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UNIVERSITY OF THE WITWATERSRAND
FACULTY OF HUMANITIES
DEPARTMENT OF SPEECH PATHOLOGY AND AUDIOLOGY

The Experience of Caring for a Child with Cerebral Palsy in Tonga, Mpumalanga: Caregivers' Stories

Joanne Frances Barratt

A dissertation submitted in fulfillment of the requirements for the degree of Master of Arts in Speech Pathology in the faculty of Humanities, University of the Witwatersrand.

August 2007

Declaration

I declare that ***"The Experience of Caring for a Child with Cerebral Palsy in Tonga, Mpumalanga: Caregivers' Stories"*** is my own work, that it has never been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Joanne Frances Barratt

August 2007

Signed……

Dedication

This dissertation is dedicated to the people of Tonga, especially the caregivers of children with cerebral palsy who have taught me more than any academic text ever could. I hope it will raise awareness about the experience of caring for a child with a disability, and that in some way you will benefit from this research.

To the caregivers who participated in this study:

"Disability is a matter of perception. If you can do just one thing well, you are needed by someone"
(Anonymous)

Acknowledgments

1. Firstly I'd like to thank my friend, colleague and the research mediator in this study, Lindiwe Thobela, without whom this study would never have been possible. Lindiwe is a remarkable lady, and over the years, she has been a source of knowledge and enlightment for me. She has shared much from a personal experience of disability, to cultural norms and beliefs to geographical locations of clients' homes, always with patience and good humour.
2. To all of the participants who so willingly invited me into their homes and shared their experiences with me. I hope, and will do my best to ensure that this does not remain a paper-based exercise but that it will serve to highlight your plight and bring about change in your community.
3. My supervisor, Professor Claire Penn, for all her guidance, knowledge and for sharing a passion for rural development.
4. My friends and colleagues who I worked with in Tonga, specifically Kokkie, Elna, Cornelia, Sejeng, Zelda, and Thembeni for making my year in Tonga such a fun, exciting and memorable experience. Had I not had such a unique and fundamentally life-changing experience, I would never have gone back to this setting. Thank you.
5. To Tina Davidson for her help with putting this paper together.
6. Finally, to my friend and colleague, Katijah Khoza for never getting tired of discussing research with me!

Abstract

Cerebral palsy is a condition primarily defined by damage to the developing brain primarily resulting in a physical impairment, although the affected individual may present with concomitant impairments. The number of children presenting with cerebral palsy appears to be increasing, and while the medical effects of this disability have been well documented in the literature, a paucity of knowledge exists on the parental experience of caring for a child with cerebral palsy, particularly in rural South Africa.

This dissertation will report on a study conducted in Tonga, a rural area of South Africa, which assessed caregivers' experiences of caring for a child with cerebral palsy. Qualitative methods, including participant observation and narrative interviews were used and the SiSwati narratives of 27 participants were transcribed and analysed using theoretical coding. A number of recurrent themes emerged including the impact of gender on caregiving, the influence of traditional beliefs and practices and the experience of western medicine. However, the pervasive nature of poverty served to influence all aspects of caring for a child with cerebral palsy. These themes are discussed in relation to current healthcare policies, the influence of the HIV/AIDS pandemic, the concept of '*ubuntu'* and socio-political aspects of healthcare.

The findings highlight the value of using cultural narratives and participant observation as a means of exposing aspects related to the experience of disability that cannot be portrayed using quantitative methods. It emphasizes the nature of disempowerment amongst marginalized communities and draws attention to the need for both multi-sectoral and community involvement to bring about transformation.

KEY WORDS: cerebral palsy, socio-political, marginalize, qualitative, cultural narratives, participant observation.

