AN INVESTIGATION INTO HOW RURAL CHILDREN WITH DISABILITIES

AND THEIR FAMILIES IN THE QWAQWA REGION

EXPERIENCE THEIR LIVES
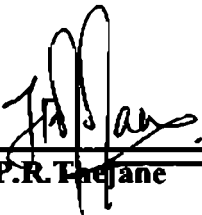
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RESEARCH REPORT SUBMITTED IN FULFILMENT OF THE

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DECLARATION OF ORIGINALITY

I Teboho Thejane declare that this research report "An investigation into how rural children with disabilities and their families in the QwaQwa region experience their lives", 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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T.P.R. Thejane

1999

DEDICATION

I dedicate this to my parents who have been the fountain of inspiration, undying encouragement and support without whom I would not have achieved as much

My beloved brothers Katleho and Lehlohonolo for their love and believing in me.

And

To all the children with disabilities in the world especially those in the rural areas. I love you all.

ACKNOWLEDGEMENTS

ABSTRACT

This study investigated how rural children with disabilities and their families in the Qwaqwa Region of the Free State province experience disability. The aim was to examine the various social, cultural, economic, and political factors that impact the lives of the children and their families. It also explored what support systems are available for the children and the families in this rural context. Seventeen children with disabilities and their families were selected through a process of purposive sampling from three areas in the region: Mabolela, Makgalaneng, and Bolata. Nine of the children are currently in primary schools, and eight do not have access to formal schooling. This was a qualitative study. The research method was the semi-structured interview. The main caregiver in each of the families was interviewed. Interviews were conducted in Sesotho and audio-taped. These were transcribed, and then translated into English. The findings in the study reveal that despite the fact that various legislation and policy documents in South Africa make special reference to the protection of the rights of rural children with disabilities, the rights of the children and families in this study continue to be violated. The study revealed the urgent need to address barriers to learning and development that these children are experiencing which are largely located in the system. Some of these are: poverty and underdevelopment; negative attitudes; lack of education and rehabilitation services; lack of access to information; inadequate social and psychological support; lack of community based and accessible support services; lack of access to information about disability; poor access to resources such as health care, and social welfare; lack of coordination between professional services and departments in the province. The study has implications for planning services to address the needs of children with disabilities and their families in this rural context.

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CHAPTER ONE: INTRODUCTION

1.1 Motivation For The Study

It is well known that services for children with disabilities in South Africa have lagged far behind the estimated need. Educational provision and support services for these children operated along racial lines with massive inequities evident in services available to black and white children, particularly African learners. Currently, the inadequacy in provision for African learners with disabilities is extreme. Despite the fact that a new government is in place in South Africa, the education of learners with disabilities continues to be a low priority in many Departments of Education in the country (Department of Education, 1997).

Research carried out by the National Commission on Special Needs in Education and Training (NCSNET) and The National Committee on Education Support Services (NCESS) (Department of Education, 1997) indicated that despite the introduction of compulsory education by the new government, many children remain excluded from formal education. A large number of these are children with disabilities. The NCSNET and the NCESS findings indicate that although some rural learners with disabilities gain access to ordinary schools, the majority are discriminated against and remain outside the formal schooling system.

Rural African children with disabilities have historically been amongst the most marginalized and discriminated against group in the country. (Department of Education, 1997; Department of Education, 1995). Site visits undertaken by the NCSNET and the NCESS revealed that a very small number of learners with disabilities are enrolled in ordinary schools.

A few community-based projects offer limited provision for learners with disabilities in rural contexts.

As would be expected, there is a dearth of information or research on rural children with disabilities in South Africa. The purpose of the present study was to investigate and document how rural children with disabilities and their families in the Qwaqwa Region experience disability

1.2 The Aims Of The Study

The aim of the study was to explore the following research questions:

- How do social, economic and political factors impact the lives of rural children and their families?

- How does the social context of the family influence the development of rural children with disabilities in this setting?

- What are family and community perceptions of disability, and to what extent these influence attitudes?

- What support systems are there present in this rural context for the children and their families?

CHAPTER TWO: PERSPECTIVES ON CHILDREN WITH DISABILITIES IN DEVELOPING COUNTRIES

2.1 Introduction

In most developing countries, including South Africa, the majority of children with disabilities live in rural areas. In this chapter, it is hoped to provide a perspective on the various social, economic and political influences that impact their lives in varied contexts by reviewing the limited literature available.

At the outset, it is necessary to clarify the terms "impairment", "handicap' and "disability" as conceptualized in this research. It is argued that there is a necessity to separate "impairment", "handicap" and "disability". In clarifying these concepts, conceptualizations by Fulcher (1989), Peters (1993), Abberley (1987) and Oliver (1990; 1986; 1984) were explored. Impairment refers to physiological lesions, and these may be genetically based, disease-based or due to some trauma experienced by the individual. Impairment, therefore, has an anatomical bases. Disability is the functional loss resulting from an impairment. Disabilities are about how people are excluded and denied access to opportunities in society by certain social practices. Fulcher (1993) explains that social practices may transform someone who has an impairment into someone who has the identity of disability

Oliver (1986) argues that these social practices are "the disabling effects of economic, social and physical environments" (p. 9). Disability, according to Fulcher (1993), is also a "procedural category" (p. 23) where an impairment may or may not be present. A disability may be independent of the presence of impairment depending on particular social

practices that prevail. For example, in the case of the many children categorized as " learning disabled", an impairment may not be present. In the present research, the focus will be on how various social, economic, political and environmental factors produce and construct disability amongst children in a rural South African context who have various impairments.

This chapter will be structured in the following manner:

First, it will explore literature that attempts to construct a theory of disability and the various discourses that impact how disability is constructed by society. It is hoped that this will form the basis for understanding disability issues in developing countries, including South Africa.

Second, the chapter will examine various societal influences on the lives of individuals with disabilities and their families in developing countries such as the cultural perceptions of disability, interaction with professionals, access to education.

Third, an analysis will be made of community-based initiatives in selected developing countries. The aim is to explore key elements of these initiatives and their relevance for development in other contexts,

Fourth, the chapter will focus on the South African situation. Emerging legislation since 1994 will be examined, and their relevance for children with disabilities and their families in rural contexts will be examined. In this section, insight will be provided on the current situation in South Africa with respect to rural children with disabilities gleaned from the limited available literature.

2.2 A Theory Of Disability

Societal ideologies impact and shape outcomes for individuals identified as disabled. Apple (1982) cited in Peters (1993) explains that ideologies are "sets of lived meanings, practices and social relations" (p 21) that professionals, policy makers, parents, and the community apply in their approach to the meaning and experience of disability. He further argues that ideologies are often backed by power and authority of politically dominant groups, and thus remain resistant to change for long periods of time.

A theory of disability has to take into account political, social, ideological, economic, cultural influences if it has to be used as a framework to understand how individuals with disabilities and their families experience their lives. Peters (1993) explains that there is a need to shift focus from the individual to the social context. It allows one to frame the experiences of individuals with disabilities within the broader societal conditions within which they live.

Peters (1993) and Fulcher (1989) present various discourses or paradigms that can serve as explanations of the way in which societal attitudes and values construct disability. These models reflect the causal relations that explain the treatment of and attitudes towards individuals with disabilities.

The medical paradigm links impairment and disability, and suggests that individuals have incapacities or diseases as attributes, and are innately

different from "normal" individuals. A medical approach sees the individual with disabilities in a victim image. Intervention focuses on health needs to effect a cure. The idea that professional expertise has to determine the individual's right to services is entrenched in this model, resulting in individuals with disabilities and their families having to accept their fate as prescribed by professionals (Peters, 1993).

A charity discourse, according to Fulcher (1993) defines individuals with disabilities "as in need of help, as objects of pity and personally tragic" (p. 28). This discourse emphasizes themes of benevolence and humanitarianism, and it expects individuals with disabilities to be grateful for services provided. It promotes the view that experts know what is best for the individual, and ignores the wants and needs of individuals with disabilities.

A lay discourse is characterized by themes such as pity, prejudice, fear, resentment, and ignorance. These themes often entrench social practices that are discriminatory and exclusionary.

The rights discourse stresses that disability is socially constructed and a historically mediated category (Peters, 1993). Lack of access to opportunities in a society is due not to the impairment but to the social, economic, and political barriers constructed by the social environment. Focus is on the rights of individuals with disabilities and their families. The themes entrenched in this model are "self-reliance, independence, consumer wants" (Fulcher, 1993, p. 30). The aim is to achieve equality of opportunity and equal access to services in society. The view that individuals with disabilities and their families have control over their own

lives and have a right to choice is stressed. This discourse rejects the deficit focus in favour of an emphasis on abilities. Individuals with disabilities and their families are no longer considered passive recipients of services from experts, but they themselves are viewed as experts. Their voices are heard and valued.

In the present study, the extent to which these discourses on disability impact the lives of rural children with disabilities and their families will be examined.

2.3 Societal Factors That Impact On Disability In Developing Contexts

2.3.1 Introduction

According to Helander (1993), it is estimated that 85% of the world's children with disabilities are under the age of 15 years of age, and live in developing countries. In addition, the majority of these children live in rural contexts. Most of these children receive little attention from the formal health, welfare and education sectors. Zinkin (1995) explains that in most developing countries, prevention of impairment seems to be a priority. The reason is that the causes of disability are linked with socio-economic factors such as poverty and disease, and the emphasis on prevention linked to community and country development becomes a priority. Therefore, children whose impairment has not been prevented are often neglected and maginalized. Limited social and educational services are available for them.

2.3.2 Societal Integration

Kisanji (1995a) points out that literature on disability in developing countries reflects the experience of western education and culture. It suggests that there exists a negative attitude by communities and society towards impairment and people with disability. Kisanji (1995a) disagrees with this perception. He argues that within communities in many developing countries, where there is a high level of illiteracy and a subsistence economy, the general pattern of behavior is one of acceptance and sympathy. People with disabilities are, within an extended family system, provided with basic needs, and are given the opportunity to participate in community activities within the limits of their abilities Kisanji (1995a) points out that for such communities "integration" and "normalization" are not new concepts. He uses his own personal observations in Africa, to support the view that people with hearing, visual and physical impairments are relatively well integrated into their communities. He further explains that in subsistence economies, in contrast with countries with sophisticated technological advancements, people with specific learning difficulties and mild to moderate intellectual impairment experience fewer problems with social integration. Kisanji (1995a) states that these perspectives have implications for western-type interventions in that the overall culture base of a community needs to be understood and capitalized on.

2.3.3 Cultural Perceptions of Disability

Traditional religion in most developing countries cannot be separated and permeates all aspects of the lives of the people. It forms the basis of cultural beliefs and practices. Kisanji (1995a) explains:

"the most significant effect of religion on disability is the motivation it provides to seek a cure, redress with God, the gods or ancestral spirits, to neutralize the 'bad eye' of non-well-wishers, and to counteract the effects of witchcraft and sorcery." (p. 194)

Ngwenya and Nkabinde (1996) conducted a study in the province of Kwazulu-Natal, South Africa which aimed to explore parents' beliefs on the cause of disability, to explore parents' concerns, and to discuss the impact of a child's disability on an African family. Out of a sample of 15 parents, three reported witchcraft being the cause of the disability; and one parent mentioned that angry ancestors were responsible for the disability in view of the fact that the child's father did not acknowledge the child as his. The mother believed that a goat had to be slaughtered to appease angry ancestors.

These beliefs are so deep-rooted that it is not uncommon for parents and relatives to seek assistance from witch doctors, herbalists, fetish priests and others to either cure the impairment or reduce its effects in some way (Kisanji, 1995a).

2.3.4   Attitudes towards disability

Kisanji (1995a) draws attention to the fact that literature in exploring attitudes towards disability may misrepresent behaviours of people in indigenous cultures. An example is the suggestion that children with disabilities are hidden away from the public (Sauter, 1978 cited in Kisanji, 1995a). Kisanji points out, and he supports this on the basis of his own experiences in Tanzania, that overprotection is the most significant factor that influences the perceived hiding away of children.

However, attitudes towards disability may be reflected in the behaviour of naming of children according to the impairment. Kisanji (1995a) gives the example of the Tanzanian names "Mpofu" meaning "blind" and "Mapula meaning "deaf. Such names could have a negative effect on the development of self-esteem and self-concept in children. In addition, the labeling effect may lead to a lowering of expectations by adults such as teachers.

2.3.5 Early intervention programmes in developing countries

McConkey (1995) undertakes an in-depth review of present knowledge of early intervention in developing countries for families and children with disabilities. He argues the need for a re-definition of early intervention to emphasize a systems perspective (Bronfenbrenner, 1979). The definition provided by Dunst, 1985 cited in McConkey, 1995, captures this perspective:

> "the provision of support to families of infants and young children
> from members of informal and formal social support networks that
> impact both directly and indirectly upon parent, family and child
> functioning" (p.64)

He points out that the aims of early intervention programmes in many countries have not been easy to achieve or sustain. In his review, he explains that one of the important lessons learned is that more therapists or teachers teaching children in specialist centres is not the answer.

McConkey (1995) suggests a number of conditions that are seen as necessary for early intervention to be a success:

- early intervention has to focus on the whole child, that is, social, emotional, physical, intellectual as well as health and nutritional needs,

- there can never be a single or universal intervention strategy. Programmes need to be individualized for a particular child, in a particular family, and in a particular social and cultural context,

- the inclusion of the child's family is critical to a programmes' success and sustainability,

- the influence of poverty and the family's social context on the success of a programme cannot be underestimated. Issues such as a decent family income, housing, appropriate health care, an integrated neighbourhood will impact the success of a programme,

- intervention services have to be ongoing throughout the child's life, including school level during which the support of pupils and teachers is critical.

Thorburn (1990) proposes certain core aims of early intervention:

- the training of all levels of people –family members, community leaders, primary level workers,

- the formation of parent groups that can both advocate for their children, as a support system for parents,

- supporting teachers and pupils with disabilities in mainstream schools, including nursery and preschool centres,

- the provision of simplified technologies at the local level to reduce the effects of impairments,

- development of literacy schemes and income generation schemes to address poverty,

- the development of primary health care programmes geared towards the prevention of disability, and to reduce the effects of further impairment

2.3.6 Parental Involvement

O'Toole (1995) explains that in many countries the world over parents do not receive adequate help and support with the care, education and training of their children with disabilities. Parents in poor and developing countries often find no help whatsoever available to them.

Ngwenya (1996) in reviewing some of the literature on parental involvement, states that in developed countries, the issue of rights of parents is being addressed. Parents participate in school governance structures, and can influence decision making as well as choice of schools for their children. Strong parent advocacy groups have developed in the disability sector. In the developing countries, parents particularly those in rural and disadvantaged areas, are stressed by poverty, illiteracy, and general underdevelopment. Balasundram (1995) explains that in developing countries the vast majority of parents are not involved in service delivery, and their experiences are not channeled into services. The author suggests that one reason for this is the expert model that prevails, that is, that doctors and professionals are the only people that can be involved in service provision and they know best. From experiences in India, Balasundaram (1995) further argues that is the lack of education and

information on disability amongst poor, illiterate and marginalized parents.

However, in many such countries parental involvement is facilitated through community-based programmes that are developed jointly with parents, and managed by members of their own communities (Balasundaram, 1995: Bean and Thorburn, 1995; McGlade and Aquino, 1995). They play a role in advocacy, help in centres for the disabled, organize support groups, and become actively involved in NGOs working in the disability sector.

2.3.7 The Family as Support

In many countries of Africa and Asia, the extended family including aunts, uncles, grandparents play as important a role as biological parents in the care, education, and welfare of young people (Kisanji, 1995). Although cultures are dynamic and changing, this is still very much the situation in rural contexts. Parents in developing countries have the advantage of being able to draw on the extended family for help and support. It is only in recent years that interventions have acknowledged and drawn on the rich resource of the family and community. (Balasundram, 1995, Pierre, 1995).

2.3.8 Education and Rehabilitation Services

The attitudes of society towards disability at any one time are reflected in the kinds of services provided for individuals with disabilities. In most

developing countries, special education services were started by churches and other voluntary (Ross, 1988), operating within the charity discourse. Generally, there was little involvement of local communities. Kisanji (1995) further explains that churches had the support of the colonial governments, and therefore, villager could not question this kind of service provision. The first schools were segregated and residential. This became the model of educational provision in most developing countries.

McConachie and Zinkin (1995) point out that many educational and rehabilitation initiatives in developing countries have historically been supported by external governmental and non-governmental organizations. These authors argue that such sources of funding can lead to their own problems such as the imposition of their own conditions and philosophy by organizations. In deciding where to allocate funding, some donors have asserted their own ideological and religious views. Often these organizations tended to appoint their own consultants rather than using and building local capacity. Often such consultants are ignorant of the local culture, and ignore the culture of the people when planning interventions. Many such projects have provided communities with generous short-term funding that resulted in the projects lacking sustainability once funding is withdrawn. It has also been found that funding is controlled by able-bodied foreigners. Furthermore, funding agencies focus on single disability groups, and do not coordinate their efforts with other groups. This results in available resources being utilized inefficiently.

It is only in recent years that services have been the subject of more critical analysis.

