teachers to visit the centre to obtain ideas. In so doing the centre will become a resource centre. They will thus assist in the facilitation of CWPDs as has been discussed.

Recommendations

The idea behind this framework is to facilitate the inclusion of CWPDs as soon as possible and as practically and feasibly as possible. Moreover, it is envisaged that continuity of training and support in formal education will be provided. This means that *any* teacher can visit the centre at any time, with the centre acting as a resource centre. Generally speaking, teachers do not have to have CWPDs in their class; consequently it is hoped that, by visiting the centre, teachers will be enlightened about how easy it can be to accommodate a CWPD. This understanding may also lead to an attitudinal change. Until South Africa changes its

teachers' training curriculum, we need to provide immediate examples on how to accommodate our CWPDs.

6.5.4.2 Laying the foundations for a CWPD's inclusion in an inclusive environment

Motivation

During the first few years of life, children construct a view of themselves and their world. Their world should be an inclusive world. If community members and mainstream teachers and children are taught to be more accepting of CWPDs, it will enhance their self-worth and build their self-esteem and confidence. A young child's sense of reality is formed from this sense of belonging and acceptance. *All* children deserve opportunities to participate in typical childhood experiences and to feel accepted and thus develop a sense of belonging.

Recommendations

If the recommendations discussed above are included in the daily lives of CWPDs, the transition into mainstream schools as they enter the mesosystemic level should be accomplished with confidence and ease. Parents/caregivers will be encouraged to take their children to church and on family outings to promote inclusion – this form part of this mesosystemic level. Transport and finances are problems that need to be acknowledged for example the Minister of the Church said he would see if he could organise transport if possible, LOTTO does also provide busses if applied for. There are obstacles but the community needs to work as a team to overcome them.

6.5.5   Conclusion:

The recommendations included in this framework may be a useful lens through which to look when attempting to reduce the impact of the negative influences facing CWPDs. It is a framework that can be reproduced in any other rural area of South Africa, as it is easy to duplicate and outsiders should be encouraged to visit, observe and carry over what they have seen.

A few final words about the framework: It is envisioned that the centre when it is developed will be a site of excellence. The centre has to have and maintain a high standard, parents/caregivers once trained will need to *approach* mainstream schools in the areas to inform them about the centre and encourage reception phase teachers to visit the centre. The KwaZulu-Natal Department of Education, which were very helpful throughout this research,

can play a crucial part in encouraging schools to use the centre to raise the awareness of their teachers training of teachers would need to take place on an ongoing basis.

This centre marks the beginning of a long journey of relationships with the entire community. "It takes the family and community on the micro and mesosystemic levels of Bronfenbrenner's Bioecological Model to raise CWPDs". The researcher acknowledges sustainability as with all new projects can be a problem, but feels that the guidelines and recommendations made above if followed will ensure its sustainability.

6.6   STRENGTHS AND LIMITATIONS OF THE STUDY

The strengths and limitations of the study must be acknowledged prior to delineating the implications of the findings for subsequent research, practice and education.

There were many strengths to this study, one of which was the researcher's gatekeeper. The gatekeeper was well qualified in all areas and proved perfect for the task, as she was able to offer the parents both advice and comfort. It was by watching her interactions with the parents/caregivers that the researcher realised and confirmed that, whatever the recommendations that were going to be made the parents/caregivers would need to be included. Furthermore, the gatekeeper knew the area very well so finding the parents/caregivers in these remote areas was no problem at all. The gatekeeper also advised the researcher as to the necessary respect that was needed when meeting the *Nkosi* and what to do in a house of mourning. The gatekeeper also knew all the stakeholders so getting to meet them was no problem.

Secondly, Kwazamokuhle School and all its staff were very helpful and were very keen to assist wherever possible.

Finally, a key strength was the wealth of information provided by all the participants in this research study. Their humbleness, their plight and their willingness provided the rich data, and without this, the researcher would have had no narrative. They also provided significant suggestions that the researcher was able to use in the development of the framework.

The limitations of the study, on the other hand, were that the following:

- The ethnographic research in this study was extremely time consuming and very expensive. Because the researcher had to return to the rural areas twice to extend research questions the use of the gatekeeper became extremely expensive.

- Spending time living in the rural areas and witnessing the difficulties and experiences becomes extremely difficult when it becomes a narrative. There are situations that are extremely difficult to narrate and much of the 'richness' can be lost.

- The same difficulty applies in convincing a reader who is "reading" the dissertation that there is a strong need for specific and immediate intervention. Being part of the community and reading about the negative impacts CWPDs face is not conducive to making an objective decision.

- Finances in this study were limited. As the GDE only pays for two years tuition, the rest of the expenses were borne by the researcher. Moreover , it was necessary to take unpaid leave to complete this study, as the GDE was only prepared to grant the researcher three days per year for her doctoral thesis. This seriously hampers students who should be encouraged to study further (see Appendix 9 for letter written to the researcher by the GDE).