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Map of Tonga

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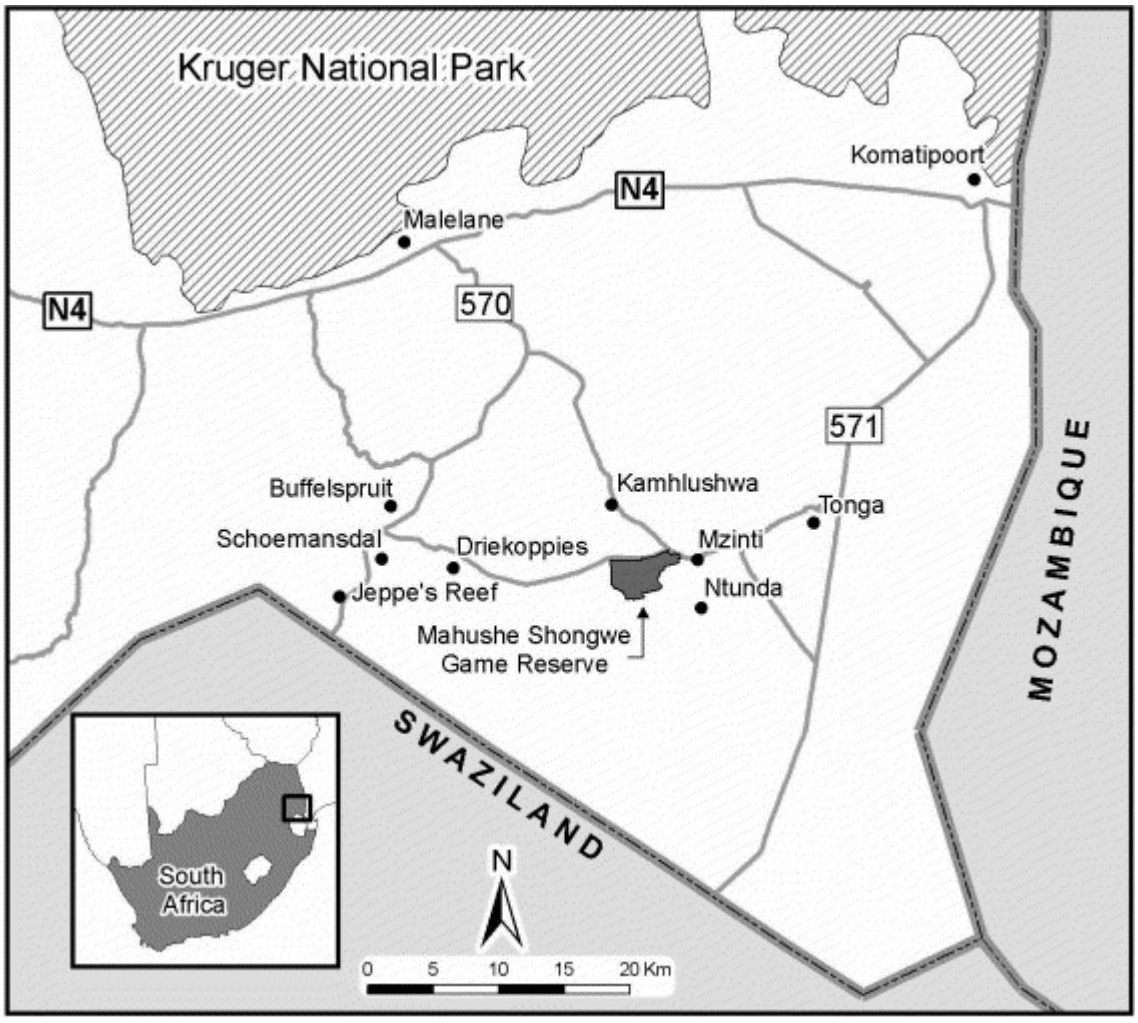


Image 1: **Map of Tonga**

CHAPTER 1
Introduction



Image 2: A mother carrying her cerebral palsied child on her back, water on her head, and firewood in each hand

This dissertation symbolizes a personal journey for me. The journey itself took me back to a place that was instrumental in my development, both from a personal and a professional point of view. There were multiple influences which motivated me to write this paper, including the professionals and patients I worked with in Tonga, events that I witnessed and experienced, and the exposure to 'real life', which I had the privilege of being exposed to there.

Compulsory community service for allied medical healthcare practitioners was introduced in 2003. This meant that speech-language pathologists and audiologists, many of whom would not have considered venturing more than a few kilometers from their homes in search of work as new graduates or who would have been looking for greener pastures outside of South African borders, were now being placed at primary healthcare facilities where no-one had ever heard of rehabilitation services. I was placed at Tonga – a rural hospital between the borders of Swaziland and Mozambique. At Tonga hospital, I found that the staff consisted of me, two community service occupational therapists, a community service dietician, a permanent physiotherapist, a Cuban and Nigerian doctor, and a few nurses. Working in Tonga was difficult, particularly in the beginning. This was partly due to the fact that I had had such limited exposure to the interplay of factors such as disability, poverty, unemployment, malnutrition, lack of municipal services, and the role of power and gender dynamics. This, coupled with an illiterate SiSwati-speaking population with whom I could barely communicate was problematic and it took me at least six months to identify what my role was in this rural hospital which had previously not had any rehabilitation services. Yet, working in Tonga during my community service year taught me many things. It taught me to be independent. It taught me to draw on resources from waste materials and forced me to be creative in my endeavours to deliver an appropriate speech therapy service without an interpreter! But mostly, my year in Tonga stirred within me a passion for the people of South Africa, their strength, sense of hope, and gratitude for the very little I was able to offer them, and as a result, my ideas of becoming a statistic associated with the brain drain very quickly dispelled!