It has been found that the small number of high cost special schools do not meet the needs of the majority of children with disabilities, in particular those that live in rural areas. In most countries, these specialized centres are situated largely in urban areas. Concerns have been raised around the following issues:

- separation from their homes of very young children in order for them to attend special residential schools,

- residential special schools undermine family cohesion and the child's sense of belonging to a community,

- limited parental involvement in the life of the school owing to long distances between school and home,

- overspending on specialized facilities that provide for a small percentage of learners in contrast to a lack of facilities in rural and disadvantaged areas,

- a high proportion of the budget in special schools is spent on non-educational aspects such as transport, building maintenance, transport, paying maintenance staff, care staff, security guards

- the children do not learn important social skills according to the traditional ways of their community,

- methods of communication with the deaf and the blind children, for example, is not learnt by their families and communities,

- the material standard of living in the residential schools to which the child becomes accustomed is much higher than that of the family and community,

- children who attend residential special schools have serious problems with re-integrating into the mainstream of their communities,

- peer solidarity developed over the years in special schools is lost once
  children leave because contact between families over a long distance is
  not practicable,

(Chaudhury, Menon-Sen and Zinkin, 1995; Department of Education,
1997; Jangira).

O'Toole (1995) strongly criticizes the fact that with regard to service
provision for the disabled, Western models, knowledge, and attitudes have
been translated directly to developing peoples. He further questions the
thinking among many civil servants and rehabilitation workers in
developing countries that western style institutions for individuals with
disabilities are the ideal and that any other model of service provision is
below standard. He points out that for the 98% of families who have
children with special needs, and who are receiving none or little services,
the issue of standards becomes irrelevant.

He further stresses that "top down" models of service delivery are
criticized all over the world. There has to be a shift in the whole concept
of development. He stresses:

"Rehabilitation can no longer be seen as a product to be dispensed; rather
rehabilitation should be offered as a process in which all the participants
are actively and closely involved." (p. 313)

In the same line of argument, McConachie and Zinkin (1995) point out
that many projects in developing countries should work with parents, in
particular in the setting of clear goals. This is important in order to avoid
misunderstanding between project workers and parents. These authors

explain that parents may have different expectations, for example, a parent may be of the view that an intervention will cause the child to walk whereas the programme goal was to help the child to function better in activities of daily living. They warn that it is necessary to listen to the aspirations of parents and families, to arrive collaboratively at realistic goals, and ideally to consult with disabled adults as advisers and role models.

Often interventions in developing countries have comprised importing programmes from developed countries, and failing to assess the needs of the community in which they are based. Goals have often been narrow and inappropriate. McConachie and Zinkin (1995) point out that importing a therapy approach or a teaching package from a developed country, and the imposing of these in different economic and cultural contexts is problematic. In addition, high cost, highly specialized, individualized packages and approaches are not realistic in a developing country, with few human and material resources. McConachie and Zinkin (1995) suggest that approaches need to have a long-term wider community focus aimed at attitude change in the community. In this way, children with disabilities may be able to enjoy a better quality of life through raised expectations of them from family and community. This will also ensure inclusion in the life of the community.

Zinkin (1995) questions the issue of framework priorities for helping chidden with disabilities in developing countries. She stresses that the question to be explored is, "whose priorities?" (p. 10). She stresses that the starting point should be to explore how these children and their families are currently experiencing their lives in their particular contexts. Professionals cannot assume that their interventions are necessarily,

appropriate and that they know what the priorities are for the children and their families. Discussions have to be initiated with the very people who will be most affected by decisions and resources allocated.

2.3.9 Training of personnel in developing countries

McConkey (1995) and O' Toole (1995b) state that in many developing countries, professionals and project coordinators appointed in projects that are funded by NGO's and international donors are inappropriate for the contexts in which they work. They have had their training in developed countries, and do not share the culture and class of the people. Even when training courses are held in the developing context, the content of the programmes derive from Western models does not depict the experiences of disablement in a developing context (Ainscow, 1994; Miles, 1989). These training models also tend to compartmentalize professional skills so that various sectors such a health, education and welfare have difficulty collaborating with each other. In a developing context with limited professionals and other human resources, inter-sectoral collaboration has to be a critical component of any intervention.

O'Toole (1995) argues that there is a need to demystify professional skills, and explore ways to share these skills with community workers, volunteers and other non-specialists. McConachie and Zinkin (1995) state that professionals have a role to play as trainers rather than workers on a one to one basis with the disabled. These authors argue that professional training courses should focus on shared training, the involvement of parents and disabled people in teaching and curriculum design, and to locate professional skills within the context. Teaching methodologies need

to be re-examined. There is, for example, a need to explore to what extent training courses value the student as a person, and value the rich experience students bring with them, and take into consideration the participants felt needs.

Finklestein and French(1993) argue that an "individual personal tragedy' view of impairment that most professionals hold contribute to the poor self-esteem and negative self-image that most individuals with disabilities and their families hold.

The "individual personal tragedy" view of impairment shared by most professionals contributes to the poor self-esteem and negative self-image that most disabled people feel (Oliver, 1993). It is of fundamental importance for a child who has impairments to be a valued member of a family, community and society.

2.3.10 Legislation and Advocacy in Developing Countries

In order to protect the rights of people with disabilities to education, employment, equal access to social opportunities, strong legislation is needed. Many developing countries do not have legislation that protects the rights of people with disabilities and their families. McConachie and Zinkin (1995) explain that in developing countries, when basic needs are not met, that is, when there is limited access to food, shelter, health care, water, the main concern of the community is survival. Werner, (1993) explains that ramps and lifts for wheelchair accessibility becomes an issue of low priority when people do not have food to eat. In most developing

countries such basic needs are increasingly difficult to meet amongst poor and marginalized communities.

However, in many initiatives in various developing countries (Werner, 1995; Stubbs, 1997; Carpenter, 1994), disabled people are being empowered to be active in advocating for their rights. McConachie and Zinkin (1995) provide the example of the work of an NGO in India, Action in Disability and Development (ADD-India). Forty landless disabled people worked with the Youth India Project in a struggle for land along with an agricultural labour union. Working with other marginalized groups can add strength to the advocacy movement.

2.4 Community Based Models Of Service Provision In Developing Countries

It order to address the above concerns, in many developing countries community based approaches to provision have been viewed as a more positive alternative. Such approaches take into account the life of the child with disabilities in his or her community, and enable greater social integration for the child. Community based provision is generally referred to as Community Based Rehabilitation (CBR). It is considered a cost-effective approach to service provision for contexts that receive limited social and medical attention, and as a solution to a lack of material resources and suitably qualified and trained personnel. CBR may be described as provision for children with disabilities and their families within their homes and communities, where they have opportunities to receive training for functional activities, including self-care, mobility and communication, education, and work in the most productive way possible

(McConkey and O'Toole, 1995). This means that resources for rehabilitation are available in the community.

Some of the key principles of CBR programmes as articulated in the literature (Chaudhury, Menon-Sen and Zinkin, 1995, McConkey, 1995; Stubbs, 1995; Stubbs, 1997) are:

- the transfer of knowledge about disabilities and of skills in rehabilitation to people with disabilities, the families and members of the community, and available health, education, vocational, and social services,

- rehabilitation is seen as including not only home training and therapy, but also educational and job placements, and the development of income generating projects to employ disabled people and their families.

- home programmes are carried out by family members of the disabled children and supervised by community workers with minimum levels of education,

- the breaking down of rehabilitation into simple tasks, carried out in small steps, accompanied and facilitated by the use of appropriate literature, and aids and appliances,

- the site of provision is mainly in the home and in community facilities

- there is active community involvement in the planning, decision-making and evaluation of the programme,

- it is a strategy for social integration and equalization of opportunities of all individuals with disabilities.

In many countries CBR programmes have evolved in different ways.

In the next section, an attempt will be made to provide insight into some of the models in selected developing countries. It must be pointed out that there is limited literature documenting initiatives in developing countries. Therefore, the analysis involves a limited body of documented knowledge.

2.4.1 Guyana Community Based Rehabilitation Programmes:

O'Toole (1994) explains that the education of children with disabilities in Guyana is largely based in the capital. In rural areas, the experience is that there is a significant gap between need and available provision. The urgent need was to find models of provision alternate to the current western models that were catering for a minority of children. According to O'Toole (1994; 1995), Community Based Rehabilitation (CBR) was seen as one such alternative. The main philosophy underlying the CBR project described by O'Toole (1994) was that education and rehabilitation was no longer to be seen as a product to be dispensed to poor, disempowered communities. The goal was to "de-mystify" rehabilitation and give responsibility back to the individual, family and community." (p. 26)

Another important goal was the promotion of sustainability by avoiding dependency. The local communities have been encouraged to take as much responsibility for the project as possible. The goal was to reinforce, nurture rather than supplant the authority of teachers, health workers, and community leaders in the regions. Education and training of local personnel was the core of the project rather than the provision of services

by external agents. Efforts were placed on helping each person realize the role they can play in the development of their community.

A pilot project was conducted between 1986-1988 with disabled children in two rural areas. The aim was to study the process of innovation and, in particular, the dynamics of community participation. On the basis of the pilot project, an expansion of the CBR programme began in 1989 in five rural areas of Guyana. The programme became known as "Hopeful Steps". The major focus of the programme was based around the use of volunteers from the community. O'Toole (1995) explains that in two of the coastal areas of Guyana that were included in the expanded programme, three times as many people required applied to be accepted as volunteers even though salary and travel costs were not paid. This was due to the strong community spirit prevalent in Guyana. Furthermore, the drop out rate of volunteers was no more than 5%. Volunteers came from a wide cross section of backgrounds: family members of persons with disabilities, nurses, schoolteachers, and midwives.

O'Toole (1995) describes the programme in one of the rural regions, the Rupununi Region – that comprises isolated and sparsely populated communities. The project in this region led to collaboration between a number of different agencies that shared the common goal of empowering the communities to help themselves. The main focus of the programme for the first three years was training workshops for identified leaders within the community. The training was sponsored by the University of Guyana's Institute of Adult and Continuing Education (IACE) . This was the first time that the University was involved in this region of the country. The region comprises 33 villages. Each of these villages was divided into five sub-regions and over the three-year period, a four-day workshop was held

in each sub-region. The workshops dealt with topics such as: early stimulation, child development, ways to create awareness in the community on disability issues, assessment, leadership training skills, literacy training focusing on the promotion of literacy and numeracy, integration of children with disabilities into ordinary schools, and ways to conduct workshops in local villages.

The outcome of the workshop was that in each of the 33 villages, CBR teams were established comprising: the community health worker, a school teacher, and a village leader. The team was intersectoral. The aim was the bring educators and health workers together in a joint model of training. O'Toole (1994) explains that the work in Rupununi is emerging into an integrated community development project. In other words, CBR has become a nucleus for development and community activities. Some of the community projects are:

• The "Facts of Life" project in collaboration with the Baha'i Health Partnership that is operating in the region. All 33 villages participated in a project in which villagers of all ages wrote poems, songs, short stories, skits, and produced posters to communicate essential health messages.

An aspect of work in the CBR programme was the promotion of literacy training that initially developed from the perceived needs of teachers. As a result a one-week workshop was held for 32 teachers in the region. This led to a series of workshops in collaboration with the Ministry of Education for teachers in the region over a two-year period. Subsequently, the Guyanese Ministry of Education invested US$50 000 in the production of literacy materials for use in other parts of the country. As a result of the literacy project, libraries have been established in 24 villages in the region.

In reflecting on the work in Guyana over ten years, O'Toole (1994) states that five lessons have been learned:

- A respect for the culture of the rural people whose strong sense of spirituality is evident in their desire to be of service to others. The project's philosophy built on these values, and attempted to inspire the people to realize the role they can play in their own development,

    The need for development projects to promote sustainability by avoiding dependence. The local people were encouraged to take responsibility for the project as far as possible. Emphasis was given to training leaders in skills of consultation, leadership skills, problem solving and decision making. The focus was, therefore, on empowering communities. Other important features of the programme that were built in to ensure sustainability were: the management of the programme was based within the rural regions, the use of the existing health and education infrastructure rather than creating new structures, and a clear match between regional needs and programme objectives,

    The need to ensure that development is in line with needs and values of the local culture,

- The promotion of collaboration between all service providers in the community, and bringing together existing resources

- A guiding principle of the project was open consultation between people of diverse backgrounds and perspectives to discuss needs, concerns and project development.

2.4.2 Community Based rehabilitation Programmes in Ghana

In June 1992, a collaborative CBR programme involving the Ministry of Employment and Social Welfare, Ministry of Health, Ministry of

Education, non-government organizations and organizations of people with disabilities was initiated. The aim of the programme was to improve the quality of life of babies, children, young people and adults with disabilities through mobilizing community resources. Ofori-Addo (1994) provides an in-depth analysis of this programme.

Ofori-Addo (1994) explains that prior to 1992, services for the disabled in Ghana were similar to that in other developing countries. Services were mainly located in urban areas whereas the majority of individuals with disabilities reside in rural areas. Available services, therefore, reached only about 2% of disabled people. Special Education provided in special schools served a very small number of children, and very rarely led to employment in adult life.

The aims of the community-based programme in Ghana were similar to those conceptualized for Guyana discussed above. The focus was on:

- raising awareness on disability issues and on utilizing community resources,

- enabling parents to be more effective in ensuring educational access for their children, and in ensuring that their children participate productively in family and community,

- developing collaboration between various service providers – health, welfare, education, and community development organizations at district level,

- to build the capacity of non-governmental organizations (NGOs) in particular, associations for the disabled so that they can play a role in

the CBR programme at village level, in mobilizing the community, and in the management of the programme.

In April, 1992, two districts from each of five targeted regions in the southern part of the country were selected to participate in the programme. Careful criteria for selection was worked out in collaboration with organizations for disabled people. After the districts were decided on, the Departments of Social Welfare and the Department of Education deployed staff to the districts who were attached to the programme.

The programme involved three levels of intervention:

- **Training of district social welfare officers**: This involved a three month training course for District Social Welfare Officers (DSWOs) and the CBR management team. The course included issues such as socio-cultural factors in rehabilitation in Ghana, the concept of primary health care, training in the community for people with disabilities, community mobilization, early intervention with babies and children. At the end of the training session, the officers were required to work in the communities, and select between four and eight communities to begin the programme. The communities that wanted to participate in the programme had to form a Community Rehabilitation Committee comprising a cross section of members of the community, including individuals with disabilities and their families. Thereafter, each community had to select two people who would be trained as local supervisors. Their role would be to support disabled people and families with individuals with disabilities,

- Training of peripatetic teachers: The aim was to train a group of teachers to provide expertise on children with disabilities in

mainstream schools. The rationale underlying this focus is that the integration of children into community life can only occur if children have access to mainstream society at an early age. Furthermore, current high cost special schools serve a small minority of children. Eighteen peripatetic teachers were posted to the target districts. The main objectives of the training course was: to develop knowledge and skills to support children with various disabilities in mainstream schools, and to build the capacity of teachers in mainstream schools; to help the peripatetic teachers to assist local supervisors in early intervention for young children; and to enable the peripatetic teachers to collaboratively with the DSSWOs in the monitoring of the CBR programme in the districts.

Following the training, these teachers organized three-day courses in the target various districts for mainstream teachers. The aim was to develop in teachers the capacity to deal with the inclusion of children in mainstream schools. The courses focused on topics such as: identification of children with special needs, classroom management, parent and community involvement,

- Orientation in the target communities: This involved the training of local supervisors. The aim of the programme was to train supervisors to identify and assess the needs of individuals with disabilities, and assist families to support their members who have disabilities.

Ofori-Addo (1994) examines the lessons learnt from this particular initiative. One of the outcomes has been that CNR committees have initiated various projects to improve services for people with disabilities

and for the community. For example, in one of the districts, the CBR committee developed a playground for the local community, and were working on constructing functional aids to enable children with disabilities to use equipment such as swings. It was felt that this would facilitate interaction between non-disabled and disabled children. Other committees embarked on income-generation activities for people with disabilities. At the individual level, Ofori-Addo (1994) explains that after one year, the programme identified 677 people with various disabilities. Of this number, 438 needed access to services ranging from functional training to income generation. Seventy were children of school age. The needs of the large number of those identified were met through the programme – through the community rehabilitation committees, local supervisors, school teachers and other community structures.

The key to the CNR programme in Ghana is seen as effective monitoring and ongoing evaluation, and a strengthening of capacity at community level.

As an outcome of the programme, a Community based Rehabilitation Advisory Committee has been set up at a national level. Its role is to coordinate programmes and ensure sustainability. A move has been made to introduce CBR in the curriculum of the School of Social Work at the University of Ghana, and to include special needs in education in the curriculum in teacher education colleges.

2.4.3 Education for All in Lesotho

The Integrated Education Programme of Lesotho is a national programme that aimed at transformation of education at the primary school level. Khatleli, Mariga, Phachaka, Stubbs, (1995) and Stubbs (1997), and Stubbs engage in a critical analysis of the programme.

The Lesotho programme is guided by principles that represent an integration of traditional Basutho approaches to education and to disabled children, and the thinking internationally on disability and education in relation to human rights. Khatleli, Mariga, Phachaka, and Stubbs, (1995) and Stubbs (1995) summarize the key principles that guided the programme:

- human rights and social justice: This principle stressed the right to equality, social integration, and social justice for children with disabilities. Disabled children have a right to equality of opportunities and to dignity. They have a right to be integrated socially, and to have services available to them within their families and communities,

- maximum community involvement: In order to ensure sustainability of the programme, community involvement and the respect for indigenous beliefs and practices was stressed,

- the transformation of schools and society to include all children: This principle implied that mainstream schools should cater for diversity in the learner population. In order to develop inclusive schools, barriers to full participation had to be removed, for example, negative attitudes, inflexible teaching methodologies.

According to these authors, the central elements of the programme are:

- changing the attitudes, knowledge and teaching approaches of teachers to enable a broader range of children to gain access to and benefit from the ordinary classroom,

- ensuring that there is no second system of education designated as special education. This meant that there will be no separate cadre of teachers, no separate training courses, and no special units.

- existing special schools in the country would be used to support mainstream primary schools,

- there will be maximum community involvement in education including parents, disabled people's organizations, NGOs, various government \ ministries, professional ministries.