- The researcher only understands very basic Zulu and as all the interviews were conducted in Zulu and later transcribed, much information could have been lost. The transcribing of all the interviews was very expensive, as was the gatekeeper.

- As much of the material was translated it was impossible to always explain the pain that these parents/caregivers feel, and much could have been lost and, indeed, watered down.

- This study was restricted to four areas, that is, Loskop, Zwelisha, Bhekuzulu and Wembezi, and the nine families that were chosen for this research. The families involved in this study all had children at Kwazamokuhle School which catered for their needs well. The findings of this study cannot be generalised to the whole province or other areas of the country, as schools that offer the support that Kwazamokuhle does might not be available in other provinces. The researcher was also unable to interview parents whose children had not been accepted by Kwazamokuhle School because they had no hand function. The reason for this is that there is a shortage of staff at Kwazamokuhle to feed children and toilet them in the boarding school children attending thus need to be independent. There is also no speech therapist at the school to teach feeding techniques. The researcher does not know where children who have no hand function are being educated at present – if at all.

- The biggest limitation is that there are so many negative influences facing CWPDs that it is difficult to prioritise them. It was for this reason that the researcher decided to begin with early intervention and inclusion to mainstream schools, and build a framework of the micro- and mesosystemic levels only.

6.7 RECOMMENDATIONS FOR FURTHER RESEARCH

There are many recommendations for further research that can be made, not necessarily all within the scope of this study.

The researcher feels that the establishment of this framework is an ideal research topic for further research. It would constitute a follow-up study and would be a project in itself. From this many themes would emerge, such as the study of CWPDs who are prepared for the mainstream environment vs. CWPDs who have had no support. It would be interesting for the researcher to know how parents/caregivers feel about having their isolation alleviated. In light of the National Health Insurance which has now been approved in South Africa, it would be interesting to do a longitudinal study on whether the benefits and services provided by this scheme do indeed reach CWPDs in the rural areas and make a positive impact on their lives.

It would also be interesting to research the role that parents/caregivers can play at other mainstream schools in the area by helping teachers and other parents/caregivers to change their attitudes and to transform classrooms so as to accommodate CWPDs.

Finally, an interesting follow up would be to research whether parents/caregivers who have learnt new skills, such as the making of wedges and sponge inserts for wheelchairs, succeed in lifting themselves out of the deprivation trap by marketing their products and establishing an enterprising business. Transport to the centre and adaptations to the road will need to be organised. The researcher is confident this can be done as was seen in the computer centre that was built and developed in the area and who offered land.

6.8 CONCLUSIONS

This study was primarily guided by the researcher's quest to understand the impact of negative influences facing CWPDS in rural areas and what could be done to reduce these negative influences. The first part of this quest was achieved through the rich data that were collected. However, the second and final part cannot at this stage be ascertained. Although a

framework has been recommended, the researcher is not is a position to know without doubt that it will succeed. These recommendations inform the reader about the context within which this research was based and the themes that contributed to the framework. Consequently, they are a synthesis of the findings in the study.

Change does not happen overnight. Still, there are many things that can be done immediately that would make a difference. Even though there is no quick fix, if we do not start now, with urgency, with unity, we will never achieve anything in the long term either. We certainly cannot wait for government to deliver on its promises, as it became clear as the research progressed that the policies are very good, but practice and policy do not meet. Without a sense of urgency, children such as those in this study will be forgotten, and the loss of potential for our CWPDs would be unforgiveable (Bloch, 2009:29).

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Appendices

APPENDIX 1: Questionnaires used

SELECTION OF THE SAMPLE

Selection of the sample

The researcher selected a sample design which should be reliable and appropriate for this research study

TYPE AND SIZE OF THE SAMPLE

The study indicates that concerning disabilities the respondents in this investigation fall into the following groups:

- Children with physical disabilities
- Children without disabilities
- Educators
- Community members-nurses, social workers, church leaders
- Parents of CWPDs
- Youth in the community

RESEARCH METHOD

This was the most crucial part of the research in order to obtain the necessary information. This research started with the study of literature done with a view to support the introduction of the problem as well as to define and elucidate the terms.