1.1 CEREBRAL PALSY

This dissertation delves into the complexities of caring for a child with cerebral palsy in a rural area in Mpumalanga, South Africa. It explores the role of culture and context in the management of cerebral palsy, the intricacies and power dynamics of gender, and the effects of poverty, marginalization and limited access to service provision in the experience of caring for a child with cerebral palsy. By employing anthropological techniques, including narrative interviews and participant observation this study allows for a better understanding of cerebral palsy in the South African context, and investigates the role of the speech-language therapist working in rural areas. Finally, this paper argues that it is impossible to deliver an effective service without reviewing the consumers' experience of the service.

The number of children with cerebral palsy in Tonga was staggering, and took up approximately 80% of my workload. The reasons for this are multi-faceted and embedded in the socio-political domains of healthcare provision. The literature states that in third world countries, the prevalence of cerebral palsy can be related to poor service provision and inaccessibility of services resulting in poor antenatal care and a large number of children being born at home, dehydration, malnutrition, and the spread and management of diseases such as malaria, tuberculosis, and HIV/AIDS (Cooper, 2002; Levin, 2005; Grimwade, French, Mbatha, Zungu, Dedicoat, and Gilks, 2003).

Cerebral palsy is described as a non-progressive disorder which primarily affects movement as a result of damage to the developing motor cortex of the brain. Cerebral palsy may vary in severity, and may be accompanied by a variety of other impairments, including cognitive impairment, visual impairment, hearing impairment, sensory impairment, speech and language impairment, impaired bladder and bowel control, and behavioural impairments (Koman, Smith, and Shilt, 2004). Cerebral palsy affects 1.68 – 2.45 per 1000 live births in developed countries (Hagber, Hagberg, Beckung, and Uvebrant,, 2001; and Colver, Gibson, Hey, Jarvis, Mackie, and Richmond, 2000), while in South Africa, the estimated prevalence of cerebral palsy is between 1% and 8%. (Couper, 2002; Christianson et al, 2002). While there is no cure for cerebral palsy, health

education and the provision of antenatal services are believed to assist in the prevention of cerebral palsy (Pellegrino, 1997). Additionally, experts in the field of cerebral palsy agree that early intervention and a multidisciplinary team approach are essential in the rehabilitation and development of functional skills in children with cerebral palsy (Hardy, 1994; and Mecham, 1996).

Due to the complex nature of cerebral palsy, a great deal of physical, financial and psychological strain is placed on the caregiver. The usually unexpected diagnosis of cerebral palsy is a shock to the parents, and may elicit a number of emotional reactions to the situation (Lewis and Rosenblum, 1974). Thus parents depend on a supportive relationship between themselves and their healthcare practitioner, in which the parents are free to voice their concerns and have access to appropriate information on the disorder. However, this relationship of trust is not always easy to establish, especially when the patient and practitioner do not share a common language. Thus there is a need to develop culturally specific and sensitive ways of obtaining a case history, understanding the needs of the patient and delivering an efficient and effective service.

1.2 Understanding healthcare in the context of South Africa

In order to understand the nature of disability in South Africa it is important to take into account the social and political history of the country which gave rise to the current status of healthcare provision. South Africa has a colonial history, as described by Bundy (1986). South Africa was discovered by the Dutch in 1652. This was followed by the discovery of diamonds and gold, which brought wealth and encouraged immigration, particularly from Europe. The British defeated the Dutch in the Anglo Boer War (1899 – 1902) resulting in the Union of South Africa, which existed under colonial rule. Independence was obtained in 1961 and the ensuing Republic of South Africa. The nationalist party came into power in 1948, operating under a policy of apartheid. The release of Nelson Mandela in the 1990's brought an end to the era of apartheid, politically, and ushered in black majority rule (Saunders, 2001). Apartheid is proven to have had a detrimental influence on South Africa's healthcare system in terms of healthcare models, accessibility and the disparate provision of healthcare based on racial