The implementation of the integrated education programme in Lesotho focused on two broad areas: awareness raising on the policy of integration and the development of indigenously produced and relevant curriculum materials. The programme began in ten pilot schools.

The programme began with awareness raising amongst the community and most professionals. People were made to understand that integration was not an option but that it was government policy. Workshops were held for the Special Education Curriculum Committee in the Ministry of Education, District Education Officers, school management, local chiefs, district administrators, and parents of children with and without disabilities. In addition, a meeting was held with the National Teacher Training College Director and staff. The aim was to explore the inclusion of a special needs education component into the mainstream curriculum.

Teachers in Lesotho needed curriculum materials for teacher development that would provide information on disability and on teaching methodologies to cater for diversity in their classrooms. A special education curriculum committee was formed to develop and review materials. This committee had representatives from various sectors: Ministries of Education, Health, Social Welfare, National Teacher Training College, Department of Early Childhood Development, the University of Lesotho, parents of disabled and non-disabled children, Lesotho National Federation of the Disabled, teachers from mainstream and special schools. This Committee went through an intensive process of producing materials relevant to the context. According to Khatleli, Mariga, Phachaka, and Stubbs, (1995) as the process evolved professional barriers were broken down and special education was, in a sense, demystified. The curricula that emerged from this process could be used for in-service and pre-service courses. The syllabi included areas such as: various categories of disability, assessment, different teaching methodologies.

The materials were introduced in ten plot schools that were selected during the feasibility study. These included schools in remote areas, schools in close proximity to a special school, schools with positive, negative, and neutral attitudes towards integration. The schools were from 8 of the 10 districts in Lesotho. There were about 20 children with various kinds of impairment in each of the pilot schools.

The first phase of the training workshops involved one teacher from each grade, and the head teacher from each of the schools. The initial workshops were three weeks in duration comprising 120 hours of training. Follow-up workshops were held every six months in which teacher

recommendations were incorporated. Following the training period, each of the pilot schools was involved in raising awareness with neighboring schools and conducting their own training courses for teachers and parents.

Stubbs (1997) summarizes some of the key lessons from one of the successful pilot schools:

- it was found that large classes (even over 100 students to one teacher) and limited resources were not an absolute barriers to integration,

- there was strong leadership and district level support,

- the project fully involved and supported parents,

- there developed an ethos of community responsibility and support,

- teachers felt that the programme helped them address an existing need in their schools and classrooms,

- Teachers felt that the training has led to a reduction in repeater and dropout rates.

This initiative in Lesotho has led to various other projects in the community:

- a parent organization was formed at the request of a parent who had a child with severe learning difficulties. This organization has twinned with a Norwegian association of Parents of Children with Mental Handicap,

- the Special Education Unit in the Ministry of Education set up an Education Assessment Team (ETA) to develop assessment tools relevant to the social and cultural context . There was a need for tests

that were local, easily accessible, and simple to use by both teachers and parents,

- a strong element of networking between various Departments in the Ministry of Education, parents, disabled people's organizations, the University of Lesotho, NGK's and other sectors was one of the positive developments in the process,

- a definite commitment by government has been one of the results of this project. The Ministry of Education has now allocated funding for the training and curriculum development aspect of the programme.

(Khatleli, Mariga, Phachaka, & Stubbs, 1995)

2.4.4 Development Programme for Disabled in India

Chaudhury, Menon-Sen and Zinkin (1995) provide an analysis of the Action on Disability and Development programme in India (ADD-India). This is an NGO that works in over 900 villages in southern India in cooperation with various rural development organizations. The organization's focus on social action and community health, and promote action for the rights of poor people in rural areas. The role of ADD-India is to work with such organizations on a partnership basis towards including disability work into the organizations' current programmes. ADD-India's basic philosophy is:

- disabled children have a right to access services in society and in the community in the same way as non-disabled,

- over-emphasis on specialized, expert-driven services for the disabled creates dependency,

- policy should not lead to separate services for the disabled. Instead every government department should include and address disability issues,

- disabled people should be given the opportunity to decide what interventions best suit their needs rather than this being decided on by professionals.

The manner in which this organization works is innovative, and warrants a more detailed discussion. ADD-India facilitators work with organizations that decide to address disability issues in their work. The process begins with what Chaudhury, Menon-Sen and Zinkin (1995) refer to as a detailed "community analysis" through fieldwork such as talking to various people in the community and conducting observations. The purpose is to obtain information on disabled people and children in the community; and to gauge what social, political, economic and cultural factors impact the lives of disabled people in the community. Some of the issues studied include: how people spend their time and money, how health centres function, local beliefs, the presence of disabled children in schools, what are available resources – both governmental and non-governmental.

Field workers for the organization are trained to deal with various aspects of community development. They organize community meetings to debate disability issues, and to obtain community commitment to support the empowerment of people with disabilities. They teach classes on disability in the village schools. As a result of this, it has been found that non-disabled children bring disabled children to school and take responsibility for them, assisting them in their studies, and including them in play activities.

In addition, field workers gather case studies on people with different impairments in different situations and contexts. This helps build a relationship with disabled people and their families. These case studies are valuable in that they provide facilitators with information on:

- the socio-political reality of disabled people in their families,

- how people with disabilities view themselves, their families, and their community,

- how disabled people live, what they have to cope with, how the family and community view them.

The outcome is not to work for disabled people and families but to empower them to form their own organizations. ADD-India trains these organizations in skills such as management and administration, social analysis, communication and leadership. The goal is that group members will eventually be able to analyze their own problems, find heir own solutions, fight for their own rights, and initiate social action, use existing structures to secure benefits and services, and to deal with attitudes of non-disabled people, and gain human dignity. Group members have interacted with schools in order to change discriminatory and exclusionary practices towards children with disabilities.

In reviewing the analysis of the programmes in the four selected countries, it is necessary to focus on the critical elements embedded in them. The following are some of the key features:

- It is clear that in all the initiatives the principle of social rights of the disabled is stressed. Of paramount importance is the inclusion of people with disabilities into the community, and the right to equal access to societal opportunities,

- A move away from an expert driven model of service provision to empowering communities to take greater responsibility for programmes to meet their needs,

- Donor funding from international organizations was needed to initiate projects such as "Feed the Children Fund" in Lesotho; "The Amici di Raoul Follereau" and the "European Commission" in Guyana; the "Swedish Organization of the Handicapped, International Aid Foundation" (SHIA) and the "World Health Organization" (WHO) in Ghana. However, the most important goal was sustainability. In all the above initiatives, the priority was to build local capacity using existing structures and resources, and to empower communities.

2.4.5 Rural Children With Disabilities in South Africa

In this section, insight will be provided on rural children with disabilities and their families in South Africa, drawing from the limited available literature.

First, key legislation and policy initiatives will be explored, and their significance for children with disabilities in rural contexts will be examined.

Second, literature on the current situation regarding service provision for these children and their families will be investigated.

2.4.6 Legislation and Policy Development in South Africa since 1994

This section will be divided into two sub-sections. First, legislation and policy development prior to the work of the NCSNET and the NCESS will be discussed. Second, the Report of the NCSNET and the NCESS, which is the most recent policy initiatives specifically for learners with special needs, will be critically examined, looking specifically at recommendations that impact on rural children with disabilities.

2.4.7 Developments prior to the Report of the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee on Education Support Services (NCESS) (November, 1997)

Since 1994 the new South African government has been committed to transforming educational policy to address the imbalances and neglect of the past, and to bring South Africa in line with international standards of recognition of human rights. Education policy documents and legislation with respect to disability reflect a move away from a welfare to a rights and developmental approach.

The Constitution of the Republic of South Africa (November, 1996) sets a constitutionally binding framework for national and provincial legislative action in the field of education. The notion of a democratic society based on human dignity, freedom, and equality is entrenched in the constitution. One of the key provisions the constitution is the one dealing with equality of rights. Section 9 of the Constitution relates specifically to the issue of equality of rights.

Sections 9 (1), (2), (3), (4) commits the government to ensuring that all individuals, including those with disabilities have the right to "equal benefit and protection of the law". It extends to all persons, including those with disabilities, protection from discrimination, and guarantees the right to have measures designed to achieve the adequate protection and advancement of persons previously disadvantaged by unfair discrimination. Section 9(3) reads:

"The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth."

It is significant that in this equality of rights provision, disability is included together with other social categories that have been relegated to a subordinate and disadvantaged status in society. Section (10) states that:

"everyone has inherent dignity and the right to have their dignity respected and protected".

Muthukrishna and Schoeman (1996) state that this clause is particularly significant for children with disabilities in that it recognizes that the issue of rights is inherent to the human dignity of the individual, and necessary for his or her full development. If human dignity is not respected, then it is a violation of an individual's human rights.

Section 28(2) states:

"A child's best interests are of paramount importance in every matter concerning the child." (p.13)

It is clear that disabled children are protected by this clause. The clause proclaims every individual's right to development to his/her full potential.

Section 29(1) states:

> "Everyone has the right to (a) basic education, including adult basic education, and (b) to further education, which the state, through reasonable measures, must make progressively available and accessible" (p. 13).

Muthukrishna and Schoeman (1996) explain that the constitution does not categorically state that learners must be educated in inclusive settings. However, if the reality of the South African situation is taken into account, where as many as 90% of disabled learners (in particular those in rural areas) do not have access to education, the natural implication of this clause is that government has no other option than to accommodate them within the regular education system. The limited number of high cost special schools which are mainly situated in urban centres simply will not be able to meet the needs of even a fraction of these marginalised learners.

Many policy documents stress the principle of education as a basic human right.
The principle implies that all learners have the right to equal access to the widest possible educational opportunities. The **White Paper on Education and Training** (March 1995) states that: Education and training are basic human rights. The State has an obligation to
protect and advance these rights, so that all citizens irrespective of race, class,
gender, creed or age, have the opportunity to develop their capacities and potential, and make their full contribution to society (p.21).

It is important to note that in this paragraph disability is not specified as would have been expected.

The Integrated National Disability Strategy Document (February 1996) argues for a human rights and developmental approach to disability that would lead to the creation of equal opportunities. The document stresses that all South Africans should

have equal access to education opportunities, irrespective of the severity of their disability(ies).

The **South African Schools Act** (November 1996) endorses this principle in section 5(I):

"A public school must admit learners and serve their educational requirements without unfairly discriminating in any way". (p.6).

However, a non-discrimination principle is not adequate in itself to ensure equality. For individuals with special needs to be treated with equal concern, it is necessary to be vigilant for and eradicate barriers to participation constructed by society.

The principle of quality education for all learners is stressed in certain documents. For example, the clause

"The paramount task (of government) is to build a just and equitable system which provides good quality education and training to learners young and old throughout the country". (White Paper, March 1995, p.17)

The provisions in the **South African Schools Act** (November 1996) regarding this principle are as follows:

"Subject to this Act, the governing body of a public school must (a) promote the best interests of the school and strive to ensure its development through the provision of **quality education** for **all** learners at the school. (Section 20 (1), p. 14)

Muthukrishna and Schoeman (1996) explain that these clauses encapsulate a vision of an education system that gives recognition to the wide diversity of needs in the student population, and which ensures a more flexible range of responses.

The emphasis on quality education for **all** learners suggests that schools have to meet the diverse needs of all learners, including learners with disabilities. These clauses protect the interests of learners with special needs, and ensures that schools will have to work towards true equality through the application of various policy instruments such as resource allocation, teacher development.

The following paragraphs in the White Paper on Education and Training (March, 1995) explains how the legacy of a fragmented and segregated schooling system in this country needs to be addressed effectively. This would include the ethos of segregation, which was historically equally prevalent in the case of children with disabilities.

" There must be special emphasis on the redress of educational inequalities among those sections of our people who have suffered particular disadvantages, or who are especially vulnerable, including street children, out-of-school youth, the disabled and citizens with special educational needs, illiterate women, rural communities, squatter communities and communities damaged by violence. (White Paper, March 1995, Chapter 4 (7))

"The Constitution guarantees equal access to basic education for all. The satisfaction of this guarantee must be the basis of policy. It goes well beyond the provision of schooling. It must provide an increasing range of learning possibilities, offering learners greater flexibility in choosing what, where, when, how and at what pace they learn."
(White Paper, March 1995, Chapter 4(6)).

Up to now choice of where disabled learners could receive their education has been extremely limited for two reasons, firstly, the right of choice of parents or learners was not entrenched in any of the policy documents; secondly, the limited access to and availability of facilities, particularly in rural areas. (Muthukrishna and Schoeman, 1996). Although current policy documents do make provision for the right of choice, there is no real true choice because resources are locked into special schools located mainly in urban contexts.

Current legislation gives recognition to parental rights in the provision of their children's education. **The White Paper on Education and Training (March, 1995)** provides for this in the clause

"Parents have an inalienable right to choose the form of education best suited for their children" (4:3).

The fact that parents may now choose for their children to go to ordinary schools is an important step ahead because this will open up opportunities for the greater majority of learners which have up to now never had access to any schooling. This has significant for the parents of rural children with disabilities.

Parental choice is, however, meaningless if it does not go hand in hand with parent empowerment and the acknowledgment of parents as partners in the

education of their children. The disempowerment of parents of children with disabilities, in rural areas in particular, has continued up to now.

Various clauses in the SA Schools Act of 1996 allows for the empowerment and training of parents, especially through the role which they will in future be able to play in governing bodies of schools (Cf. sections 5(9); 19 1(a) and (b); 23 (5); 24 (1)). Very few parents are, however, as yet aware of their rights and as it will still be some time before schools are eager to admit learners with disabilities. Parents will need to be empowered to stand up to authorities who refuse to accord their rights. (Muthukrishna and Schoeman, 1996)

Any future policy on special needs education must develop these principles and make provision for not only advice and counseling for parents, but also for their empowerment. They, and through them their communities, must be seen as a valuable resource in the development of their child. A service model that concentrates on expert intervention without parental partnership is outdated and weak.

The White Paper on an Integrated National Disability Strategy (February, 1996) stresses that

> "Every learner has unique interests, abilities and learning needs, and respect for diversity should be promoted"
> and that emphasis should be placed on
>
> " curriculum development to ensure flexibility, addition, and adaptation" (3:2).

These clauses suggest that all learners are entitled to participation in the curriculum. It would imply entitlement to flexible and sensitive responses to

individual characteristics of learners, and a broad and balanced curriculum that can cater for student diversity.

It is clear that all the above legislation and policies are set within the rights discourse. They protect the rights of rural children with disabilities and their families as a historically marginalized group. Clearly articulated are principles such as: the right to a basic education, the right to curriculum access, the rights of parents in the education of their children, the right to protection from discrimination, and the right to quality education to enable learners develop to their fullest potential. However, although policy and legislation is firmly in place, there has been little development in terms of practice, and service provision that impacts the lives of this sector. Rural children with disabilities continue to be one of the most marginalized and discriminated groups in the country.

2.4.8 The Report of the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee on Education Support Services (NCESS), November 1997

The NCSNET and the NCESS were set up by the President in October 1996 for the purpose of advising the Minister of National Education and the Department of National Education on issues concerning the restructuring of education for learners with special needs. The terms of reference of these structures included taking into account the commitments of the government to the realization of equity and redress in all aspects of education.

The Report of the NCSNET and the NCESS was released in November, 1997.
The principles that underlie the recommendations in the Report include the following:

- Human rights and social justice for all learners: The Report stresses that every learner has the right to quality education, and to be treated with dignity and respect. The Report clearly is set within the discourse of human rights and social justice (Peters, 1993; Fulcher, 1989).

- Participation and social integration: Any kind of service provision must provide the widest possible opportunities for learners to participation in their communities. In other words, educational and other services must promote social integration,

- Equity and redress: Educational change must focus on removing barriers to access experienced by historically marginalized communities in the country, in particular, learners with disabilities in disadvantaged and rural communities,

- Community Responsiveness: The Report stresses that "education must be relevant and meaningful to the lives of all learners" (Department of Education, 1997, p. 54). Education must prepare learners for successful integration into he community, and facilitate maximum involvement of the community. It also states that the strengths of community support already present in communities must be drawn on,

- Equal access to a single inclusive education system: All learners must have access to a single education, integrated education system, regardless of differences in terms of physical, intellectual, social, emotional, language, or other differences. The education system must be responsive to diversity. This has particular implications for rural learners with disabilities who have limited access to the few special schools in the country situated largely in urban areas. The implication is that they should have access to mainstream schools in their communities,

- Cost effectiveness: The need to create education provision that is cost effective, affordable, implementable and sustainable is stressed. It is clear that the building of high cost schools in rural areas would contradict this recommendation. An alternate form of service delivery that is

community based using resources in communities may have to be explored.