QUESTIONNAIRES (Relating to violence)

EDUCATOR'S INTERVIEW

1   Are you aware of any violent acts towards CWPDs in this school?

2   If so, what happened?

3   What did you do about it?

4   Do you think it was effective?

5   Does your mission statement include a school safety plan?

6   Are the parents and community involved in violence prevention programmes?

7   Are truancy rates of CWPDs increasing?

8   Tell me more about violence towards the CWPDs? What do you think contributes to this?

9   In your opinion what do you think can be done to reduce violence towards the CWPDs?

10 Are you satisfied with the SAPS ability to follow through with crimes that are reported?

LEARNER INTERVIEW SCHEDULE

1   Do you experience any violence in your day?

2   What happened?

3   How did you feel?

4   Are there any areas that you are afraid to be in?

5   Will you report any incidents of violence and bullying?

6   If you do who will you report it to?

7   What do you think causes violence?

8   What do you think can stop violence?

PARENT INTERVIEW SCHEDULE (parents of children with physical disabilities)

1   Do you feel afraid that a violent act might be committed against your child?

2   Is so, where and by whom?

3   Do you feel you will have the necessary support if this should happen?

4   What do you think the causes of violence are towards your child are?

5   What do you think you are able to do about this?

6   Are you involved in school and community activities?

7   What do you think government can do to help your child?

8   Do you think if everybody in the community works together, this violence can stop?

COMMUNITY MEMBERS INTERVIEW

DESIGNATION (Therapists, Social workers, nurses etc)

1   Are there any violent acts against CWPDs in the community that you are aware of?

2   What do you think are the causes of this violence against CWPDs in your community?

3   Can you give any examples of violence that you have experienced?

4   Are you involved in any community activities?

5   Do you think that being involved in the community in any way can reduce this violence?

QUESTIONNAIRE RELATING TO INCLUSION

1.   DEFINING DISABILITY

   1.1.   What is disability?

   1.2.   What do you think of when you think of disability?

   1.3.   How would you describe a CWPDs?

   1.4.   What do you think are the causes of disability?

2.   ATTITUDES TOWARDS CHILDREN WITH PHYSICAL DISABILITIES IN THE AREA?

   2.1.   How are CWPDs treated in your area?

   2.2.   What is their situation here?

   2.3.   According to your view what are the disadvantages of living in a rural area?

3. **ATTITUDES OF FAMILY MEMBERS** (parents, siblings, relatives and friends)

   3.1.   What was your initial reaction as parents after being told about the disability of your child?

   3.2.   What was the attitude of your spouse towards you and the disabled child?

   3.3.   What is the attitude of the siblings towards the disabled child?

   3.4.   What is the attitudes of your friends towards the CWPDs?

   3.5.   Did you share your problems with your friends?

   3.6.   What was the attitude of your relatives when it became apparent that your child was disabled?

   3.7.   What was the attitude of the community towards your child?

   3.8.   What is the status of the disabled child in your culture?

   3.9.   Does the community share/care concern for your child?

   3.10.   Are you aware of any organisations for CWPDs in your area?

   3.11.   Do you accept the Disability of your child?

4. PROBLEMS AND NEEDS OF CHILDREN WITH PHYSICAL DISABILITIES

   4.1.   What do you think are the major problems facing CWPDs?

   4.2.   Do you think the needs of CWPDs are different to those of able-bodied children?

QUESTIONS

1 Do you wish your child to be separated from mainstream schooling?

2 According to you view, what are the advantages of placing children with disabilities in a mainstream school?

3 According to children with physical disabilities, what are the advantages of being placed in a mainstream school?

4 Would you prefer your child to be in a special school?

5 Do you wish to attend initiation school?

5. RIGHTS OF CWPDs

   5.1.   Do you think CWPDs have special rights?

6. INTERVENTIONS

6.1. How could people in your area help to improve and include CWPDs in all areas of the community?

6.2. How could you improve the situation of CWPDs?

7. According to your view as parents, are CWPDs exploited?
8. According to you view are they discriminated against?
9. Do you believe that the existing belief in the community is that they are incompetent?

THE FOLLOWING QUESTIONS NEED TO BE ASKED IN ORDER TO PROMOTE BOTH EDUCATIONAL AND SOCIETAL INCLUSION AND HAVE AN UNDERSTANDING OF HOW TO BEST ACHIEVE THIS

1 What experiences did you encounter in your society due to your disabled child?
2 According to you, what are the disadvantages of having a disabled child?
3 Which problems do you experience because of your disabled child
4 Who cares for your child when you are not available?
5 What type of report do you usually get from caretakers?

THE INVOLVEMENT OF PROFESSIONAL HEALTH WORKERS IN FAMILIES WITH DISABLED CHILDREN

According to the literature review, the life of a disabled child needs the devotion and assistance of professional health workers. The professional health workers play a major role of bringing forth all the relevant techniques of improving the physical and healthy conditions of CWPDs. The provision of walkers to make the children mobile, or communication devices are essential for promoting full inclusion. Their attitudes and knowledge play a crucial role in the life of the disabled and their families.

Questions will be asked to determine whether the professional health workers or the paramedical staff is involved in the care and treatment of the disabled child, more especially as part of a mutual relationship in their families.

1 What is the professional health worker's attitude when you bring your child to the clinic for a check-up?
2 Is transport to the clinics a problem for you and your child?

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THE ROLE OF THE CHURCH?

The following question was posed to determine the role of the church towards the child with a physical disability.