lines (Dowdall, 1991; and Nightingale, Hannibal, Geiger, Hartman, Lawrence, and Spurlock, 1990). This history is described by Goldstein, Ntuli and Coulson, (1998). During the 1960's the increasingly repressive laws of apartheid resulted in the forced removal of people from their land. These policies resulted in widespread poverty and suffering, much of which is still evident today. The healthcare provided by the apartheid government was racially-biased with large well-equipped hospitals emerging in the Afrikaner strongholds such as Pretoria and Stellenbosch, while facilities in the 'homelands' were under-funded, under-equipped and under-staffed (Goldstein, Ntuli and Coulson, 1998). In addition, the facilities were based on race, frequently resulting in two facilities serving different racial groups within a kilometer of each other. Following the murder of Steve Biko in 1977 a growing number of doctors and other healthcare workers found it increasingly difficult to work both with and in institutions that supported the apartheid regime, resulting in the development of organisations, including the Medical Association of South Africa (MASA) and the National Medical and Dental Association (NAMDA) which strived to constitute healthcare for all. This developed into the emergence of progressive health organisations in the 1970's and 1980's in keeping with the resurgence of community resistance to apartheid in many sectors of society. As the apartheid regime fell into crisis at the end of the 1980's there was a shift from oppositional politics towards development. The National Progressive Primary Healthcare Network (NPPHCN) was formed and aimed to promote the far-reaching concept of primary healthcare, including preventative and promotive healthcare. The nature of this struggle was described by Father Smangaliso Mkhatshwa (as cited in Goldstein, Ntuli and Coulson, 1998) in his key note address at the NPPHCN where he said *"The struggle for health and the struggle for social justice in South Africa are the same"*.

As a result of South Africa's history of health provision, disability was previously regarded as a health and welfare issue and services were provided according to the medical model of healthcare provision (White Paper on an Integrated Disability Strategy, 1997). People with disabilities very seldom had any say in the aims, objectives and management of organisations designed to 'care for them'. This meant that the emphasis was on dependence and the nature of the impairment. Thus, all interventions were based

on assessment, diagnosis and labeling, and therapy programmes did not take into account the everyday needs of the client (White Paper on an Integrated Disability Strategy, 1997). As a result, these programmes disempowered disabled people and isolated them from mainstream society, preventing them from accessing fundamental social, political and economic rights.

Today, many attempts have been made in South Africa to address the inequalities of the past. A shift has been made from the medical model to the social model of service provision which is based on the belief that the circumstances of people with disabilities and the discrimination they face are socially created phenomena and have little to do with the actual impairment itself (White Paper on an Integrated Disability Strategy, 1997). Thus it is society's lack of skill in using and accepting alternative ways of participation that excludes people with disabilities.

The White Paper on an Integrated National Disability Strategy (1997) has identified women, children, the elderly, people with disabilities, people with intellectual impairments, people with Acquired Autoimmune Deficiency Syndrome (AIDS), and those living in rural areas as particularly vulnerable populations who require support in breaking down the stigma attached to their conditions and thus escaping from the experience of living on the margins of society. While it is important to target these 'high-risk' groups, this needs to be done with a great deal of sensitivity, as Sobo (1993) noted that classification according to sex, race and oppression creates forces on people's beliefs surrounding disability and on their perceived power to address risks that in reality are enmeshed in social, cultural and economic problems.

Although both women and children are identified as vulnerable populations, both remain susceptible to the effects of power and gender dynamics. According to the United Nations Research Institute for Social Development (2006), in sub-Saharan Africa, women in rural areas spend in excess of five hours a day collecting water and firewood, cleaning the home and preparing meals, and caring for the children. HIV/AIDS has intensified the burden carried by many African women and girls as they are required to care for patients

over the course of their decline. Girls may be removed from school, while the elderly are left to care for children orphaned as a result of AIDS. The responsibilities and family costs associated with caring for the sick and disabled are heaviest in countries where the social and healthcare infrastructure is poor. Accordingly, the introduction of user fees in healthcare facilities discriminates against women by placing an extra burden on their shoulders (United Nations Research Institute for Social Development, 2006). Thus as healthcare providers we have the responsibility of assisting in the empowerment and education of women in terms of their constitutional rights.