Some of the key recommendations of the NCSNET and the NCESS, that have particular relevance for rural learners will be discussed:

- All centres of learning would develop an ethos of inclusiveness and a supportive environment for all learners, responsive to diversity in the learner population. The implication is that irrespective of disability or differences in learning style or pace, or social differences, learning programmes should accommodate the needs of all learners,

- The emphasis should, therefore, be on building the capacity of all centres of learning to address diverse needs, drawing on existing expertise within the formal education sector and from the non-formal sector. As the capacity of all centres of learning develops, it is expected that most learners who are currently not able to access education would be able to participate fully in ordinary rather than special schools. This would include rural learners with disabilities,

- The Report recommends that a moratorium be placed on the building of new special schools. It suggests that funds be utilized on resourcing and building the capacity of all schools and centres of learning to accommodate diversity. In this regard, particular mention is made of rural schools. Current special schools should play a central role in this process of capacity building of ordinary schools,

- The Report recommends a community based approach to support to the schools. The strengths of existing community support systems in South Africa should be capitilized on and developed further. This would include local government structures, relevant NGOs, support personnel in primary health care, and other community organizations. The Report suggests that each school should establish a centre-based learning support team (CLBT) made up of teachers, parents, learners, and other community members. The main role of this team is to address barriers

to learning and development, and ensure that the school is an inclusive environment,

- In order to build the capacity of the CBLTs, specialist education support personnel such as therapists, psychologists, social workers should be attached to district or regional offices. In other words, there would be district support teams available. This would be of particular importance for historically disadvantaged and rural communities in that such a structure would make support more accessible to schools and communities,

- The Report also suggests the development of a range of learning contexts that would include ordinary schools, special schools, classes or units, resource centres, specialized programmes for particular learners such as enrichment programmes, bridging programmes. This recommendations, therefore, allow for the placement of learners with disabilities within ordinary schools. An implication can be the development of units within a cluster of mainstream schools for learners for learners requiring "high need" support in a rural context. Such an approach ensures that learners are educated within their communities rather than in residential special schools that are situated long distances away from learners' homes and communities. The Report stresses that specialized learning contexts should be defined by the curriculum offered rather than by the category of disability. In addition, specialized learning contexts such as special schools should be located close to the community they serve. If residential placement is required, community homes close to or adjacent to the educational institution should be a priority development. Again, such an approach emphasizes that learners must be educated within their communities so that there is maximum community involvement and social integration.

In this section, the aim was to show that the most recent policy document to emerge, the Report of NCSNET and NCESS, proposes recommendations

that, if translated into practice, can impact positively the lives of rural children with disabilities and their families.

2.4.9 Current Situation in South Africa with Respect to Children with Disabilities

According to the Report of the NCSNET and the NCESS (Department of Education, 1997), most African children with disabilities have been denied equal and appropriate education opportunities. During the apartheid era, support services that did exist operated on racial lines with inequalities in provision to black and white learners, particularly African learners. As stated earlier, the most marginalized learners and the most discriminated against have been rural learners with disabilities, and other special needs such has those experiencing learning difficulties.

Therefore, current inadequacies in terms of provision for African children with special needs, particularly children with disabilities is extreme. As in other developing countries, the limited number of high cost special schools serve a small minority of children with disabilities. For example, in the province of Kwazulu-Natal there are approximately 44 special schools, for children with clear disabilities, the majority located in urban centres. These special schools for children provide for approximately 6 050 learners (Rocher, 1996). The population of children in the province is estimated to be 3, 903, 011. If approximately 5% of the population of children have with clear disabilities – a conservative estimation for a developing context (Muthukrishna, 1995), it can be estimated that there are approximately 195,150 children with clear disabilities in the province that has a total population of approximately 8 417 021 people (Central Statistical Services, 1998). Of this figure, the majorities of these children live in rural areas, and are totally out of the education system. Thus, it can be seen that current

provision in Kwazulu-Natal is inadequate in the extreme with only about 6050 children with clear disabilities able to access formal education.

There have been suggestions that many children with disabilities are "mainstreamed by default" (Department of Education, 1995). However, according to the Report of the NCSNET and the NCESS (Department of Education, 1997), all research and site visits carried out by the Commission and Committee showed a very low level of enrolment of learners with disabilities in ordinary schools. This research also documented the existence of a few community projects offering limited provision to out of school children with disabilities. However, it must be borne in mind that rural schools are the most poorly resourced in the country (Department of Education, 1997), and it is unlikely that the needs of children with disabilities in such contexts are being adequately addressed. The Report of the NCSNET and NCESS cite statistics gathered by the Human Sciences Research Council (HSRC) as part of the Commission's and Committee's research process. This research gives a picture of the situation in one provinces in the country, the Eastern Cape. More than half of the 72 magisterial districts in the province have severe classroom shortages. It was not uncommon to find a teacher-pupil ratio of more than 90:1. In one school, it rose to 165:1. The findings showed that 73.5% of all schools in the Eastern Cape do not have electricity, and 33.7% do not have access to running water within walking distance from the school. In this research, teachers and parents in disadvantaged rural contexts indicated that the meeting of basic needs for schools and pupils had to be met before any effective teaching can occur.

The development of educational provision and support services in the country have been defined by a strong adherence to a medical, deficit orientated model (Fulcher, 1989; Peters, 1993). This model led to the negative attitudes, stigmatization, and marginalization of learners with

disabilities, and the portrayal of them as in need of help. The White Paper on the National Disability Strategy (Office of the Deputy President, 1997) criticizes this model, and argues that it undermines the rights of individuals with disabilities, and denies them a status as productive and equal citizens in society.

Currently, although attempts are being made in some sectors, particularly in policy initiatives, to move away from a medical to a rights model, the dominance of this model in current provision is still entrenched. There is little attempt to question how the education system is failing to meet the needs of the majority of learners with disabilities in the country (Department of Education, 1997). Learners with impairments in rural contexts are disabled by an educational system that has relegated them to the periphery of concern, and has failed to provide for their needs.

The Report of the NCSNET and NCSNET (Department of Education, 1997) suggests that a major barrier to learning and development for learners with disabilities are negative attitudes in society. The Commission and Committee found that negative attitudes, lack of awareness and labeling result in the needs of children with disabilities not being met in the country. Discussions with parents revealed that the birth of a child with disabilities leads to ostracism from the community, and for women it can lead to ostracism from the immediate family. The finding was that this was reinforced in some communities by negative attitudes towards disability evident in some religious and traditional beliefs. The Commission and Committee found that teachers often respond negatively to the inclusion of a child with a disability in their classrooms, and that learners with disabilities are not valued in the school environment. A lack of awareness and inadequate training of teachers compounds the problem.

CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY

3.1 Research Methodology
3.1.1 Qualitative Research

This study used a qualitative research methodology. The present study aimed at exploring how a sample of rural children with disability and their families experience their lives. The aim was to gain insight into what the world appears to be to participants. Furthermore, through an analysis of those perceptions, to gain insight into the social processes and structures that organize their world. In other words, the aim was to gain insight into qualitatively different ways in which people perceive, understand, and experience the world around them. According to Sherman & Webb (1988) qualitative research is a research methodology that allows this kind of investigation. They explain that qualitative research implies:

> "a direct concern with experience as it is "lived" or "felt" or
> "undergone" (p. 7).

As stated, the aim of the present study was to attempt to understand experience as its participants feel it or live it as far as was possible.

Sherman and Webb (1988) explain that in qualitative research, the qualitative aspect is found in experience and is not disengaged from it. He further points out that experience is "bounded" in a specific value context. Events cannot be understood fully if isolated from their contexts. Therefore, qualitative research focuses on natural settings – and is sometimes referred to as naturalistic inquiry (Patton, 1990). The

researcher does not attempt to transform the research setting in any way, nor does the researcher have attempt to establish any kind of predetermined course. The aim is to understand naturally occurring phenomena in their particular contexts.

In qualitative research, experience is studied holistically. Patton (1990) explains that the qualitative researcher searches for totality and complexity, that is, the unifying nature of particular settings. It involves a detailed study and understanding of the subjects social environment as a whole – in its temporal, geographical, political, socio-cultural context. In other words, the aim of qualitative research is to understand experience as unified within certain boundaries.

Glen and Peshkin (1992) contend that the openness of the qualitative inquiry allows the researcher to approach the inherent complexity and to respect it in its own right. The researcher avoids simplifying social phenomena (Patton, 1990). The most interesting aspect is that through the entire research process the assumption made is that social interactions are complex, and that the research will uncover some of the complexity. Therefore, the qualitative researcher is able to enter the research area without placing value judgement and pre-conceived hypothesis. He or she is able to interact with the situations as they present themselves.

Glen and Peshkin (1992) further explain that qualitative research opens a gateway for the researcher to learn about social phenomena from a variety of perspectives. The qualitative researcher deals with multiple socially constructed realities. As human beings living in societies our value system and things we believe in, are to a greater extent socially constructed. Realities about phenomena in different communities could differ or may even be similar. In the present study, it was believed that as a qualitative researcher one is afforded the opportunity to encounter

multiple socially constructed realities about phenomena. It means the experience of disability could be viewed from different perspectives and could even interpreted differently. By interacting with the individuals from different communities, it was hoped that to explore their interpretations and views about disability from their own perspectives. The researcher will have the opportunity to explore similarities and differences between the different subjects and their families regarding their experience of disability.

The purpose of qualitative research is to describe the essential qualities of phenomena, to interpret the meanings and relationships among those qualities, and to give a reasoned judgement about their significance and value. The aim of such research is to understand things better. Therefore, according to Sherman and Webb (1988) it can mean explanation and interpretation. Hutchinson (1994) states that

> "Grounded theory is a form of social criticism, it does make judgements about identified patterns of social interaction. The mere documentation of social phenomena evokes an awareness that social reality is communally contracted and is thus subject to change" (p. 126).

Qualitative research can offer rich and complex explanatory schema of social phenomena. It was hoped that the present study would yield such rich information on the complexities of life for children with disabilities and their families – information that could inform social change.

3.2 Design of the Study
3.2.1 Research Methods

The research methods selected for the present study had to be consistent with the aims of qualitative research explained above. It was felt that the semi-structured interview would be the most effective strategy for data collection. One of the reasons is that interviews allow for the exploration of issues that may be too complex to investigate through by quantitative means. Semi-structured interviews allow the researcher the latitude to tailor questions to the responses of the subjects. In other words, the researcher can follow up on critical issues raised by subjects and perspectives not even contemplated by the researcher. Thus the research tool is open and flexible. The researcher is not bound by the rules of standardization, and the need to ensure replicability.

This issue is of particular importance in the present study because the researcher was interacting with a historically disadvantaged, marginalized and disempowered community. Bannister, Burman, Parker, Taylor and Tindall (1994) point out that research is conducted within power relationships. The question to be constantly aware of is: whose purpose is the conversation pursuing. From the beginning, it was felt the researcher in the present study had to be particularly aware that the research had to be conducted "with" the subjects rather than "on" the subjects. The researcher had to constantly reflect on this role and experience during the fieldwork.

Furthermore, the researcher had to take into account that the majority of people in rural communities are not literate. Therefore, a semi-structured interview would be a more effective tool. A questionnaire, for example, would have been problemmatic.

An interview schedule was constructed that focused on broad areas of concern around the key research questions or issues in the study (refer to appendix 1). Bannister et al, (1994) warn that the interview schedule has to be treated flexibly since if adhered to too rigidly the researcher may fail to probe the subjects' perspectives effectively, and may serve to intimidate subjects.

During interviews, the researcher has to take care that the various questions including probes are open-ended in order to ensure that subjects are not led to a particular perspective or formulation. Interviews were conducted in Sesotho and audio-taped. These were then transcribed and translated into English for the purpose of this study.

3.2.2 Research Process

Since the present study was a qualitative study, the fieldwork was considered the central activity. Going into the field meant having direct, personal contact with the subjects in their own environment. Qualitative research approaches stress the importance of getting close to the people and situations being studied in order to understand the personal realities of their everyday lives (Patton, 1990; Banister et al., 1994). Patton states that this makes possible "description and understanding of both externally observable behaviors and internal states (worldviews, opinions, values, attitudes, symbolic constructs and so on)" (p. 47).

Since the researcher is a resident in the Qwaqwa region, entering the field did not pose any major problems. The researcher had first hand experience of the people and their culture. The researcher also shared the language of the people which is Sesotho. The advantage the researcher had was that he was not seen by the community as an outsider. This ensured

an openness and willingness by most families to share their personal lives with the researcher.

The first stage in the research process involved selection of the subjects: a group of children with disabilities and their families. A form of purposive sampling was employed. It was decided to select children between ages 4-16 who had clear disabilities, that is, visual disabilities, physical, disabilities, hearing impairment. The researcher decided to confine the study to three rural areas in Qwaqwa: Bolata, Makgalaneng, and Mabolela. These were randomly selected from areas that were deemed "clearly rural" in that the communities were subsistence farmers, and lived largely off the land.

The next step was to obtain permission to conduct the study from the authorities concerned. It was also decided to include both children who were in a formal school setting, and children who currently have no access to schooling.

The Education District Manager in the Phuthaditjhaba area was contacted who proved extremely helpful and cooperative. After a lengthy meeting, permission was granted for the study. It was decided to use primary schools in the area to assist with identifying subjects for the study. The Education District Manager informed the remedial education co-ordinators in the district about the study, and discussed the feasibility of using schools in the area to assist with the identification of subjects. After these consultations, final permission was granted for the researcher to contact primary schools from the three rural areas identified. In addition, health care givers and the social workers who serve mainly in the three rural areas were consulted by the schools and the researcher.

The researcher worked with three ordinary schools in each of the areas to identify target children. The selection of schools was done with the

assistance of the education department district manager. All primary schools in the three areas were contacted and informed of the proposed study. However, only those schools that indicated an eagerness to participate in the study were included. Three target schools were then randomly selected from each of the three areas. As a result of this process, the following was the total number of schools that participated in the study: Mabolela area − 3 schools; Makgalaneng area − 3 schools, and Bolata − 3 schools.

The aim was to work with pupils and teachers in order to find a pool of children in the communities who had clear disabilities. This would include children who were both in school and out of school. It was felt that the teachers and pupils would be the best resources to use since there was no official audit done nor data available on children with disabilities. In order to locate "out of school" children with disabilities, it was decided to use the "child to child approach" discussed in Miles (1995). The study by Miles (1995) was conducted in Lesotho. School children were used as researchers in obtaining information on the children with disabilities in the community. To achieve this task, the researcher requested the teachers to ask their pupils to inform the school if they knew any child with disabilities in the community. Data was forwarded to the researcher. In addition, all teachers at the schools were requested to provide the researcher with a list of children in their classes with disabilities.

During my interactions, with the teachers it became apparent that the researcher and the teachers had a different understanding of the child with clear disabilities. Teachers tended to include children with learning difficulties. A brief meeting with all the teachers from those schools became imperative. The idea behind this meeting was to clarify the researcher's conceptualization of a child with a clear disability, and to

ensure that all participants had a shared understanding of the children in question.

Finally, the researcher had to select families who were prepared to cooperate with the researcher, and participate in the study. There were some families who were not keen to participate. It was obvious that they were not comfortable with sharing their personal lives with the researcher. If more time was available for the researcher to spend with the community, it is likely that the researcher would have built a sense of trust with these families. The final number of subjects identified was 17, and all were included in the study.

It must be mentioned that the challenge for the researcher was that this research process proved extremely time-consuming, both during the stages of subject selection and the interviewing of subjects. For example, often appointments were made, and subjects were unable to keep them for various reasons.

3.2.3 Selection of Subjects

As stated, out of the above process, 17 children were identified for participation in the study. Six were from the Mabolela area; 5 from the Makgalaneng area, and 6 were from the Bolata area. Nine of the children were in schools. Many of these were integrated into the schools on an informal basis in that attendance was irregular.

Demographic details on the children are summarized in Table 1.

The children's ages ranged from 6 years to 16 years. The 8 of the 9 children who were in school were located in classes ranging from grades 2 to grade 5. It was clear that their level of academic performance did not

match the grades in which they were placed. It seemed that they were placed in the most appropriate social groupings, taking into account their chronological ages. One child was in a day care centre for children with disabilities run by a mother. Six of the children were at home with no access to appropriate schooling.

Five of the children were female and 11 were male. Thirteen of the families were female-headed households. Only 3 can be described as comprising nuclear families, that is, both parents and children. A profile on each of the subjects is included in appendix 3.

3.2.4 Qualitative Data Analysis

Interviews were audio-taped, and transcribed, and thereafter, translated into English. An important point to be made is that qualitative, naturalistic research is concerned with exploration, discovery and inductive logic. The researcher attempts to make sense of a situation without imposing pre-existing expectations on the context under study. Patton (1990) explains that such an analysis begins with specific observations and builds towards general patterns. Theories about what is being experienced are grounded in the context rather than imposed on the setting through hypotheses constructed prior to the fieldwork. In the present study, it was hoped that general patterns across subjects or cases would be identified when the data is analyzed. Drawing from Patton (1990), it was decided that the first stage in data analysis was to explore and gain an understanding of individual subjects and their families as fully as possible. Following this the unique characteristics of the individual families would then be combined and aggregated across all the families included in the study.

The goal would be to explore and understand multiple interrelationships and patterns.

Qualitative analysis of the data was carried out by both narrative reconstruction of the subject's accounts and experiences and categorization of personal accounts into themes that emerged.. The main aim was to understand each individual child's life and its family's life experiences, and identify commonalties or differences.

CHAPTER 4: RESULTS OF THE STUDY

4.1 The Family

The composition of the family unit differed in each of the seventeen households.

Of the 17 families, 13 were female-headed households. Three can be described as nuclear families, comprising both parents and two children. In 6 families, the grandmother's pension is either the main source of income, or it contributes to the household income. In one of the nuclear families, the father is the breadwinner, whereas in the other nuclear family both parents are employed.

4.2 Perceptions about the Disability

All 17 caregivers have a vague perception of the kind of problem the children are experiencing. None of the children were assessed in any formal way since birth, nor were parents given any insight into the nature of the disability. Some of the responses were:

> "SP has a brain problem. Actually, he does not understand a thing, he just can't comprehend things. At school he is not learning anything. You know he is 14 years old but he is unable to learn. He is like a child in Sub A. He is a person who needs constant supervision, because he also touches and handles hot water. He actually does not have an

understanding to distinguish between dangerous things. You know he still can't differentiate between morning and afternoon, he can't even tell what time it is". (Mrs. MS)

"He is not progressing at school. He is not learning anything. Personally I thought he was being naughty, but as time went I got reports that he is becoming uncontrollable.... he tears books and stuff and I was then called over to the school. He is not performing at all in school ... like I'm saying there is nothing that seem to be going into his brain. When he was still young I just took it for granted that, he is just a naughty child, who doesn't listen to what you tell him to do." (Mrs. STBO).