1 How often do spiritual groups visit you to encourage you concerning the care of your child?

2 Does the church accept CWPDs the same as children with no disabilities?

3 What is the attitude of the church or spiritual group towards CWPDS?

4 Do you think that witchcraft is a cause of disability?

5 Is the family blessed to have a member with a disability?

GENERAL QUESTIONS REGARDING AND RELATING TO INCLUSION

1 Do CWPDS need a special place to stay?

2 How much trouble is it to have CWPDs at a party, in town or church?

3 Do CWPDs need to be educated?

4 What do you think are the causes of disability?

5 Do you know of a method of preventing disabilities from occurring?

WHAT DIFFERENCE WILL THE CONTRIBUTIONS OF CHILDREN MAKE?

Listening to children and what they have to say about violence and inclusion and possible solutions makes a big difference. Adults don't always know what concerns children most ((Violence against children, 2005:7). It is only possible to understand and prevent violence if children themselves speak out about their ideas and experiences.

QUESTIONS POSED TO PEERS REGARDING INCLUSION? (Ben-David, 2003).

1 Would you have a CWPD as a best friend?

2 Would you go to town with a CWPD?

3 Would you play games with a CWPD?

4 Will you invite a CWPD to your home?

5 Do you think a CWPD should be able to come to your school?

6 How would you feel if you had a brother or sister with a disability?

7 Are you prepared to eat with a child with a physical disability?

8 Do you laugh when you see a CWPDs?

9 Are you afraid of CWPDs?

10 Do you feel sorry for CWPDs?

11 Do you tease CWPDs?

12 Can you have fun with a friend with a physical disability?

13 Would you be prepared to share a desk with a CWPD?

14 What are the disadvantages of attending school with the disabled?

15 What are the advantages of sharing a school with the disabled?

QUESTIONS POSED TO CWPDs

1 Do you have a best friend?

2 Would you like to go to your friends houses?

3 Are you afraid to go out without your mom/gran (question asked according to the child's background)?

4 Does anybody tease you?

5 Who can you tell?

6 Has anybody ever hurt you?

ATTITUDES TOWARDS DISABILITIES AND WITCHCRAFT

According to the literature study most people in the black community believe in the existence of witchcraft and its power. Questions on attitudes towards disabilities will be asked to determine whether disabilities are associated with witchcraft, since many of the youth in the black community are involved in burning houses and people as promoted by witchcraft ideologies (Baloyi, 1997:214).

1   Do you think the disable are bewitched?
2   Are the parents of disabled children bewitched?
3   Are the parents witches?
4   Do you think disabilities are a punishment or curse?

THE IMPACT OF THE ATTITUDES OF TEACHERS TOWARDS INCLUSION

The attitudes of teachers comprising the willingness to partake in the implementation of inclusive education towards CWPDs will affect whether the implementation of inclusion will be successful or not (Sidogi, 2001:84). Teacher attitudes and values play a central role in the successful implementing of inclusion. The way teachers perceive competence in inclusive education, the values they hold with respect to the task and their concern about the interpretation of the change also form their attitudes towards inclusive education (Sidogi, 2001:84). It is therefore necessary to understand these attitudes and perceptions.

1   What does inclusive education imply?
2   What does the concept "learners experiencing barriers to learning" imply?
3   Does your school provide adequate ground and building facilities for CWPDs?
4   Do you think that inclusive education can work in your school? Why?
5   What are the attitudes of teachers in general towards implementing inclusive education?

APPENDIX 2: Consent form

Sanibonani

Igama lami nginguBrenda, ngingowakwaBen-David. Ngiliqhamukisa kwelaseGoli lapho engizinze khona, ngizimisele ukuba nani isikhashana esifishane lapha kwelaseMtshezi. Ngisebenza ngabantwana abakhubazekile, ngizokujabulela ukwazi nokuthola kabanzi umqondo nekhono umphakathi walapha eMtshezi namaphethelo onalo ngabantwana abakhubazeke ngokomzimba. Ukuhambela kwami lapha eMtshezi kuyingxenye yocwaningo lwezifundo zami, zoqeqesho lwaseNyuvesi yaseMzansi neAfrica. Lolucwaningo luzongisiza ekwenzeni abantwana benu amalunga amukelekile omphakathi waseMtshezi namaphethelo.

Ngiyaniqinisekisa ukuthi amagama enu nawabantu abathintekayo, nolwazi engizoluthola nenizonginika lona ocwaningweni engizolwenza nani, konke kusezandleni eziphephile futhi ngizokugcina kuyimfihlo. Nivumelekile ukungimisa ningibuze imibuzo makukhona lapho ningaqondi khona noma kungezwakalanga noma kungezwakali. Ninalungelo futhi lokungiyekisa uma ningasafuni ngiqhubeke nocwaningo engilwenzayo, kanti futhi uma ningakhululekile noma ningathandi ukungiphendula imibuzo engizoyibuza noma engiyibuzayo, nikhululekile ukwenza njalo.