1.3 Disability in South Africa

Disability is not a phenomenon specific to the South African context. It is a global phenomenon of huge proportion, eliciting growing local, national and international concern. A conservative global estimate of the prevalence of disability suggests that a staggering 537 million people in the world suffer from significant disability (UNDP, 1998). Very few reliable statistics exist on the prevalence and nature of disability in South Africa, largely due to a historical failure to integrate disability into the mainstream government statistical processes (White Paper on an Integrated National Disability Strategy, 1997). The World Health Organization (2005) estimates that two thirds of the world's disabled population reside in developing countries, and recent estimates of the prevalence of disability in South Africa suggests that 13% of the total population are disabled, 5% of whom are severely disabled (Central Intelligence Agency, 2007). However, it has been noted that the available statistics appear biased towards individuals with '*obvious'* physical and medical disabilities, and in this way exclude those with *'hidden'* disabilities, such as learning problems and psychiatric conditions (Gauteng Department of Health, 1996). Thus the estimates of prevalence of disability are believed to be conservative. Narrow definitions of disability, a lack of consistency among agencies and the use of disparate demographic methods appear to result in under-estimations and under-reporting of the prevalence of disability (Smart and Smart, 1997). Furthermore, it has been reported that factors such as poverty and the continuing spiral of violence in South Africa have contributed to a greater prevalence of disability in the country than has been reported (Kwa-Zulu Natal Department of Health, 1997).

This lack of reliable information on the nature and prevalence of disability in South Africa has lead to the majority of people with disabilities being excluded from mainstream society and as a result this population has been prevented from accessing fundamental social, political and economic rights (May, 1998). The exclusion experienced by people with disabilities and their families is the result of a range of factors, namely (May, 1998):

- The political and economic inequalities of the apartheid system
- Social attitudes which have perpetuated stereotypes of disabled people as dependant and in need of care, and
- A discriminatory and weak legislative framework, which has sanctioned and reinforced exclusionary barriers.

Helander (1984) adds that in developing countries people with disabilities are largely without access to or knowledge of the most basic health and social services. In South Africa, as a result of the structure of health and rehabilitation services under the apartheid regime, there has been a lack of implementation of primary healthcare service provision and an inequitable provision of services in terms of accessibility, appropriateness and funding, particularly across the variables of race, class, gender and level of urbanization (Kwa-Zulu Natal Department of Health, 1997).

1.4 The current status of speech therapy provision in South Africa

According to Levin (2005) most speech-language therapists in South Africa are women, of whom the majority are white, English or Afrikaans speaking, while most clients requiring speech therapy services speak indigenous languages. Although therapists in South Africa have honed their skills with regard to successful intervention in a multi-cultural and multi-lingual society, the mismatch in language and culture between the therapists and the clients and their families remains a major challenge to intervention. As a result, this creates barriers in the provision of an equitable healthcare service. Penn (2000) states that ultimately one advantage of working cross culturally is that it helps us to see what the real and critical issues are within our own professional culture.

Based on the above, this study strives to develop a sense of 'cultural speech-language pathology', which Penn (2000, p. 72) defines as *'an approach to diagnosis and therapy that reflects a sensitivity to cultural and linguistic influences and their interface with communication disorders'*. Cultural speech-language pathology strives to maximize the flow of information and to optimize clinical effectiveness by examining issues that do not only relate to the language disorder, but also a range of cultural indices such as family, gender, history, geography, socio-economic status, religion, education, myths and personal attitudes (Penn, 2000).

At present nearly all developmental and intervention data available are based on the assessment of "normal, white mainstream children from middle-class two parent families" (Westby and Erikson, 1992). Seeff and Bortz (1994) point out that often this western data is taken to be normal and even when attempts are made to adapt an approach to local experience, the premises remain western. As the ramifications of this concept are particularly evident in our multi-cultural South African population, it is essential that speech-language pathologists begin establishing a much-needed database of diverse socio-cultural beliefs and practices.

Additionally, the lack of information regarding issues surrounding culture is seen as a major obstacle to the provision of appropriate services to the diverse, multi-cultural South African population. In addition to this, if we believe that children learn most of their language in everyday interactions with those in their environment, then it becomes expedient for the speech language pathologist to examine what occurs during these interactions (Seeff and Bortz, 1994).

As speech-language therapists practicing in the field of community work, we have an obligation to develop a cultural sensitivity towards our clients, either through methods specific to our own profession or by adopting methods developed by other disciplines and to pass this information on to students and practitioners in our field. We need to develop tools that are sensitive enough to capture the very personal nature of the experience of

disability and communication impairment. In addition, we need to review the experience of the services that we provide to patients and take these into account when evaluating, planning and implementing policies.