"His problem is actually with his eyes. He doesn't seem to see well, he can't see very clearly. Especially those things far away, he has problems reading things he doesn't seem to see the letters or something its' like he just see images. There is no one in the family with that kind of problem. Actually, I do have a problem with my eyes, but with me its just old age." (Mrs. HT, grandmother)

He has problems growing, he is behaving younger than his age, he also has problems with spoken language, the problem is with his brain. Since he was a small boy he could not crawl, he also started walking later than normal"." (Mrs. LS)

He cannot be left alone ... he is all over the place.. he climbs up the trees, rafters of abandoned houses. The other day he had to have stitches above the eye". (Mrs. STBO)

"KH is born disabled. He actually has a problem in his brain, which makes him to be unable to use his legs and other parts, he is actually in a wheel chair. KH was actually born like that It is not safe for him to be left alone at home - because he can't do anything for himself, someone has to push him around in his wheelchair." (Mrs. MK)

4.3 Perceptions about the Child's Ability

The caregivers have made observations of the children's strengths and difficulties from their own day to day experiences with the children.

"I do not think he will be able to have a job – or even do some manual work. He can't even do gardening – even if he plays with his friends ...when they build toy cars with wire ..... he is incapable of that." (Mrs. MK)

"She interacts well with the other children, she likes people and she has many friends and they are always around. I think it's because of her good heart. She is capable of any physical things her peers are doing. When you teach her something on a very slowly pace she understands." (Mrs. MMA)

"From my observation, I realized that he is talented in using his hands, because some of the things he does with his hands are very appreciable and artistic. Yes, I see him working with ....maybe technical work or something" (Mrs. ML).

"From my observation, I realized that he is talented in using his hands, because some of the things he does with his hands are very appreciable and artistic. Yes, I see him working with ....maybe technical work or something" (Mrs. ML).

"I know he can do better at school if his eyes are healthy. TH is able to tell what has been said at school. The problem is with written things because it is difficult to make up what is written. He complains that he can't see clearly on the board. He is not learning much." Mrs. HT).

4.4 Attitudes towards Disability

All the caregivers expressed feeling of shock, guilt and disappointment when discovering that there was a problem with their children. They also indicated that there was nowhere they could have turned to for support at that stage. One mother described her experience in the following way:

"When I discovered that he has a disability ... to tell the truth I was in shock, you must understand my other child are fine. You know as an expectant mother, you expect a beautiful healthy baby, but when discovering that there is something wrong with them you are overwhelmed with a feeling of guilt and disappointment. You actually ask yourself questions like what went wrong - and you can't find the answer - that is what is most frustrating." (Mrs. MK)

behaving and performing as expected....... they sometimes tease him. I mean other children at school ." (Mrs. LS)

Although teachers were generally supportive of parents, one of the mothers expressed her experience of lack of understanding and empathy for the child on the part of some teachers:

"You know with teachers, a teacher is something amazing. Even though I have been taking him to the doctor and submitting letters to the school .... it happens that sometime he meets another teacher who will terribly handle him because they don't have the time." (Mrs. STBO)

Cultural perceptions of disability influence attitudes. The caregivers explained their experience of community attitudes as follows:

"I do not know the cause. It is just the way he is born, I think that the way he is naturally. People in the community have their own perceptions about everything - some attribute it to witchcraft - some think I have done something wrong, thus the child is with a disability." (Mrs. MHT)

"Some of the neighbors attribute his condition to sorcery. They say someone who hates my family did something to make him always faint so that he does not progress in life. They say because he is the only boy. I don't know what to believe, but as I said before I think that is the way he is naturally". (Mrs NM)

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"You know as people we quickly blame or give reasons like witchcraft. Maybe when one was expecting the child, one got bewitched, things like that." (Mrs. ML)

"The community have their own thing to say about his disability Some think it's God's will and others think some one did this to my child. Some think it's a sign of some kind. You know people say a lot of nonsense." (Mrs. MTeb)

4.5 Interaction with Professionals

Lack of information and lack of warmth on the part of professionals both at the time of at the time of being told about the disability and during on going contact, have been found to be sources of dissatisfaction by parents.

From the interviews, it is clear that the families obtain very little support from professionals, in particular, social workers, and medical practitioners. No advice is provided on how to intervene with the children, or where families can access support. In most cases, these professionals are located at the nearest hospital (a bus ride of about one and a half-hours away). One of the caregivers has no idea where professionals who could help them are located.

The following responses typifies this:

" I even took him to Bethlehem to see doctors. He said this child has a problem, and there is nothing they can do for him

at the school because they are only teaching children who are educable. He said there is a problem in his head." (Mrs. MHT)

"I don't know of any services where I can get help for my child." (Mrs. MT)

"I am aware of people called social workers, but I do not know what they do."(Mrs NM)

"In my community there is no such help available... there is no where one can go for help with a child with a disability. : I once took LER to a what is it eh... psychology. They did not really help. They only told me he has a speech problem which a very obvious thing and from there nothing further happened. They said I should send him to a special school. There is no special school in Qwaqwa ... not that I know of.
There are no services in our community ... I was told for speech therapists I need to take LER to Bloemfontein or Johannesburg. Unfortunately I could not because I did not have medical aid." (Mrs. ML)

"I took him to social workers but I eventually decided to stop because there was no progress. Social workers are supposed to help people with problems and disabilities – things like food, clothes and grants for the disabled. I do not know the cause of his disability. The doctors never gave me an answer – they were giving me a whole range of different reasons. Some said it was his nerves, some said it's his nature that he was born like that". (Mrs. MS)

The response of one of the caregivers regarding her interaction with professionals reflected another dimension – power relations in the community.

It is clear that this particular caregiver feels that factors beyond her control are affecting her inability to access help from social workers. She is also disempowered in the circumstances to make any attempts to assert her rights:

> "Yes, I have been to the social workers for assistance - but there is one person who sabotages my attempt to seek help. The mother to these children is not taking care of them so I thought the social workers would help, but the man in charge was involved with my daughter at some stage. Now that they are not together any more, he is making things difficult for me. It is rather a long story, which I am not prepared to go into details. It's actually about my daughter in law's name - they are questioning if it is a maiden name or the one given in marriage, and they don't want to believe when I tell them what I know. Now the children are orphans whereas their mother is still alive. I cannot ask her (the mother) to help take care of the children If only you knew her - one irresponsible human being. (Mrs. HT)

One of the caregivers who was widowed expressed the problems she was experiencing with government bureaucracy:

> "Unfortunately, I am not Aware of any organizations which can help me with my child and other needs. But I filled forms twice, applying for assistance from the government but nothing transpired from that. My husband used to work for the

government, I went there to claim his money and I was made to fill in some forms which did not help even today I haven't received a thing. I filled the forms in 1996, I also filled others again in January 1997. Firstly, they said the problem was with the child's birth certificate - seemingly the numbers were not clear according to them. We are still waiting." (Mrs. LS).

4.6 Current Educational Provision

Nine out of the 17 children are in ordinary schools However, it is clear that the schools are unable to respond to the educational needs of these children. Child MAJ is 16 years old, and in grade 5. It is likely that he is good potential academically. Despite being over-age, and although there has been no attempts at curriculum adaptation, he has made progress. From the observations made, he seems to be a cerebral palsied child. All the 9 children currently at primary schools are not making progress academically.

> "The nearest school is at least 10 minutes away... a ten minute walk. He is not getting good education... It's because he is not getting any speech training at an ordinary school. If he were at a school where teaching will invest time in training him it would be better. I think the government should help with LER. ...like it is doing with the other children." (Mrs. ML)

It is encouraging that is that teachers at these schools requested the caregivers to admit the children to school rather than have the children remain at home with little stimulation. The schools seem to provide some support to families in this rural context.

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"When I took him to school he still didn't have language. He could not talk. Teachers at the school nearby suggested that I take him to school so that he will be able to interact and learn from other children. Now his speech is clearer." (Mrs. MS)

"He is not at school at present - you see the problem is that he is not progressing, but sometimes he goes and some other times he just stays at home. At first, his teachers were not happy about him going to school when he wants to, but since they realized his problem they are a little understanding. But they tried everything but they are unable to teach him, despite all their efforts he still does not understand things a person his age finds easy to comprehend." (Ms MM)

One of the mothers, Mrs. MK, has a child of 9 years old who from observations appears cerebral palsied. The child was initially at an ordinary school, and as he grew older the mother had difficulty carrying him to the school each day. He then remained at home until a group of mothers who have children with disabilities began a day care centre. However, in some cases because parents live a great distance from the centre, children do stay in.

The determination of this mother to create services for her child and other children in the community are reflected in her words:

"At home I try and make sure I talk to him and teach him things and ask him questions. As a mother who didn't have enough education, I really want my child to have some kind of education. I want my child to be educated. I don't want my

child to be a burden to any one when I gone, I want him to be
active intellectually. That is why I actually came up with the
idea of this school, because our children with disabilities could
not be taught in other schools in the community, because it is
difficult for them to run like other children or they cannot not
use some of their body parts effectively. Well, it was tough at
first. I tried to organize mothers or children with disabilities,
and naturally people thought I'm just doing something
impossible. But I was determined. Firstly, I wanted to make
sure that these children are taken care of whilst parents are at
work as well as being taught something. So after a lot of hard
work some parents joined me." (Mrs. MK)

Mrs. MK also expressed her desires regarding her child's future
educational provision

"I would love him to go to a school where teachers are
prepared enough to work children like ours, where teachers
only teach disabled children so that they learn at their own
pace, and here is constant supervision for our children,
because they need assistance.
Obviously, parents should take the responsibility of their
children's education but seeing that, children with disabilities
are taxing in terms of facilities needed ...... I think the
government should assist because the disabled are also citizens
like any one else. At home, I try and make sure I talk to him
and teach him things and ask him questions. As a mother who
didn't have enough education, I really want my child to have
some kind of education. I want my child to be educated. I

don't want my child to be a burden to any one when I gone, I want him to be active intellectually."

4.7 Family and Community Support

The caregivers indicated that there was support from the family – but this support was seen largely in terms of financial support towards basic needs. Just one caregiver felt that the family and community were supportive of the child at a social level. Two of the caregivers have contact with other mothers who have children with disabilities, one of them being the mother who is involved in the running of the day care centre.

Comments were as follows:

" We cope with our problems ...we survive, we really survive through God's help. It is, however, difficult to pay the school fees for all the children that they require from school. It is forty rands. I do not get support from the community ...There is no one helping me, I am all alone with the children. I do not know any parents who have children with disabilities. There are no organizations or a hospital who gives me help." (Mteb)

"It is very difficult to cope .... you always have to keep an eye on him, but we are surviving. There is no school for this kind of child around here, but the doctor said he knows of some school some where. He then investigated the prices, and I found the fee to be too high for me.
My family does support me ..... yes, because they do give me money to help in taking him to the doctors. There are no other organizations that can help me in this community. I do not know of other parents who have a child with a disability. (Mrs. MT)

"Some people understand and are sympathetic and they encourage me that I should be thankful to have a child than not to have any at all, but other's have their own problems to worry themselves about my child."(Mrs MDIM)

"My family is supportive. The only family I have is my mother and my children, so of course, my mother supports me in every way possible. There is not any support you get from the community. I cope in taking care of my children's needs - through the mercy of God, we just live one day at a time. I do not know other parents who have children with disabilities. I am not aware of any around " (Mrs. LS).

One caregiver made reference to support specifically for the child with disabilities:

"Yes, my mother is the breadwinner but we get by just fine. We understand M. - we have been living with him since birth, so there is no problem. Our whole family understand his problem and also help with some other things – when my mother needs something for the family. Yes, we do get some support – like help from church -with things that we need, like food. .... sometimes clothing". (Ms MM)

4.8 Concerns for the Future

The overwhelming concern expressed by all the caregivers is what will be the future of the children in the event of death of the caregiver.

> "It is very difficult to manage financially because I am a pensioner, now what ever I buy as food if it gets finished before the next pay day then it means trouble. In short, I can say it is a struggle. What concerns me most is wondering what the future holds for him and also for the other children. Seeing that their mother left them with me and went to live somewhere with some one else. I am old now ...." (Mrs. HT – grandmother).

Other concerns expressed were: that the children one day have a job and independence, more appropriate educational provision needs to be provided by the government, and money to meet basic needs.

> "We need to eat, drink and we need clothes, that is all we need. If only he could go to a school where he would be taught and trained to cope with this world's pressures and demands - so that he can take care of himself."
> (Mrs. HT).

> "I am concerned about what my child is going to become in the future. I wonder if life is going to be good to him. I am also

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concern of what whether the government is prepared to help its disabled citizens."
(Mrs. MK)

" I know of one family with a child with disabilities. We used to meet and discuss our children. We used to talk about our concerns, the future of our children and many other things ... like what kind of adults they were going to be...... what kind of lives they are going to lead. Specifically, my worry is who is going to take care of him when I'm gone. My major concern is wondering what is going to be the end of him, that is, what kind of school is there for him. You see.. if he can get a school which can provide some future for him. If I could afford that type of school I would send him to it. If only he can get a school that will teach him to fend for himself.. I'll be happy ..... so that he can have some future. If parents need to pay, then I'll have to find means to do so ... because my concern is with his future. My worry is I am not going to be with him forever." (Mrs. MS)

"I am concerned of what is going happen to this child when I am gone. I am the only person she has in her life. My worry is who is going to take care of her, because I can not imagine her getting married. Men are not interested in girls like her. "
(Mrs MK)

CHAPTER 5: DISCUSSION OF FINDINGS AND RECOMMENDATIONS

The findings from data gathered in this study provided in-depth information on 17 children with disabilities and their families from the perspective of the main caregiver. The results highlight the various social, economic and political factors that impact on the lives of the children and their families. In this section, an attempt will be made to explore in more depth the themes that have emerged in the context of literature reviewed on other developing countries.

5.1 Meeting the Basic Needs of Families

In the case of all the families, the main concern is financial – a struggle to meet basic needs. All the caregivers expressed their disillusionment in the fact that the present government has done nothing to alleviate the economic problems of rural people, and that there has been no attempt to provide facilities for rural children with disabilities. The majority being female headed households make the income per family a mere minimum. It is clear that these children live in conditions of under nourishment which would negatively impact developmental outcomes of a child with disabilities. The Report of the NCSNET and the NCESS (1997) stress the need to address socio-economic barriers to learning and development, for example, lack of access to basic services, and poverty and underdevelopment.

Community based projects in developing countries are exploring a more holistic, integrated approach to service delivery. Programmes to improve

the lives of individuals with disabilities take place in the context of whole community development and involvement (O'Toole, 1995). Projects focus on essential health awareness, literacy development, income generation for the community. The focus is also on health promotion in communities. A fundamental principle of this approach is the bringing together of the various sectors such as health, labour, transport, welfare, education and NGOs, to address problems and promote development collaboratively (Department of Education, 1997).

5.2 Educational Provision and Rehabilitation Services

The findings in this study indicate that none of the 17 children and their families have access to appropriate education and rehabilitation services. Parents in the study believe that current special schools are inaccessible to them because of the high school fees required. Although nine of the children are in ordinary schools and may be benefiting from the socially from interacting with other children, the curriculum is largely inaccessible to these children. On the positive side, it is commendable that teachers at the local schools are open to having children with disabilities in school. The families seem to have no problems gaining access to local schools in the community. In some instances, teachers have requested that the child be placed at the schools. However, the caregivers have indicated that the teachers do not have the skills to respond to the needs of the children. In South Africa, in order to meet the needs of rural children with disabilities and their families, there is an urgent need to find alternate models of service delivery to the current western models that serve only a minority of children. Lessons can be learnt from some of the initiatives currently underway in certain developing countries, as reviewed in chapter two.

5.3 Community Based Support to Families

The findings in this study revealed limited available support for the family within the community. Some of the expressed and observed needs of the families in this study were: lack of finances to meet basic needs, lack of employment, poor health care, lack of access to appropriate education and early intervention programmes for their children with disabilities, limited emotional and social support from the community, lack of income generation projects for families of children with disabilities.

One finding that emerged very clearly is that all the families, including the mother who runs a day care center, lack knowledge and information on the nature of their children's disability. They have a very naïve understanding of the impairment, and how to intervene with their children. Building on parents knowledge about disability will lead to their empowerment, and will impact their ability to serve as advocates for their children and community. There is a need for community based programmes to uplift the community and, to build a network of support. CBR programmes in many developing countries (O'Toole, 1995) work on transferring knowledge and skills about disabilities from professionals to people with disabilities, families and members of the community. For example, home programmes for children with disabilities are conducted by family members and supervised by trained community members. This leads to a support networks within the community being built up over time.

In South Africa, voluntary societies such as parent organizations have functioned mainly in urban areas, and have made a major contribution towards recognition of the needs of families and have set a lead in service provision. Collectively such organizations have represented a powerful voice in shaping government policy and provision. There is a need for

such structures, in particular, parent support groups, in rural areas that are relevant for families and disabled children. They can provide information and a point of contact where parents can meet one another. Baird and McConachie (1995) in their discussion of services in Britain explain that the feelings and behaviors of parents of children with disabilities after being told the diagnosis can be likened to a bereavement process. For most parents there is a period of initial shock, followed by sadness, and frequently anger and sometimes denial. Lack of information and lack of warmth on the part of professionals have been found to be important sources of dissatisfaction. The primary need for families at this stage is for emotional support and another parent of a child with a similar diagnosis may be the best person to offer that support. For families already trying to cope with the stress of having a child with a disability, having to fight for services is an added stress.