Inhloso yami enkulu ukusiza abantwana abakhubazekile, ngakho-ke maninemibuzo ezoba lusizo kini nikhululekile ukuyibuza nami ngizozama ukuyiphendula ngokwethembeka njengoba ngineminyaka eyishumi nesishiyagalombili ngisebenza ngabantwana abakhubazekile.

Ngiyabonga.

Obhalile

NguBrenda Ben-David

Igama: ....

Ushicilelo: ....

Ngikuqondisisa kahle konke okuqukethwe yilencwadi futhi ngizimisele kakhulu ukubamba iqhaza kuloiucwaningo.

APPENDIX 3: Colour Coding to find emerging themes.

(1)

1. Would you have a CWPD as a best friend?

   YES

2. Would you go to town with a CWPD?

   YES

3. Would you play games with a CWPD?

   YES

4. Will you invite a CWPD to your home?

   YES

5. Do you think a CWPD should be able to come to your school?

   YES

6. How would you feel if you had a brother or sister with a disability?

   FINE WE WILL HAVE THE SAME BLOOD

7. Are you prepared to eat with a child with a physical disability?

   YES

8. Do you laugh when you see a CWPDs?

   YES

9. Are you afraid of CWPDs?

   NO

10. Do you feel sorry for CWPDs?

   YES, SOME LOOK FUNNY AND
   OTHER CHILREN LAUGH AT THEM

11. Do you tease CWPDs?

YES

12. Can you have fun with a friend with a physical disability?

YES

13. Would you be prepared to share a desk with a CWPD?

YES

14. What are the disadvantages of attending school with the disabled?

N\A

15. What are the advantages of sharing a school with the disabled?

They will be equal
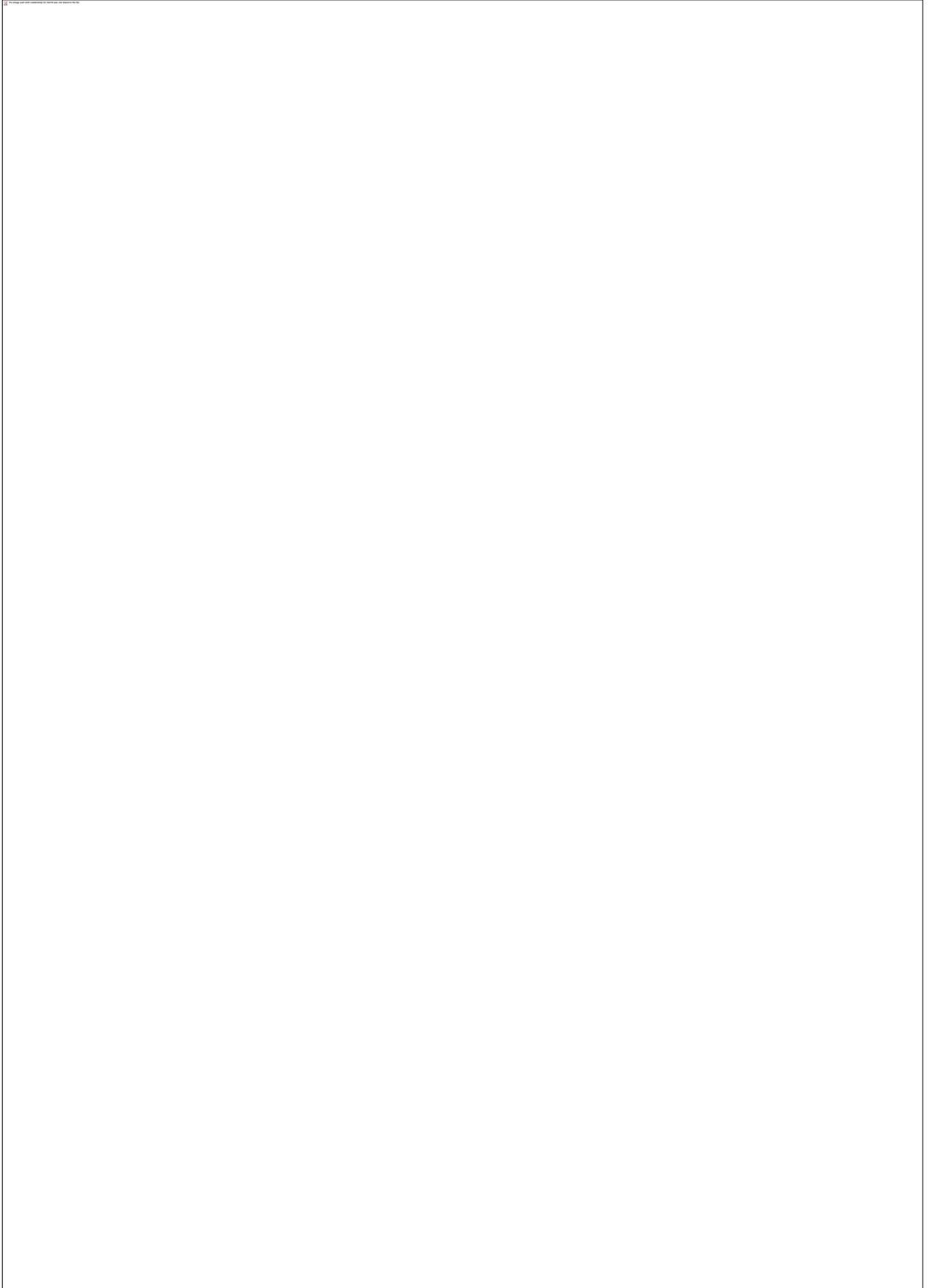
The image part with relationship ID rId3 was not found in the file.