1.5 Outline of the research

Chapter 1 has attempted to provide a description of both the history and current position of healthcare provision, specifically speech-language therapy in South Africa. Additionally it has briefly addressed the overwhelming phenomenon of disability, explicitly cerebral palsy in South Africa. Based on this, this dissertation strives to develop an understanding of what it is like to care for a child with a disability in Tonga, Mpumalanga. This study aims to provide an account of the experience of caring for a child with cerebral palsy in Tonga, Mpumalanga. It will explore caregiver experiences of day-to-day life with a disabled child, the involvement and engagement of the community in relation to caring for disabled children, and the caregivers' experiences of western healthcare provision in Tonga. Below is a brief outline of the study:

Chapter 2 is divided into three sections, namely cerebral palsy; the experience of caring for a child with a disability; and the role of context and culture in relation to disability.

The section devoted to cerebral palsy will review cerebral palsy as a medical concept, as well as international trends in the management of cerebral palsy. It will address the similarities and differences in the presentation and management of cerebral palsy in first world countries and in South Africa, and will review the role of the speech therapist in managing a child with cerebral palsy, and will address the current status of research into the area of cerebral palsy.

The section that reviews the experience of caring for a child with a disability will explore common reactions to disability, and the effect that disability has on the family. It will investigate the role that gender plays on caregiving activities, as well as the role of religion in coping with disability.

Finally, in the section relating to the role of context and culture in relation to disability, status of disabled persons in post-apartheid South Africa and disability as a sociological construct will be reviewed. It will address the effects that both poverty and HIV/AIDS have on disability, and will consider the role of the traditional healer in management of medical conditions in South Africa. Finally it will place the study in context by providing a social, cultural and geographical description of Tonga.

Chapter 3 will address the methodology used in this study. It will discuss the specific aims and objectives of the study and discuss the value of using qualitative data. It will discuss the sensitive nature with which the participants were accessed and highlight the instrumental role of Lindiwe Thobela, the Community Based Rehabilitation Worker and mediator of this research project. The training of the research mediator will be discussed in detail as well as the demographics of the participants. It will highlight the participants' willingness to participate and their obvious need to be empowered. Additionally it will address the themes of personal experience of cerebral palsy, the impact of poverty, gender roles, traditional beliefs and practices, and the experience of western medicine, and will discuss the value of using narrative interviews and participant observation as a method for providing insight into the lives of the participants.

Chapter 4 will evaluate the success of the methods employed in this study and discuss the results which emerged from the study according to the themes probed in the interviews. The data will be discussed according to the following themes: personal experience of cerebral palsy; the experience of poverty; the interplay of gender dynamics; the role of cultural beliefs and practices; and the participants' experiences of western medicine. This will be discussed in relation to themes that emerged upon qualitative analysis of the field notes, translated and transcribed interviews, and the reflections of both myself and the research mediator, as prescribed by Maykut and Morehouse (1994), and will highlight the need for this marginalized community to be heard.

Chapter 5 will provide a general discussion of the findings, implications and limitations of the study. The emergence of 'unspoken themes' will be discussed, and the concept of 'ubuntu' will be reviewed. Finally this chapter will endeavor to redefine the role of the speech-language therapist working within a rural context and make recommendations for the development and implementation of healthcare policies.

Finally, **Chapter 6** will address the current position of this study in terms of service provision, policy development and research in South Africa. It will make recommendations for the training of undergraduate students and for improving on current healthcare policies and provide recommendations for future research that will be meaningful to the 'researched' community.

1.6 Conclusion

It is acknowledged that South African speech-language therapists bear a remarkable responsibility in terms of service provision in a multi-cultural and multi-lingual society. The literature, however, reveals a paucity of reliable information and methods of engaging with our clients has impacted severely on the planning, development and implementation of services and intervention strategies aimed at preventing disability. If we as speech-language therapists working in the public sector are to deliver a service which is effective and efficient, it is imperative that we review and evaluate healthcare policies, and the implementation of healthcare in context, and that we listen to our patients as they, as consumers of this service, are the ones best able to inform us of our successes and failures and indicate the reasons behind these. This implies that as speech-language therapists we need to transform from the traditional role of the speech-language therapist to a role where we are actively involved in advocating the rights of marginalized communities. We need to be accountable to the populations that we serve and provide a service that encompasses context, culture and individual needs.