5.4 Coordination of Professional Services

As expected, the findings reveal virtually no support for the children and their families with respect to early identification and intervention, appropriate educational provision, and other forms of support and are forms of social support. Health and welfare services seem inaccessible to rural these families. Those families that did attempt to seek help from professionals met with no success.

Limited services are available at the nearest hospital which is a one and a half-hour bus ride away, but parents have been unable to obtain adequate support. O'Toole (1995) in reviewing the Guyana initiative, stressed the importance of the use of existing infrastructure, and the collaboration of all professional services within a community at the district level. The Report of the NCSNET and the NCESS (Department of Education, 1997)

recommends the development of community based support services. The strengths of existing community support systems must be drawn on. The Report states that

"boundaries between 'lay' and specialist support would be blurred as well as boundaries across different professionals" (p. 65).

Pooling together resources in a community based approach to service is the only way to go in a country with limited professionals and other human resources. Such an approach will make services more accessible to people. De Carpenter (1996) drawing from experiences in Jordon argues that professionals need to move away from a focus on the direct needs of clients and their institutions, to becoming facilitators for community based approaches.

The Report also recommends that specialist support personnel from health, welfare, education and other sectors be rationalized to the district level. They should be involved in training and coordination of services, and providing support to various community-based initiatives. Carpenter (1994) suggests the following ways in which district support structures can assist in the development of local provision:

- Awareness raising and sensitivity to the needs of individuals with disabilities and their families,
- Empowerment of communities in their attempts to develop a voice and a power base from which they can begin to develop,
- Education of communities in the role of preventing individuals with impairments from becoming disabled and handicapped by their impairments,

- Assistance to schools in curriculum development, and in creating schools that are responsive to diversity,

- Training and development courses to empower teachers and community workers in skills and knowledge to provide support to children with disabilities and their families such as early identification and intervention.

5.5 Teacher Development Programmes and Curriculum Access

It is imperative that the welcoming ethos in many rural schools that admit children with disabilities is a strength that must be further developed. The urgent need for teacher development programmes to build the capacity of these schools to respond to diversity needs to be addressed. Community-based innovations in countries such as India, Lesotho, Guyana that are similar contexts to South Africa, discussed in chapter two, are encouraging, and provide good lessons of practice. The philosophy underlying these initiatives is inclusion (Unesco, 1994). Some of the principles of this philosophy when applied to schooling contexts are:

- every child has fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning,

- every child has unique characteristics, interests, abilities and needs, and therefore, education systems should take into account diversity;

- children with special educational needs must have access to regular schools which should accommodate them with child-centred pedagogy capable of meeting these needs,

- ordinary schools with this inclusive ethos are the most effective means of addressing discriminatory attitudes and building an inclusive society in the most cost-effective way.

Booth & Ainscow (1998) extend on this conceptualization of inclusive education. They argue that in any one country barriers to learning such as a lack of facilities, the need for curriculum reform, insufficient and inappropriate teacher education, school attendance, problems of family poverty, cultural dislocation, street children, problems of disease, and differences between the language of instruction and the home language and, disability affect the participation of learners in schools. Barriers can be located within the learner, within the centre of learning, within the educational system, and within the broader social, economic and political context. Barriers to leaning and development may include amongst others, lack of access to basic services, poverty and underdevelopment, attitudes, inflexible curriculum, inadequate and inappropriate provision of support services, lack of parental recognition and involvement, lack of human resource development strategies, and disability. The emphasis in intervention should be on uncovering and minimising barriers to learning rather than identifying and treating defects of students. Inclusion is about maximising the participation in education of all students whatever the origin of their barriers to learning. The findings in this study have served to uncover some of the barriers to learning and development in this rural context for the children and their families. The Report of the NCSNET and the NCESS also recommends that teacher development programmes should incorporate an inclusive philosophy in order to create schools that respond to diversity.

Key components of education and rehabilitation programmes need to be explored in terms of relevance for the South African context. Some of

these are: promotion of sustainability to avoid dependency; education and training of local personnel as the core of any project; holistic training programmes that deal with issues such as early stimulation, literacy training, awareness of disability issues; inclusion of children with disabilities in ordinary schools, leadership training skills; developing curriculum materials for in-service, school based teacher education programmes.

The Report of the NCSNET and the NCESS (Department of Education, 1997) recommends the establishment of school based learning support teams in each school. One of the roles of this team should be to work in collaboration with district support teams and other schools in a district or circuit to develop school based teacher education programmes. One of the components of such programmes would be to develop the capacity of schools to respond to diversity in the learner population. Ainscow (1994) argues that initiatives have to have conceptual clarity. In his research in various developing countries, the focus has been on teacher development in the context of whole school improvement. The aim has been to use human resources within schools and communities rather than search for experts from outside the community and learning context. Ainscow (1994) describes a collaborative teacher development project initiated by Unesco that drew together practitioners mainly from developing countries. The core of the project was a school-based approach, and a curriculum view to accommodating diversity in the classroom. It encourages teachers to challenge their thinking about children with diverse needs, and to interrogate the social, political and organizational processes that are external to the child, abd impact learning and development. In other words, the curriculum and organization of the school are questioned.

The development work in Lesotho (Khatleli et al., 1995) was guided by a similar philosophy. Teacher development curriculum materials were

designed that were relevant and appropriate for the context. Various stakeholders such as parents of disabled and non-disabled children, teachers, disability organizations, the University of Lesotho, NGOs, the Ministry of Education were involved in the process.

5.6 Societal Attitudes

In all cases, the children with disabilities are cared for in the family and within the community. The attitudes of the community are varied. Some families indicated that the community was sympathetic and supportive. Some people tended to label the children as "not normal". The Sesotho word "sehole" that is used, is extremely harsh and derogatory; and could be translated as meaning "imbecile". They also viewed all children with disabilities as one homogeneous group, to whom the word sehole is often a, pplied.

Cultural perceptions of many community members was that the disability was the result of sorcery and witchcraft. In a few families there was evidence of overprotection.

Societal expectations of "normality " in society have profound implications for the development of personal identity, and therefore put particular pressures on individuals with disability and their families. Educational philosophy internationally, including that in a number of developing countries has moved towards a policy of including disabled children into ordinary schools, despite problems of resources. One way to change attitudes is to include children in educational and social settings together with ordinary children.

The quality of life is determined primarily by the attitudes of parents, the family and the community, and by the social and physical barriers the child and the family encounter. An important component of interventions

in this context has to be awareness raising and social integration of the disability in an attempt to change attitudes, sensitize communities to disability issues, and address myths that impact how disability is constructed.

5.7 Employment and Independent Community Living

One of the concerns of a number of caregivers in the study was about the future of the children with disabilities, in particular, concerns about employment possibilities and independent citizenship. Other concerns were about the safety of the child, the future of the girl child who no one will marry, and about future care once the caregiver has died.

McConkey (1996) stresses that child with disabilities needs to experience life as a valued member of a family, a community and society, and to feel that he or she belongs to a social group. He describes projects undertaken by The Cheshire Foundation International in a number of developing countries such as Thailand, Sri Lanka, the Phillipines, Malaysia, aimed at helping people with disabilities to become full participants in their community. The project largely involves vocational and life skills training. These projects included a range of service models to prepare people with disabilities for a productive life in their communities. Life skills with an emphasis on personal care, household skills, and socio-academic skills such as handling money, and vocational training for supportive and competitive employment must begin at an early age.

McConkey (1996) reviews these service models, and suggests some key components that need to be included in a training model that is community based:

- the active involvement of the family is essential to promote the development of independence skills such as communication, independent mobility, and personal self-care,
- education at schools need to be focused on the individual, and relevant to the local environment, leading to productive work and independence.
- a training programme has to address the low expectations people with disabilities have of themselves as workers,
- vocational projects should be community orientated, for example, the projects need to be managed by local persons, the products produced through the project should meet local needs, and volunteer helpers should be from the neighbourhood..
- there should be partnerships between the service and the community it serves.

One of the outcomes of the work of the Cheshire foundation International was a "Training for Work' package that includes video material that draws on examples of good practice in developing countries.

CHAPTER 6: CONCLUSIONS AND IMPLICATIONS OF THE STUDY

The findings in this study have important implications for service provision for children with disabilities in this rural context. It is clear that the principles of human rights and social justice for all citizens enshrined in a

policy documents that have emerged in South Africa since 1994, have not been translated into practice. The rights of rural children with disabilities and their families to achieve equality of opportunity and equal access to services in society, and their right to full citizenship continue to be violated.

The various Provincial Departments, including Health, Welfare, Education, need to form partnerships to address the service needs of rural children with disabilities and their families. Some of these needs are: community-based support networks to give families social and psychological support; educational provision and rehabilitation care within local communities; support for children and families within the education, health, and welfare systems.; information about available services, and training programmes for employment and independent living.

This study is significant in that it provides information critical to the conceptualization of framework priorities for children with disabilities and their families in a rural context. As Zinkin (1995) argues - the question to ask when planning service provision is, "whose priorities?". Professionals and policy makers assume that their interventions are appropriate and they know what the priorities are for children and their families. It is critical that interventions take as a starting point information

on how these children and their families are experiencing heir lives in their particular context.

Attention must be drawn to that fact that this study was conducted in one rural context and in one province in the country. Further research in other rural contexts in other provinces will be valuable to future planning for service provision.

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APPENDICES

Appendix 1: Interview Schedule

1. Tell me about your family.

2. What kind of a disability does your child have?

3. What are some things that your child can do? What are some of the difficulties he or she has?

4. How did you feel when you discovered that your child has a disability?

5. How does the community support your child and your family? What is the attitude of the community towards a child with disabilities?

6. Have you had any contact with professionals such as speech therapists, physiotherapists, doctors to discuss your child's problem?

7. What kind of education provision does he or she have access to?

8. What are some of your concerns with respect to your child and your family?

Demographic Details Table 1 (Appendix 2):

Table 1:

Name	Gender	Age	District	In/out of school	Female headed families (*)
DIS	F	6	Mabolela	out	*
MAN	F	9	District 1	in	*
TH	M	9		in	*
TS	M	12		in	*
SP	M	14		out	*
KH	M	9		out	*
MAP	F	13	Makgalaneng	out	
MAG	M	15	District 2	in	*
LER	M	11		in	*
SB	M	14		in	*
SEIP	F	12		out	
LK	M	16	Bolata	in	*
TEB	M	14	District 3	in	*
MAJ	M	16		in	*
THB	M	11		out	*
DIM	F	14		out	*
TBO	M	12		out	

Appendix 3: Profile of the Subjects in the Study

• The abbreviated name of the caregiver interviewed is provided in brackets with respect to each child.

Introductory Comments

In each of the families, homes are built of either mud and wooden poles, corrugated iron sheets, hollow concrete blocks made in the community. Families tend to add on rooms gradually to the existing home over the years to cater for the growing extended family. None of the families have running water in their homes. At present, all the families in this rural context have access to running water from communal taps situated along the roadside within a few hundred metres from homes. Water is collected each day from these taps in buckets by children and women. In some cases, the researcher observed that wheel barrows are used to transport the water to the homes. All the families have pit toilets away their homes in the yard. These are not communal.

The nearest main town, Phuthaditjhaba, is approximately a one and a half hour bus ride away. The nearest hospital is in this town. There are small clinics that operate in certain locations within some districts. These are manned by nurses with doctors visiting occasionally.

1. Child SP (mother, Mrs MS)

SP is a fourteen year old boy. His problem appears to be developmental and possibly, neurological. According to his mother, he is not developing in the same way as his age peers. She believes that he is "mentally

retarded", and behaves like a little baby. SP goes to school sometimes but he is not on the class register officially. The teachers allow him to sit in class. At present, he is not in school. He is reported to need constant supervision, especially at home. According to the mother, he tends to "act irresponsibly around the house". For example, he touches hot water, and is unaware that he can hurt himself. SP lives with his mother and sister in a three roomed house. Outside in the yard is a pit toilet. At the time of the interview, the mother was out of a job but she was to start a new one shortly in the main town. The mother is the sole breadwinner. She said that she does not earn much. When it is financially difficult, she obtains assistance from her mother who is a pensioner. This is a female-headed household.

The neighbors are helpful. They take care of the child if the mother needs to go somewhere, and cannot take him along. Everyone in the community likes the child and they are compassionate towards him. According to the mother, the church and the people in the community regard him as "not a normal person". The mother's concern for the future is about what is going to happen to the child when she is dead. She does not think he can either hold a job or obtain any kind of work.

The mother, Mrs. M.S. gave her views on the child's problem:

> **"SP has a brain problem. Actually, he does not understand a thing, he just can't comprehend things. At school he is not learning anything. You know he is 14 years old but he is unable to learn. He is like a child in Sub A. He is a person who needs constant supervision, because he also touches and handles hot water. He actually does not have an understanding to distinguish between dangerous things. You know he still can't differentiate between morning and afternoon, he can't even tell what time it is.**

Regarding his ability, she indicated that:

> "I do not think he will be able to have a job – or even do some
> manual work. He can't even do gardening – even if he plays
> with his friends ...when they build toy cars with wire ..he is
> incapable of that."

On his early years she said that:

> "From birth his mobility was delayed. When I took him to
> school he still didn't have language. He could not talk.
> Teachers suggested that I take him to school so that he will be
> able to interact and learn from other children. Now his speech
> is clearer. It's just that he is a person who cannot differentiate
> if a thing happened today or yesterday ...he does not know the
> time of things".

Her perceptions on the cause of his disability are:

> "Some people in our community said it is just an abnormality.
> At church they regard him as not a normal person.
> The community take him as a person who is not complete ..who
> is abnormal. I think it is his nature .. that is how he was
> born...since I have known him since his birth.. he was not
> doing things he was supposed to do ....for his age he was
> always delayed.

Mrs. MS made these comments on his social behaviour:

> "The only thing he likes doing is drive around toy cars, even bricks or any other thing he can lay his hands on.

On his health status, she said that:

> "He is healthy. He suffers from the common cold like everyone else suffers from. I get medication from the clinic for this.

She is the sole provider for her child:

> " I am not receiving any support from them. He is my responsibility alone".

Mrs. MS stated that she does have support from her community:

> "When I am not at home my neighbours look after him for me until I'm back. My other neighbours also take care of him because they know what type of person he is".
>
> I do not receive any support or help from the church, hospital, NGO's etc".

Mrs MS has virtually no contact with other parents who have children with disabilities:

> " I know of one family with a child with disabilities. We used to meet and discuss our children. We used to talk about our

concerns, the future of our children and many other things ...
like what kind of adults they were going to be.. what kind of
lives they are going to lead. Specifically, my worry is who is
going to take care of him when I'm gone."

She indicated that she does cope with caring for SP.

"I do cope. You know, at his age you still need to supervise
how he washes himself. Everything he does needs to be
supervised. I always have to be with him. I should be with him
all day long – if not for different needs – the need for money.
But due to these needs and not having someone to look after
him – I have to leave him and go to work. It is better when the
schools are open . He spend most of the time at school."

She has had some contact with professionals in the nearest town:

"I took him to social workers in the main town which is about
1hour 20mins away by bus for help. I eventually decided to
stop because there was no progress in his development. Social
workers are supposed to help people with problems and
disabilities – things like food, clothes and grants for the
disabled."

Regarding her perceptions on the cause of the disability, she said:

"I do not know the cause of his disability. The doctors never
gave me an answer – they were giving me a whole range of
different reasons. Some said it was his nerves, some said its his
nature that he was born like that".

Regarding educational provision, she indicated that:

> "They say in Qwaqwa there is no school for him. The social
> workers said they are still going to build it.
> They said that they will build a special school in this area but
> even today it has never materialized."

Some of her concerns about the future are:

> "I know of one family with a child with disabilities. We used to
> meet and discuss our children. We used to talk about our
> concerns, the future of our children and many other things ...
> like what kind of adults they were going to be what kind of
> lives they are going to lead. Specifically, my worry is who is
> going to take care of him when I'm gone."
>
> My major concerns is wondering what is going to be the end of
> him, that is, what kind of school is there for him. You see .. if
> he can get a school which can provide some future for him. If I
> could afford that type of school I would send him to it."

> "I need someone to look after him while I am at work".

> "If only he can get a school that will teach him to fend for
> himself.. I'll be happy .. so that he can have some future. If
> parents need to pay, then I'll have to find means to do so ...
> because my concern is with his future. My worry is I am not
> going to be with him forever."

2. Child DS (Mother: MDS)

DS is a 6-year-old girl she lives with her mother, two other sisters and a brother. She is from a female-headed family. DS is not in school. Her mother is the sole breadwinner. She is employed as a domestic worker in the nearest town. She was not comfortable with divulging the actual amount she earned. She has a small business from home. This involves buying sweets and snacks from the main town, and selling these in the community. DS 's impairment appears to be both neurological and physical. It is likely that she is cerebral palsied. She drools, and has a hand function difficulty. She also seems to have clear developmental delays. She needs constant supervision, and all her physical needs have to be met by the mother. The mother's concern is about what the future holds for the child.

The mothers perception about the child's problem:

> "The problem is with her right arm and hand. They are not
> functioning normally. She is at present not in school because
> she often faints. She sometimes hurts herself when she falls.
> Sometimes she gets sick and very weak for a long time so that
> is why she has to be at home".

Regarding her child's abilities, she indicated that:

> "I believe if she can overcome her sickness of fainting, maybe
> she might be able to learn to use the other "normal" hand
> effectively. She might even learn something from school, but if
> she still has this problem I don't see her holding any job. She

needs someone who understand her condition, who will always be around her".