QUESTIONNAIRE RELATING TO INCLUSION

1. DEFINING DISABILITY

   1.1. What is disability?

   Disability is when you are not okay upstairs + maybe if you are involved in a car accident and break a leg sickness as well

   1.2. What do you think of when you think of disability?

   Tragedy + misery, pity → people feel shame for you and you will always have difficulty

   1.3. How would you describe a CWPDs?

   I think of a child who has difficulties, a child who wants to do things that others his age can do but he cannot — barriers — in doing things

   1.4. What do you think are the causes of disability?

   being upset in pregnancy, mother bewitched too much stress, epilepsy, + you got burnt you get disabled

2. ATTITUDES TOWARDS CHILDREN WITH PHYSICAL DISABILITIES IN THE AREA?

   2.1. How are CWPDs treated in your area?

   Well, especially my son, my son is also happy and does not have a problem

   2.2. What is their situation here?

   fine

   2.3. According to your view what are the disadvantages of living in a rural area?

   painful heat because they to cannot do what they do and up being aggressive

   what I can see as a problem is the toilet toilet is outside, and it is not built nicely my own accomodation as I am staying with my sister

QUESTIONS POSED TO PEERS REGARDING INCLUSION? (Ben-David, 2003).

1. Would you have a CWPD as a best friend?
   1) Yes   1) Yes   1) Yes   3 ✓

2. Would you go to town with a CWPD?
   1) Yes   1) NO   1) Yes   2 ✓ 1 ✗

3. Would you play games with a CWPD?
   1) Yes   1) yes ~not running ones~   yes

4. Will you invite a CWPD to your home?
   1) Sometimes
   2) yes
   3) yes

5. Do you think a CWPD should be able to come to your school?
   — NO — the school is not for children that are
     paralysed other children will laugh at them
   — n — yes

6. How would you feel if you had a brother or sister with a disability?
   1) Bad
   2) PAIN FOR THEM
   3) No Problem

7. Are you prepared to eat with a child with a physical disability?
   1) yes   1) yes   1) yes

8. Do you laugh when you see a CWPDs?
   1) NO   1) yes   1) NO

9. Are you afraid of CWPDs?
   No   1) NO   — NO

10. Do you feel sorry for CWPDs?
   1) Yes + some have to sign
   2) Yes — they cannot do anything - they cannot run
   3) Yes — they get busten of

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11. Do you tease CWPDs?

1| No

3| No — other childre will

3| No — othe r wan g

12. Can you have fun with a friend with a physical disability?

1| Yes   2) Yes   3| Yes

13. Would you be prepared to share a desk with a CWPD?

1| Yes   1| Yes   1| Yes

14. What are the disadvantages of attending school with the disabled?

15. What are the advantages of sharing a school with the disabled?

No — not this oc — no teacher — no people will to help with talets. Nobody will play with them, they will get pushed they can't use their hands for most games Alot of teasing here. I get tease n a lot

— small legs and Big head

Bad IDEA — they will be laughe n dot faught with — Childre must stay in th special shoo they can't do nothing

EMERGING THEMES:

1. **ACCEPTANCE**

"They are the same as us'

2. **PITY**
   "I feel sorry for them"
   "I feel bad for them"
   "Yes, they cannot do anything"
   "Yes, they get laughed at"

3. **MOCKED/TEASED**

Acceptance but not total "can come to mu house only sometimes"

" Some look funny and other children laugh at them"

4. **ACCEPTANCE/CONDITIONAL**

"I will have one as a friend but not go to town with them" (Its too much work).

5. **NON-ACCEPTANCE**
   " I laugh when I see them"
   "They should not be allowed to come to this school, other children will laugh at them"

APPENDIX 5: Positive outcomes to the survey conducted.