By acknowledging that disability is essentially a human rights issue, it implies that disability research should inform the activities of a wide range of government departments and institutions in society, requiring intervention from all sectors. In the

current context of transformation in South Africa, The White Paper on an Integrated National Disability Strategy (1997) has motivated for collaborative, intersectoral efforts in developing viable solutions for the problems faced by people with disabilities, spear-headed by appropriate information gathering and research. For this vision to be realised, it is crucial that all relevant stakeholders accept their responsibility to empower people with disabilities and enhance their quality of life by engaging in research around key disability issues. As South Africa's professional resource base, we as healthcare professionals have a responsibility to harness our research capacity in order to advance and implement emergent policy imperatives within the context of national reconstruction and development.

Thus this study strives to appreciate comprehensively what it means to care for a child with cerebral palsy in a region heavily burdened by the effects of poverty, gender discrimination, HIV/AIDS, lack of municipal services, reduced levels of education and literacy, and stigma related to disability. It will assert that a description and understanding of the social environment and context is essential for an overall understanding of the experience of disability and in so doing will strive to inform healthcare workers and policy makers on the most effective and efficient way in which to provide an equitable service that is valuable to the consumers of the service.

1.7 Glossary of Terminology

Apartheid	-	The policy or practice of political, legal, economic, or social discrimination, as against the members of a minority group (Britannica Concise Encyclopaedia, 2003)
Community	-	A group of people having common rights, privileges, or interests, or living in the same place under the same laws and regulations (Britannica Concise Encyclopaedia, 2003).
Community Based Rehabilitation Worker (CBRW)	-	Disabled person employed to work within the community with the aim of community development, equalization of opportunities, and social integration of persons with disabilities. It is implemented through the combined efforts of disabled people, their families and communities, and the departments of health, education and social services (White paper on a Integrated National Disability Strategy, 1997).
Cultural Broker	-	A local person within a community acting as a mediator within a setting, informing an outsider on the policies, practices, behaviours, structures and attitudes within a given community or setting (Hosmer, 1997).
Gogo	-	SiSwati term for grandmother

Marginalization	-	The state of being considered unimportant, undesirable, unworthy, insignificant and different resulting in inequity, unfairness, deprivation and enforced lack of access to mainstream power (UNDP, 1998).
Medical Model Of Disability	-	A disempowering model that views disabled people as dependent and the responsibility of society. This dependency disempowers disabled people and isolates them from mainstream society and in this way prevents them from accessing fundamental social, political and economic rights (White paper on a Integrated National Disability Strategy, 1997).
Nkulu	-	SiSwati term for grandfather
Research Mediator	-	Person employed to moderate the interactions between the researcher and the participants. Particularly useful where the researcher is not a member of the community being researched. See cultural broker (Hosmer, 1997).
Social Exclusion	-	Isolation from mainstream social activities, including family life, education, and employment, resulting in disempowerment and marginalization (White paper on a Integrated National Disability Strategy, 1997).

Social Model of Disability	-	The social model is based on the belief that the circumstances of people with disabilities and the discrimination they face are socially created phenomena and have little to do with the impairments of disabled people. The underlying belief is that the 'cure' to the 'problem' of disability lies in restructuring society (White paper on a Integrated National Disability Strategy, 1997).
Traditional healer	-	A person recognized by the community as competent to provide healthcare by using vegetable, animal and mineral extracts, as well as methods based on social, cultural and religious beliefs, as well as the prevailing knowledge, attitudes and beliefs regarding physical, social and mental well-being and the causation of disease and disability in the community (Ashworth, 2005).
Ubuntu	-	A Zulu philosophy of life that states that the well-being of the individual and his or her interests are possible through the community whereby the community becomes a web of relationships (Teffu, 1994).
Umuthi	-	A Zulu term meaning either 'medicine' or 'poison', and refers to substances fabricated with an expert hand, designed to achieve either healing or illness (Ashworth, 2005).

CHAPTER 2
Background to cerebral palsy in relation to neurological impairment, context and culture



Image 3: One of the participant's homes

Caring for any child involves considerable resources, but the demands of these resources are often increased when caring for a child with a disability. These demands have implications for the physical, financial and emotional health of the caregiver. This chapter will review the literature on three aspects related to this study, namely:

- Cerebral palsy

This section will review cerebral palsy as a medical concept, as well as international trends in the management of cerebral palsy. It will address the similarities and differences in the etiology, nature and management of cerebral palsy in South Africa, as well as evaluate the role of the speech-language therapist in managing a child with cerebral palsy. Finally this section will address the current status of research into the area of cerebral palsy.