Mrs. MDS expressed her feelings when she discovered that her child had a disability:

> "When seeing that there was a problem with her, I got very shocked and unhappy. What shocked more was the discovery that she also has seizures. This comes at any time and I am afraid this can happen and she might fall into the water or into a pit or something

Mrs. MDS said she had some contact with the professionals:

> "I took her to the clinic, so that the nurses could look at her problem, because she was fainting frequently. The nurses told me she is born with this sickness, and there was no medicine they could give her to cure this".

She is the sole provider for her children:

> "It is difficult to manage especially financially. You see I am the only one providing for all my children, and the other two are in school".

She is concerned about the child's future, she said:
> "I don't think she will have a good life, because she is not in school, maybe if we could afford those schools where they teach people like her, but I hear they are far and expensive"
> I am also concerned about her safety, I am afraid to let her wonder around by herself because she might fall into a pit or

something and if there is no one around to help her she might
be in great danger".

On the community support she said that:

"My children are supportive of me and the community is
sympathetic with me and my child but there is no support that
I receive from them as the community, her everyone have their
own problems".

3. Child MAP (Grandmother: Mrs MAM)

MAP is a thirteen year old girl. She is has a neurological problem, and
appears to have cerebral palsy. She has poor muscle control in her limbs.
Her heads control is poor. Speech is not clear. She is out of school. MAP
lives with her grandmother, her aunt and her aunt's three children Her
biological parents live elsewhere. They seldom visit, and rarely provide
financial assistance to meet MAP's needs. The grand mother is a
pensioner, and the aunt works as clerk at the supermarket in the main
town. The grandmother's concern is that the child's parents do not seem to
want to be with the child, and she is worried what will happen to the child
when she dies.

Regarding the child's disability, the grandmother said:

"She has a condition that makes her talk to herself, and throw
her head backwards as if there is something that's pulling her
head backwards. Her speech becomes unclear. It is as if her
tongue is too big for her mouth. The granny and the aunt do
not have any idea of what the problem is or what might have

caused it. They think there may be something wrong in her brain, that makes her behave the way she does."

Regarding attitudes towards the child:

"The family is fine with MAP they take her as one of them and they love her. The only problem they have is that her parents don't seem to care a lot about her. They do not visit frequently, and the other two siblings who do not have the disability live with them."

The grand mother is concerned that the parents should become used to the idea of having their child around, because she is now old. She worries about what is going to happen when she dies.

4. Child SEIP (Mother: Mrs. MS)

SP is a twelve year old girl, and she lives in a nuclear family of six comprising her grandmother, father, mother and three other siblings. They all live in a five-roomed house. The father is the sole breadwinner. SP has a physical disability and also appears to be cerebral palsied. She is also epileptic. She is not in school because she needs constant supervision.

The family does not get much support from the community. According to the mother, they consider her " not normal". Some are sympathetic. Others suspect the child has been bewitched. The mother's concern is that the child is not in school. The mother feels that it will be difficult for her to have a job as she gets older. She is uncertain of the future of her child. SP's impairment involves her arm and hand. They do not function normally. The reason she is not in school is that she has episodes of fits. She needs constant supervision. She used to stay at home for a long time

not going to school because of her health so that is why she out of school according to the mother. She was at school up to Sub B.

The mother stated:

> "If the child could overcome the fits, she may able to learn to use the other "normal" arm and hand effectively. She might learn something, but if she this condition continues, I cannot see her holding a job. She needs some one who is close to her and who understands her, so that when she falls, they can care of her".

The mother stated that:

> "I was shocked when seeing that she there was something wrong with her hand and arm. I was more shocked when the child started having fits and fainting. The community members just decided that it is witchcraft. My other children are fine there is nothing wrong with them. Can you imagine how shocking it is to have one with such a condition? It leaves with a lot of sad emotions, you blame yourself.... it's sad."

She tried to get medical help for the child:

> "The nurses told me it's a problem she was born with, there is no medicine they could give her to cure her. The nurses there said they can't do anything for her. They did give me medicine to give to her.
> But now she is not taking it anymore, it has been sometime now. That medicine did not seem to help, it used to cause headaches.
> Unfortunately we don't have the bottle to show you now."

There is a local mainstream school, but because she needs constant supervision given her disabled arm as well as her episodes of fainting, she is not in school.

> "She can't go to school, she needs to be looked after because of her condition. She needs help because she can only use one hand. My mother takes good care of her because she says at home with her."

The mother says it is difficult to manage especially financially as there is only one breadwinner in the household. The other children are in school and they need to be fed, clothed, and they have to pay the necessary money to the school.

She thinks given the fact that the child is not in school, it will be impossible to get herself a job that will pay her. So she is uncertain about the future.

5. Child THB (Mother: Mrs. NKT)

There are five family members besides THB. There are two brothers and one sister. The mother is the only bread winner ,and there is no father. The other children are in school they are 14 and 16 years old. The mother is the only breadwinner. There father and the mother are separated.

> "There are five of us in the family. I am the only one looking after all this children and it is not easy. I can not give them everything they want because there is no money. He left me with all these children and he does not even think about them. Money has to be demanded from him before he can give any."

The mother believes the problem with THB is "an under-developed brain". He is dependent for everything. He is not in control of his body. He just sits around and he needs to be supported to sit firmly. The mother says she does not know what caused the disability.

> **"The problem is with his brain, because even his body parts**
> **are just stiff, he can't use them. He is just as you see him, he**
> **just sit there and does nothing."**

The mother indicated that she was surprised and shocked to see that THB was not like her other children. She has not had any further contact with the professionals except the doctors at the hospital during birth.
Mrs. NKT says the community sympathises with her for having a child with disability. Most of them, however think it is an abnormality:

"I hear all kinds of interpretations to what caused the disability. Some say someone is responsible....it is witchcraft, and some say maybe something went wrong when the child was still developing in the womb."

The child is not in school because there is no school that will accommodate him. According to the mother he cannot be taught. She has never heard of any school that could take him and teach him.

> **"He just sit at home, because he can't go to school. If he is at**
> **school who will take care of him? Teachers don't have time.**
> **Again who will teach him? He can't learn anything.**

Mrs. NKT's concern is that, given the fact that her other children are fine and they will eventually make life for themselves. She hopes one of the siblings will be kind enough to take care of him.

"I do not know what is going to happen to him. I am very worried because I don't know when I will be gone forever, and if the child will be looked after properly."

6. Child DIM (Mother: MDIM)

DIM is a fourteen-year-old girl. Her family is made up of seven members. She lives in a female-headed household. In the family, there is her mother, grandmother, and two brothers aged 20 and 17. There is also her uncle and his wife, and their 2-year-old baby. The mother, uncle and his wife are breadwinners. DIM is not in school. The family members are not very sure of what her disability is, but stated she seems to be developing very slowly intellectually. The mother stated that she thinks and behaves like a child of a much younger age. She enjoys playing with very young children and seems to identify with them. Community members are generally reported to be sympathetic, even though others sometimes say hurtful things to her. The mother obtains such information from the other children in the community. Sometimes, other people refer her to as a "mad person". The mother believes because of her disability, she will not benefit from an academic programme at school. The mothers concern is that DIM will not be able to be independent in life. She will need family support. She hopes that the other siblings will support DIM.

Both the mother and the uncle are not sure of what the problem is. They believe that the child, DIM is just not normal, because:

" physically she is fine but mentally she is not developing as she is supposed to. She behaves and thinks like a small child way younger than herself. She also enjoys playing with younger children that her peers. Her speech is also not clear. She seems to have problems with concentrating.

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If told something she does her own thing because she obviously forgot or got something more interesting to do. Her brain seems to be   growing slowly or maybe has stopped but I don't understand what's   wrong."

Regarding attitudes of the family and in the community:

"The family accept her they way she is, it is their belief that she is naturally like that. However, some members of the community believes some one has a hand in this child being born like that. They suspect witchcraft.

Most of the people are supportive even though there are those who are negative and call her nasty things names such as 'sehole' ."

The mother has never had any contact with the professionals.

"No, I never had any contact with them. I don't know if they can do anything for her, maybe I should take her to them."

DIM is not in school, according to the mother.

"This child just don't have the brain to be in school. If she is not learning anything here at home what can she learn at school."

The family is both socially and financially supported within the community. There are those who sympathise and those who just don't care.

"Some people understand and are sympathetic and they encourage me that I should be thankful to have a child than not to have any at all, but other's have their own problems to worry themselves about   my child."

The mother's concerns is that, she hopes the brothers and other family members could be always supportive and caring towards DIM. when she is no longer around. She does not want DIM to be alone and without family support.

> **"I hope that these other children of mine are sensible enough to be kind and to take care of her when I am no longer around."**

7. Child TH (Mother: MT)

TH is a nine year old boy. He is not progressing in school. He has been promoted from one grade to the next after he has failed a grade more than twice. His level of academic performance is very poor, according to the class teacher. The mother feels that he is learning a little by being at school. The child seems very hyperactive. He is reported to like running around and climbing trees, and high walls of abandoned houses. He had to have a few stitches above the eye from an injury he suffered when he fell from the rafters of an abandoned house. This is female-headed family. The mother is the breadwinner. She is helped financially by the other two daughters. The one holds a job at the municipality offices, and the other is a clerk at the local police station.

The mother explained the child's problem:

> **"He is not progressing at school.... he is not learning anything.**
> **"Personally I thought he was being naughty, but as time went I got reports that he is becoming uncontrollable.... he tears books and stuff and I was then called over to the school. I even took him to Bethlehem to see a doctor. He said this child has a problem, and there is nothing they can do for him. At the**

school .... because they are teaching children who are
educable. He said there is a problem in his head.
When he was still young I just took it for granted that he is
just a naughty child, who doesn't listen to what you tell him to
do."

The mother continued that:

"He cannot be left alone ... he is all over the place... he climb
up the trees, rafters of abandoned houses. The other day he
had to be stitched above the eye".

When asked whether she interacted with any professionals, she said:

"I do not know of any services where I can get help."

She explained her experience when she realized that something was
wrong:

"When I realized that something was wrong ...I had sad
feelings, but I still took him to the doctors at Phuthaditjhaba
until I was referred to the one in Bethlehem.
I really don't know what is the cause...."

There is no support from the community. Relatives sometimes help
financially, especially to take the child to the clinic or doctor. The family's
concern is that they hope the child could go to a school where teachers are
trained to deal with and teach children like him.

Regarding the child's schooling experience:

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"You know with teachers, a teacher is something amazing. Even though I have been taking him to the doctor and submitting letters to the school. It happens that sometimes he meets another teacher who will handle terribly because they don't have the time".

"Really the child is not progressing at that school, even the doctors confirmed that he cannot be taught at such schools he needs special kind of education. This will enable him to learn at his own pace and to get teachers who are trained to train and take of children like him."

She explained that there is no support system in the community:

"It is very difficult to cope .... you always have to keep an eye on him, but we are surviving. There is no school for this kind of child around here, but the doctor said he knows of some school some where he then investigated the prices and I found the fee to be too high for me."

"My family does support me ..Yes, because they do give me money to help towards taking him to the doctors. There are no other organizations here that can help me in this community. I do not know of other parents who have a child with a disability.

Regarding the child's socialization:

> "He does nothing in particular except the usual running
> around and being mischievous. His sister always encourage
> him to read."

With respect to his physical health:

> "I would say he is a healthy boy, except a continuous cold
> which blocks his chest. Yes, he does take medication.
> The doctor gave some medication for his condition, he says
> there is nothing they can do for him at that ordinary school,
> the only thing this doctor does is to dose him with pills. He only
> said they will help him to be better and probably grasp
> something at school."

Her concerns about the future?

> I really worry about him, because I want a good future for this
> child. We just need him to lead happy life …to be able to take
> care of himself as he grows up, to be independent.
> I'm not really sure what job he will one day be able to do ….
> anything that would make him happy is fine with me."

> "He needs to get to a school with teachers with relevant
> training so that he can be able to learn. Also for them to be
> able to understand and help him when his problem starts.
> The doctor also told me that he should go a school where
> teachers will be able to handle him because the one he is at
> those teachers can't deal with him."

8. Child TBO (Mother: STBO)

The child is a 12-year-old boy. His immediate family comprises four members. He lives with his father, mother and his grandmother. He is an only child. The family lives in a four-roomed house. The father works at a factory in the main town, and the mother at a supermarket. The parents feel something might have gone wrong during pregnancy because there is no one with a disability in the family. There is no support for them in the community. They do obtain support from relatives. The child has a physical disability. He has not had use of his legs since childhood. The father seemed uncomfortable to discuss the child's disability, and asked to be excused during the interview.

Both parents stated that they have accepted their child's disability so that they can go on with their lives. They said that they were afraid for a long time to have another baby, but now they are fine, and they are ready to have another baby.
The mother stated:

> **"If it's your child you cannot do anything but accept him as he is. We were given him by the Lord so we can not complain."**

The mother commented on the early years:

> **"When the baby became older and it did not crawl, they became more concerned and it became very clear that there was something very wrong with him. The doctors at the hospital said he has no feeling in the feet."**

Regarding schooling:

> "TBO is not in school, because of immobility. We wish there
> was a school where there are teachers who are willing to teach
> and take care of children like this.
> At present, He can not go to school, no one will look after him
> at school. So he is better here at home even though we will love
> for him to learn."

According to the mother, the family supports one another, the relatives are sympathetic and so are the other community members. Although some do not seem to care at all.

> "We do get help from the relatives if we need anything like
> transport or some money when we have serious financial
> problems, which seems often these days".

Financial implications of buying a wheelchair and other essentials for the child and other family needs area concern.

They have concerns about the future, the mother explained:

> "The only concern they have is how is he going to fend for
> himself in this world. They hope they will live long enough to
> help him along so that eventually he can take care of himself."

9. Child TS (Grandmother: Mrs. HT)

TS is a 12 year old boy. His family has four members. He lives with his grand mother, sister and uncle. He is in grade 3. He has a visual disability in that he is partially blind. His performance in school is not satisfactory.

He has to sit as close to the chalkboard as possible to be able to see what the teacher has written. According to the grandmother, he cannot read the writing in the textbooks. His family is a female headed one. The grandmother looks after all the family members on her old age pension. The family lives in a three-roomed house, which has an outside room for the uncle. Water is available from a communal tap in the yard. The mother of the children lives with a male friend. She left the children with the grandmother, and provides no financial or other support. The grandmother has tried many times to obtain a social welfare grant for the children but has been unsuccessful. She is concerned about what is going to be become of the children when she dies. The uncle is unemployed.

The grandmother's perception of the problem:

> "His problem is actually with his eyes. He doesn't seem to see well, he can't see very clearly. Especially those things far away, he also has problems reading things he doesn't seem to see the letters or something its' like he just see images."

Her perceptions on the cause of the disability: perceptions about the cause of disability:

> "He was born with an eye problem. Actually I do have eye problem, but with me it is just old age. I really don't know what is the problem with his eyes, because when the sun is bright he frowns."

Regarding his schooling experience:

> " I pay his school fees from my pension. He is not very good at school work."

> "Here unfortunately we don't have a school for children who cannot see properly. I hear that there is one now in Phuthaditjhaba but it seems it's for those who can't even distinguish between day and night."

> He needs a school that is the one, which would be appropriate for his needs. But if the fees are too high - obviously I wouldn't be able to pay. Let me put it this way, at the moment, I'm struggling to survive, fifty rands to me is a lot of money. I think you can understand."

> The government must pay - what is the government for, is it not supposed to help people like the needy and the ones with disabilities? Of course, it should assist it does not have to pay for everything.
> If I had someone helping me financially I would love to get all the children everything they need including appropriate education facilities. For those who can afford to pay a minimum I think the government should assist."

She explains the difficulties she has caring for the children:

> "I cannot leave him at home alone – he is still very young".
> No one cares about my children. I've committed myself to these kids - no one cares, that is why I always pray that the government should come to our aid."

Regarding community support:

"They don't offer me anything - financially, they help me when I need the roof to be fixed or maybe when the door is falling apart. I don't get anything from no one – there are no organizations that I can go to for help for my child".

"Personally I don't know of any other parents who have a child with a disability, but children know of other children with similar conditions.

Her concerns:

"It is very difficult to manage financially because I am a pensioner, now what ever I buy as food if it gets finished before the next pay day then it means trouble. In short, I can say its a struggle."

"What concerns me most is wondering what the future holds for him and also for the other children. Seeing that their mother left them with me and went to live somewhere with some one else. I am old now".

"We need to eat, drink and we need clothes, that is all we need"

"If only he could go to a school where he would be taught and trained to cope with this world's pressures and demands - so that he can take care of himself.

Interaction with professionals:

> "Yes, I have been to the social workers for assistance - but
> there is one person who sabotages my attempt to seek help.
> The mother to these children is not taking care of them so I
> thought the social workers would help, but the man in charge
> was involved with my daughter at some stage. Now that they
> are not together any more, he is making things difficult for me.
> It is rather a long story which I am not prepared to go into
> details. It's actually about my daughter in law's name - they
> are questioning if it is a maiden name or the one given in
> marriage, and they don't want to believe when I tell them what
> I know. Now the children are orphans whereas their mother is
> still alive.
> I cannot ask her (the mother) to help take care of the children
> If only you knew her - one irresponsible human being."

She indicated that she is unaware of services for the disabled:

> "I do not know of any services available for children with
> disabilities. To be honest I don't."

10. Child MAN(Grandmother: Mrs. MMA)

MAN is a nine year old girl in grade 2 . She is from a four-member
family. There is no one employed in her household. The family relies on
the grandmother's old age pension to meet their needs. They grow their
own vegetables, and raise a few chickens for their eggs. There is no
electricity. Water is fetched in buckets from the communal tap, which is
situated along the street. MAN. have a physical disability. According to
the family, she is performing poorly at school. According to the teachers,

she "seems to be in her own world". The family explained that when teachers teach her she cannot recall or understand information. They feel that her disability is "mental as well."