I _SAMSON MUZIWAKHE DLADLA_ my occupation is _WARD COUNCILLOR_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _26 - 05 - 2010_   SIGNED: _____

CONTACT 073231 9716

SAMSON M. DLADLA

SIGNATURE

DATE 26/05/10
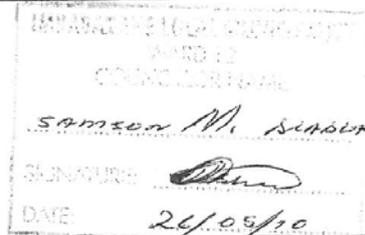
I _FEZILE   HADEBE_ _036 352 4552._ _083 9742956_, my occupation is _Thekazulu Self Sufficient Project PROJECT DIRECTOR_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

I do feel that the community centre is needed in
this community because there is no facility that
caters for disabled peoples skills development around this area.

DATED: _26/05/2010_   SIGNED: _____

I _PHUMZILE   MABASO_   , my occupation is _Parent of disabled child_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

I Support THE IDEA---

DATED: _26.05.2010_   SIGNED: _MABASO_

I KHANYISILE KHUMALO my occupation is Community Rehabilitation
and I feel that this community centre with the correct resources can address the needs of Facilitator
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 26-05-2010   SIGNED: Khumalo.

I SAMUEL M. MNCULWANE, my occupation is INJUNA.
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

Ngiyasibona isidlingo sokwakhiwa kwesikhungo
sigqiza umphakathi wesizwe. Omama
abangasebenzi nabantwana abakhubazekile.

DATED: 27-05-2010   SIGNED: Mnculwane.

I NXELE SIBONGILE, my occupation is EDUCATOR
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 01-06-2010   SIGNED: Hlubele

I Katrien Steyn, my occupation is Occupational Therapist,
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 28/5/2010   SIGNED: Steyn

* some areas specifically need discussion. All depends on good
planning and excellent management!

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I _PN. Strydom_, my occupation is _SM._
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _28 June 2010_   SIGNED: _____

I _MRS A.S. MADLALA_, my occupation is _EDUCATOR_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _02.06.2010_   SIGNED: _____

I _S. P. DLAMINI_, my occupation is _SCHOOL PRINCIPAL_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _04 JUNE 2010_   SIGNED: _____

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I Gugu Jamile , my occupation is EDUCATOR
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 01-06-2010   SIGNED: _____

and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 26.05.2010   SIGNED: _____

I ZONDANI HAPPINESS MTHALANE, my occupation is PARA-LEGAL
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 28-05-10   SIGNED: _____

UMTSHEZI SUPPORT CENTRE

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I _P. M. DUMA_ , my occupation is _DRIVER_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _02.06.2010_   SIGNED: _PMA_

I _THULECENI DLAMINI_ , my occupation is _Comm. HEALTH WORKER_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

I FEEL THIS CENTRE IS NEEDED AND IT WILL HELP
PARENTS AND CHILDREN WITH DISABILITY A LOT.

DATED: _26/05/2010_   SIGNED: _T.L.D_

I _Lungi Radebe_ , my occupation is _Community Rehabilitation Facilitator_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

I feel that this project is needed and it will help
parents and children with disability in the
community.

DATED: _27/05/10_   SIGNED: _Radebe_

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I FEULE HABEBE 036 352 4552. 083 974 956, my occupation is ROJECT DIRECTOR Thelaizulu Self Sufficient Project

and I feel that this community centre with the correct resources can address the needs of children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

I do feel that the community centre is needed in this community because there is no facility that caters for disabled peoples skills development around the area.

DATED: 26/05/2010   SIGNED: Kaune

I NXELE SIBONGILE   , my occupation is EDUCATOR

and I feel that this community centre with the correct resources can address the needs of children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 01-06-2010   SIGNED: Stubede

I B. A. F RAGELE   , my occupation is Educator (Special Ed.

and I feel that this community centre with the correct resources can address the needs of children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: 26. 05. 2010   SIGNED: G Huum

I _S. P. DLAMINI_ , my occupation is _SCHOOL PRINCIPAL_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _04 JUNE 2010_   SIGNED: _SPDlamini_

I _Gugu Jamile_ , my occupation is _EDUCATOR_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _01 – 06 – 2010_   SIGNED: _____

I _SAMSON Muziwakhe Blablh_ my occupation is _WARD COUNCILLOR_
and I feel that this community centre with the correct resources can address the needs of
children with disabilities in the rural areas and that there is a need for it.

I do not feel that this community centre is needed in the rural areas for the following reasons:

DATED: _26 – 05 – 2010_   SIGNED: _____
        Contact 0732319716

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GUIDELINES FOR EARLY CHILDHOOD DEVELOPMENT SERVICES

EVERY CHILD HAS THE RIGHT TO THE BEST POSSIBLE START IN LIFE.
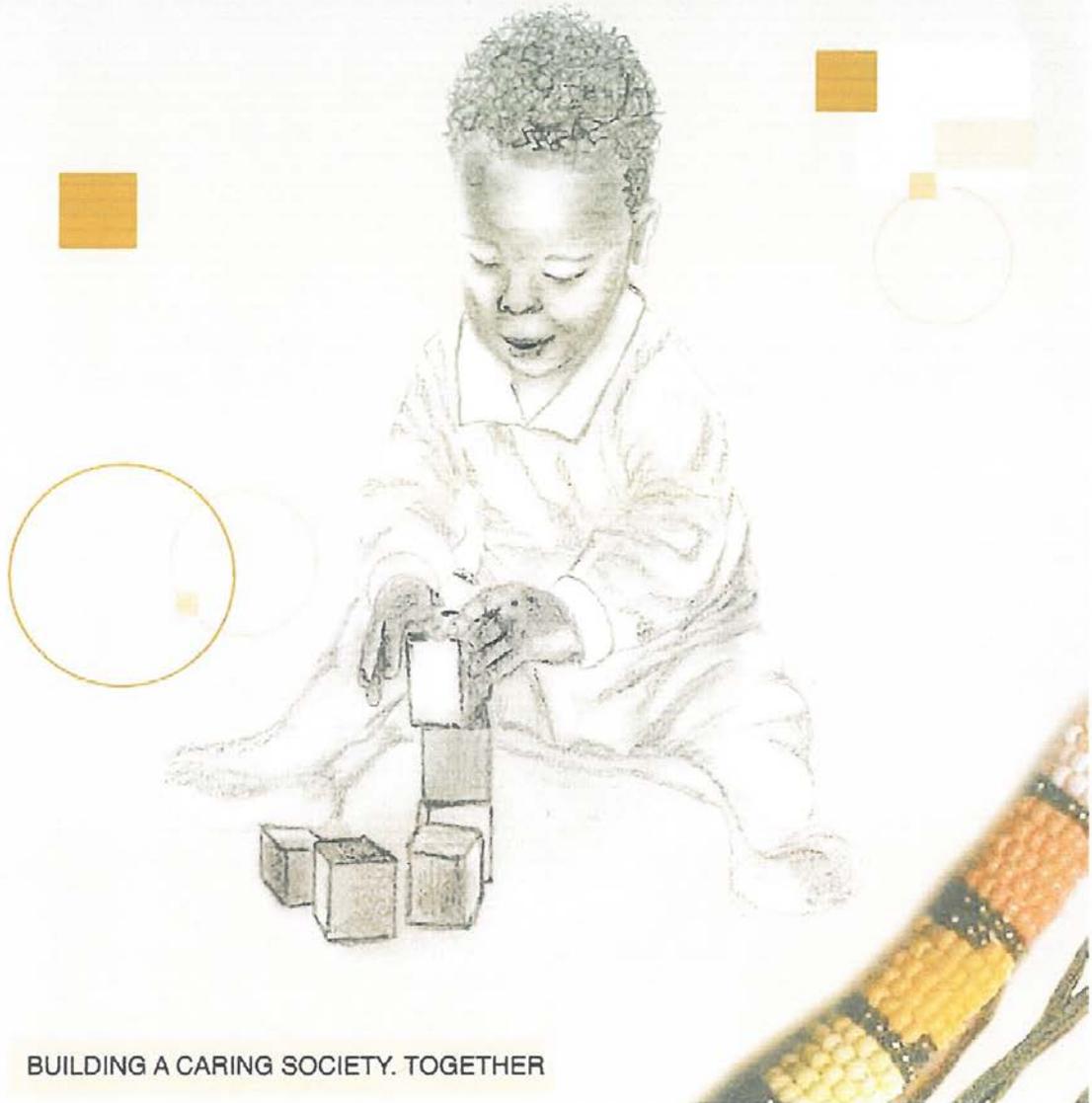
BUILDING A CARING SOCIETY. TOGETHER

social development

Department
Social Development
REPUBLIC OF SOUTH AFRICA

unicef

PROVINCE OF KWAZULU-NATAL
ISIFUNDAZWE SAKWAZULU-NATALI
PROV___ KWAZULU-NATAL

DEPARTMENT OF EDUCATION
UMNYANGO WE MFUNDO
DEPARTEMENT __ AN ONDERWYS

THUKELA DISTRICT ERIK	ISIFUNDANA SASOTHUKELA	_OTHUKELA

Ikheli Address Acres:	Corner Queen and Keate Streets Ladysmith 3370	Isikhwama Seposi: Private Bag: Privaatsak:	Private Bag X 10041 Ladysmith 3370	Ucingo: Tel: 036 6365264 Telefoon: Fax __ 4638 5284
Imbuzo Enquiries: N.A. NDLOVU ___ er		Inkomba PERMISSION Reference: TO DO Verwysing: RESEARCH		Us___ Date __/12/2010 Datum:

ATTENTION: Mrs. B. Ben – David

PERMISSION TO DO RESEARCH AT KWAZAMOKUHLE SCHOOL

Your request to do research at KiwaZamokuhle School has been granteed . Please liaise with the school with regards to your needs and other logistics.

N.A. NDLOVU
CES-SDSS