The grandmother's concerns are about the future of her grandchild, in particular, "who is going to take care of her". The grandmother indicated that no one will marry her.

The mothers perception of the child's disability:

> "Her left leg is malformed and she limps. So she has to walk
> slower than everyone else, I think she also has a mental
> problem because in school she is reported to perform very
> badly ... I mean you can tell from her school marks. She does
> not seem to comprehend what is been said in the classroom.
> At home she sometimes answers without thinking first because
> anything that come to mind she gives as an answer. If you look
> at the questions asked and her answers, she often give answers
> which are far from what the questions required".

Her perceptions on the cause of the disability:

> "To tell the truth I don't really know what might have caused
> the disability, she born like that, maybe something went
> wrong when she was developing before birth. I think
> something must have gone wrong also in the manner her brain
> was developing, because its not working like it should and that
> makes her to perform bad in school"

Perceptions on the ability are:

> "She interacts well with the other children, she likes people
> and she has many friends and they are always around. I think
> it's because of her good heart. She is capable of any physical
> things her peers are doing. When you teach her something on
> a very slowly pace she understands."

Regarding community perceptions about the disability she had this to say:

> "Community members don't have much to say about her
> disability, rather than she is abnormal, some are sympathetic
> towards her. There is no support from any one. We survive
> by growing vegetables and selling some snacks I buy from the
> main town and sell in the community".

Her concerns for the future were:

> "I am concerned of what is going happen to this child when I
> am gone. I am the only person she has in her life. My worry is
> who is going to take care of her, because I can not imagine her
> getting married. Men are not interested in girls like her".

11. Child LER (Mrs. ML)

LER is an 11-year-old boy. There are six family members in his
household, including himself. The other members are his mother,
grandmother, his twin sister, and the youngest sister who is six years old.
They live in a six-roomed house. It has two other incomplete rooms that
are currently being constructed. LER is in grade 3. This is a female-

headed household. The mother is the breadwinner. At the time of the study, the mother was studying for her matriculation examinations. She is engaged in part-time study as an adult student. She is employed in the main town in one of the factories that manufacture clothing. She says she does not earn much, and did not want to disclose her salary. LER was born prematurely. He impairment appears to be neurological. He also has a speech problem. . He is not performing well at school. The mother believes that the premature birth was the cause of his disability. Labour was also induced, and forceps were used in the process. According to his mother, she notices injuries to his head at birth.

The family and relatives are supportive. The mother is concerned that LER finds it very difficult to read and to write. He is unable to discriminate letters of the alphabet and words. In view of his speech problems he finds it difficult to speak, according to the mother. She is concerned that at the school the child is not getting much of an education because his speech is not developing. He obtains no help with his speech problem.

Regarding his disability:

> "He has problems with speech, he takes a while before a word can come out of his mouth. He also gets anxious to give an answer to a question especially when he realizes the other person getting impatient."

Regarding his schooling:

> "He has problems when answering questions in school. When he is struggling and taking too long to say an answer, the teacher rushes him. But he is treated like any other child in school."

Perceptions about his ability:

> "From my observation, I realized that he is talented in using
> his hands, because some of the things he does with his hands
> are very appreciable and artistic. Yes, I see him working with
> ....maybe technical work or something."

According to the mother, LER has a problem with speech, he also have problems with grasping information. She I noticed this when he was doing Sub. A. He is one of twins. They were premature babies. There is no other person with disability in the family.

The mother explained:

> "When I discovered my child had a child's disability, my spirit
> was broken, and I worry a lot. You know I think, maybe, that
> is, according to me..... I think the cause is because they were
> born pre-mature, and then LER came through with the help
> of instruments they used to pull the twins out. I realized that
> on his head after birth in Bloemfontein, he had some marks
> As I've indicated that during birth, when I was delivering
> him.....he was helped along with those things. Again the time
> space him and his sister was long. The sister came easily, but
> the brother took long."

She commented on the attitudes of community:

> "You know as people we quickly blame or give reasons like
> witchcraft. Maybe when one was expecting the child.. one got
> bewitched, things like that."

There is no help from professionals in the community:

> "In my community there is no such help available... there is no
> where one can go for help with a child with a disability. : I
> once took LER to a what is it eh... psychology. They did not
> really help. They only told me he has a speech problem which a
> very obvious thing and from there nothing further happened.
> They said I should send him to a special school. There is no
> special school in Qwaqwa ... not that I know of."
> "There are no services in our community ... I was told for
> speech therapists I need to take LER to Bloemfontein or
> Johannesburg. Unfortunately I could not because I did not
> have medical aid."

Regarding current schooling experience:

> " He is not getting good education... It's because he is not
> getting any speech training at an ordinary school. If he was at
> a school where teaching will invest time in training him it
> would be better."

I think the government should help with LER ...like it is doing with other
children

The mother's concerns:

> " Some of the things that concerns me most is the fact that he
> finds it difficult to read and to write, especially his disability
> with the written language bothers me the most. It would be
> better even if he has speech problem but if he could have sense

of the written language it would be better. Yes, and it really break my heart, I mean he can't even write the word, "mother"."

"Our needs are basically monetary ones, because without money life is almost impossible to sustain. We really need money because if I had money I would have long sent him out to those special schools they are talking about. He needs to go to a special school so that he can receive speech training and many other things children like him need."

12. Child SB   (Mother: Mrs. LS)

SB is a 14-year-old boy in grade 4. He lives with his mother and sister. The father is deceased. The mother is lost her job, and is currently unemployed. They have a three-roomed house. When the mother needs some money, she obtains it from the child's the grand mother who lives nearby. This is a female-headed family. S.B appears to have intellectual disabilities. He is an average performer academically, according to the mother. The mother's concern is that the family is living in poverty. They cannot meet basic needs. She is concerned about what will happen if she does not find a job soon. The family has a piece of land where they grow vegetables.

The mother described his disability:

"He has problems growing, he is behaving younger than his age, he also has problems with spoken language, the problem is with his brain. Since he was a small boy, he could not crawl. He also started walking later than normal."

"When I discovered his condition, it was very shocking and disturbing. I was actually shaken by this. Here at home it is better because we understand him, but at school since he is not behaving and performing as expected. They sometimes tease him. I mean other children at school."

"You know I think the life we are living might have been the cause.
Poverty and nature maybe. I just think poverty might cause some problems with birth, or it could be nature's way of doing things.
People in the community - some think there probably something wrong with me or something went wrong during pregnancy."

Regarding support from family and community:

"My family is supportive. The only family I have is my mother and my children, so of course, my mother supports me in every way possible. There is not any support you get from the community. I cope in taking care of my children's needs - through the mercy of God, we just live one day at a time."

"I do not know other parents who have children with disabilities. I am not aware of any around."

She stated that she did not know of any services for children with disabilities:

"Unfortunately I am not aware of any organizations which can help me with my child and other needs. But I filled forms twice, applying for assistance from the government but nothing transpired from that. My husband used to work for the government, I went there to claim his money and I was made to fill in some forms which did not help. Even today I haven't received a thing.

I filled the forms in 1996, I also filled others again in January 1997

Firstly, they said the problem was with the child's birth certificate - it seemed the numbers were not clear, according to them. We are still waiting."

Her concerns:

"Well, I am obviously concerned about his future, also the fact that he skips school. I am also concerned about getting a job, I've been trying to get a job for some time but jobs are difficult to get. We need enough food, obviously I need to get a job so I can get money. I think since the government promised better life for all, it will be better if we can get jobs. Things like housing come next, you can have a house but if you don't have a job how can you be able to live in that house. It is now very difficult, only those who are have contacts get jobs.

"I think SB needs to be treated like any other human being. I would have loved to see him as police man, but now I don't know what he can do. He says he wants to a soldier."

About her child's education:

> "I want him to go to any good school. I've heard people talking
> about special schools, but personally I have not seen them."
> I love for all my children to have the best, but situation I am in
> makes it impossible. If only they could give me the money they
> used to deduct from my husband salary. They always tell me,
> they are waiting for a response from Bloemfontein. Because
> that is where they say, they sent my forms for the money.

13. Child MAG (Mother NM))

M.A.G is a 15-year-old boy in grade 5. He lives with his family of 6,
which includes his mother, older sister, and three younger brothers aged
10, 8 and 5. Water is available from a communal tap in close proximity to
the house. The house has three rooms. It is a female-headed household.
The mother is the only breadwinner. The older sister sometimes helps
financially when she gets casual employment in the main town
He is physically disabled in that he does not have full use of one arm and
hand. The sister is not satisfied with his performance at school. She
believes that he is lazy, stubborn, and refuses to be helped. There is no
support from the community. On one occasion, they received old clothes
from the church. The community accepts the child like any other child. He
socializes with other children in the community.
The sister's concern for the future is that he finishes school. She hopes he
can obtain a job one day, and become independent.

The mother's perception of the child's problem:

"He has problems with comprehension, he does not comprehend things he is taught . I think they don't make sense to him. His performance is bad on school work. I realized way back that he had a problem with his school work, but he liked school"

"He is not at school at present - you see the problem is that he is not progressing, but sometimes he goes and some other times he just stays at home. At first, his teachers were not happy about him going to school when he wants to , but since they realized his problem they are a little understanding. They tried everything but they are unable to teach him, despite all their efforts he still does not understand things a person his age finds easy to comprehend."

Regarding family and community support:

"Yes, my mother is the breadwinner but we get by just fine". We understand MAG - we have been living with him since birth, so there is no problem. Our whole community understand his problem, and also help with some other things – when my mother needs something for the family. Yes we do get some support – like help from church -With things that we need, like food. Sometimes clothing".

Her concerns:

"Ready, I don't have much to say except that he should go to school and work hard. We just need enough money to get us by. If we could have enough food and clothing to live comfortably, as well add some more rooms to the house."

> I think MAG needs the same things we all need in life. I think he needs to go to a school - any school where they can teach him so he can pass."
> I am not aware of any schools for children with disabilities in the area. When he grows up I really don't know what work he will do, what ever is available I guess".

I have not tried to get help outside the community:

> "I am aware of people called social workers, but I do not know what they do".

14. CHILD TEB. (Mother: Mrs. Mteb)

TEB is a 14 years boy in grade 4. According to his family, he is performing poorly in school. They believe that he is lazy. His family comprises 5 members, that is, TEB, his mother and two brothers. The older brother is not in school. According to the mother, he hangs around with other boys who are not in school. The youngest is in school . They live in a four-roomed house. This is a female-headed family. There is no one employed at the moment. They survive on the money the mother makes from selling snacks and cool drinks in the community. Water is available from a communal tap.

He appears to be cerebral palsied and diplegic. The mother does not get any support from the community. Her concern is that the child is not performing well at school. She is concerned about how he will survive in the world without an education.

Regarding his disability:

"His problem is with his arm and leg. They restrict his motion because they are not fully functional, the hand is turned in and the leg is malformed. He was born like that.

I am not really sure what the cause is because he was born like that, maybe he is like that by nature. Maybe God wanted that. I am actually always at home so I do not really leave him alone ... but I would not mind leaving him for a while to get something from the shop.

"When I realized that my child had a disability... I have never been more shocked and confused"

Regarding whether she obtains support from the community:

" We cope with our problems ...we survive, we really survive through God's help. It is however difficult to pay the school fees they require from school for all his children in school. It is forty rands."

"I do not get support from the community ...There is no one helping me, I am all alone with the children. I do not know any parents who have children with disabilities. There are no organizations or a hospital who gives me help."

According to the mother, TEB is in school. The school is quite near. All the children are at the same school. TEB is in Std 5 now, and he was supposed to be in Std 8. He has been repeating certain levels many times. He is having problems at school.... He fails subjects like Afrikaans. With other subjects he is satisfactory. He hates homework, when he is supposed to study he refuses.

He gets help from his sister. If he has a problem with homework, he asks his Alice for help."

Her concerns:

> "My concerns are basically around the lack of money.
> Money will solve my problems...then I'll be able to get TEB
> and my other children through school, and I'll also be able to
> take care of myself and my family. We need food, for
> example, the mealie meal I bought if it finishes now, then I'll
> be in trouble because we will go hungry. If one could have
> enough money to sustain the family I think that would do."

Social workers were not helpful:

> I have been to the social workers. I actually requested them to
> at least, offer my child some grant. The lady in charge, said
> there is no way they can help me with a grant .She said there
> is no way they can have children receiving grants.

Regarding community attitudes:

> "The community have their own thing to say about his
> disability.
> Some think it's God's will and others think some one did this
> to my child. Some think it's a sign of some kind. You know
> people say a lot of nonsense.

15. Child LK (Brother: BL)

LK is a 16-year-old in grade 5. He lives with his family of nine members. This is an extended family with cousins, aunts, a brother and a grandmother. LK's brother takes care of him. His mother had recently died. The grandmother's old age pension is also used to provide for the family. The brother is employed as clerk at the magistrate's court.. The main house has four rooms and there is a separate room in the yard for LK and brother.

LK's disability seems to be neurological. He has a physical impairment and speech problem. According to his brother, he is not performing very well at school. The brother is concerned that LK finishes school. The brother feels that L.K. is "good with his hands", and may be able to go to a trade school.

The brother's perceptions about the child's problem:

> **"I think there is something in his brain that disturbs him – when he has difficulty understanding things as they are. He also has problems with speech. He experiences difficulties in grasping things. He is been that way since he was a small child. His sister is hard of hearing"**

> **"Some people in the community say he is disabled and he should be taken to a craft school. Even his teachers say the same. Personally I feel, if he still wants to go to school it is fine, then he can go to that craft school after completing. I think it will better for him to use his hands than where he is supposed to talk. I also think he will encounter serious problems in communicating in English".**

Regarding family and community support:

> "We cope - we manage to take care of everyone - with the help of granny (grandmother). I do not know of any services for children like LK around here .The family members are supportive.
> There are no outside organizations that could help that I know of. I do not know of any other families who have children with disabilities here".

LK does socialize with other children:

> "He just plays with friends at home. Well, when it comes to things like studying and books, he doesn't like it. We do encourage him to do his school work."

16. Child M.A.J. (Mother: NM)

M.A. J is 16 years of age and in grade 5. He lives with his mother, and two sisters who are 9 and 7 old. The household is female headed. The mother is the only breadwinner. She works in a factory near the main town. The family has a three-roomed house. According to the mother, M.J. is hard of hearing and has epilepsy. He is not performing well at school. The community attributes the child's condition to witchcraft. The mother is concerned about the financial situation of the family. They have difficulty making ends meet. She is also concerned what is going to become of her child in the future.

The mother Mrs. NMAJ gave her views on the child's problem

> "MAJ is hard of hearing and he has epilepsy, he is in school
> but he is not performing very well. Even here at home because
> of his hearing problem you need to be loud enough or face him
> when talking so he can hear you or follow what you are saying.
> He also takes long to understand what is required from him if
> asked to do something".

Mothers perceptions on the cause/s of his disability:

> "To tell the truth I don't know what might have caused this,
> maybe he was meant to be like that. I cannot explain because
> he is born like that, the other children are just fine. I suppose
> people are born differently. That is just the way he is".

Her perceptions regarding the child's ability, she indicated that:

> "Apart from being hard of hearing, being epileptic and being a
> little slow in comprehending things, he is a bright boy. He
> always likes to help. He enjoys staying at home and to help
> around with the household duties, but sometimes he wants to
> help even if you don't need help, he can be very stubborn. He
> is also very sensitive.
> MAJ has a very good heart. He plays very well with her sisters
> even though sometimes he sits all by himself and just keep
> quiet".

Community support and perceptions about the disability:

> " I do not receive or get anything from the community. Everything I need I have to make means to get it myself, It is hard but we manage just fine. Some of the neighbors attribute his condition to sorcery. They say someone who hates my family did something to make him always faint so that he does not progress in life. They say because he is the only boy. I don't know what to believe, but as I said before I think that is the way he is naturally".

She is not aware of any mothers who have children with disabilities in the community

> "Here in the community I haven't heard of any child who has the same disability as my child, but I think there might be some I don't know really. There are adult people who are hard of hearing I but I think those might be because of old age, but I don't know of any child who is hard of hearing in the community".

Mrs. NMAJ stated that she is concerned about the child's future:

> "I worry that we don't have enough money to survive, my other worry is I always ask myself what is going to become of this child. I just hope he will be able to get a job. I wonder if his epileptic condition is going to be any better with time, because I will not be around for long to take care of him. His sisters will obviously get married and go away. So if he is not well who will provide for him".

17. Child KH (Mother: MK)

KH is from a family of three that includes himself, his mother and sister. He is physically disabled and in a wheelchair. He appears cerebral palsied. He is totally dependent. He is not in school but attends a day care centre started by his mother and a group of other mothers who have children with disabilities.

At the moment Mrs MK teaches the children. The other mothers help to cook for the children and some take care of the children during the day. There are children who stay over at night. . Some of them live far away and because of transport difficulties, it is impossible for parents to come and pick them up each day

Mrs. MK describes her initial feelings on discovery that her child has a disability:

> "When I discovered that he has a disability. To tell the truth
> I was in shock, you must understand my other child are fine
> You know as an expectant mother, you expect a beautiful
> healthy baby, but when discovering that there is something
> wrong with them you are overwhelmed with a feeling of guilt
> and disappointment. You actually ask yourself questions like
> what went wrong - and you can't find the answer - that is
> what is most frustrating."

Regarding her perceptions on the cause of the disability, Mrs. MK said:

> "I do not know the cause. It is just the way he is born. People
> in the community have their own perceptions about