- The experience of caring and coping with disability

This section of the chapter will address the parental experience of coping and caring for a child with a disability. It will explore common reactions to disability, and the effect that disability has on the family. It will investigate the role that gender plays on caregiving activities, as well as the role of religion in coping with disability.

- The role of context and culture in relation to disability

This section will review the status of disabled persons in post-apartheid South Africa, and will discuss disability as a sociological construct. It will address the effects that both poverty and HIV/AIDS have on disability, and will review the role of the traditional healer in management of medical conditions in South Africa. Finally it will place the study in context by providing a social, cultural and geographical description of Tonga.

2.1 CEREBRAL PALSY

2.1.1 Definition of Cerebral Palsy

Cerebral palsy is the term used to describe a range of non-progressive syndromes of posture and motor impairment that results from an insult to the developing central nervous system (Koman, Smith, and Shilt, 2004).

Cerebral palsy was first identified by W.J Little in 1843 and has been described as one of the most common causes of severe physical disabilities in children. Cerebral palsy is caused by irreversible brain lesions occurring before, during or shortly after birth (Mecham, 1996). In the literature, cerebral palsy is defined as '*an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development'* (Mutch, Alberman, Hagberg, Kodama, Perat, 1992, p.9). It may range from mild to severe, with 50-75% of affected individuals suffering from mental impairment (Mecham, 1996). Cerebral palsy may be characterized by spasticity, movement disorders, muscle weakness, ataxia, and/or rigidity (Koman et al, 2004); however, the peripheral manifestations of cerebral palsy depend on the magnitude, extent and location of the insult to the brain, brainstem or spinal cord (Kuban and Leviton, 1994). Damage to the immature central nervous system may occur during the following phases of development (Bax and Brown, 2004):

- Prenatally (due to brain haemorrhage, maternal infection, or environmental factors such as maternal exposure to radiation),
- Perinatally (due to birth asphyxia), or
- Postnatally (due to head injury, infection, or anoxia).

Other factors associated with cerebral palsy include rhesus incompatibility, chorioamnionitis, maternal infection, antepartum vaginal bleeding, second stage labour lasting more than four hours, untreated hyperbilirubinaemia, fetal anoxic events, and fetal infection, such as meningitis (Nelson and Grether, 1999).

In many cases it is impossible to specify the exact cause of neurological impairment in the developing brain. However, the most frequent cause of cerebral palsy has been linked to haemorrhage of the vascular system of the brain, in which the blood that infiltrates the brain tissue destroys nerve cells (Koman et al, 2004).

The cerebral palsies have been variously classified but for the purpose of this study, classifications as described by Love and Webb (2001) will be used:

- Spastic cerebral palsy as a result of damage to the pyramidal tracts, and may present as paraplegia, diplegia, quadriplegia, hemiparesis or monoplegia.
- Athetoid cerebral palsy as a result of damage to the basal ganglia and may affect the arms, legs, neck and/or trunk
- Ataxic cerebral palsy as a result of damage to the cerebellum and may affect the arms, legs and/or trunk.

Although these classification systems exist, the presentation of cerebral palsy is not always clear-cut, and thus children with cerebral palsy frequently have mixed presentation and may present with associated impairments (Bax and Brown, 2004). Pimm (1996) states that cerebral palsy affects the motor system, and often other systems controlled by the brain. The associated impairments may include speech, language, feeding, oro-dental, visual, cognitive, hearing or behavioural impairments. Koman et al (2004) state that more than 50% of persons affected by cerebral palsy are able to walk without assistance, while 25% require assistance and a further 25% are immobile and rely on others to move them. Neurological problems are common with 50-75% of persons affected by cerebral palsy presenting with mental retardation, the condition being accompanied by seizures in 35% of cases, sensory impairment in 97% of cases, hydrocephalus in 9% of cases, visual impairment in 20-40% of cases, and urinary incompetence in 23% of cases (Hutton and Pharoah, 2002). Patterns of spasticity with resultant muscle imbalance can result in muscle shortening, joint contractures, bony deformities and/or joint dislocation. Secondary impairments, such as drooling and facial grimacing associated with effortful movement may also develop (Mecham, 1996). Additionally, the individual with cerebral palsy may suffer from functional abnormalities

as a result of impaired muscle tone. These may include breathing impairments as a result of deviations in the position, size, and shape of the larynx; and/or an obtuse thyroid angle caused by deviations of the muscles; articulatory impairments as a result of contractures in the tongue, lip and jaw, which may affect language in terms of expressive output, and speech in terms of dysprosody (Hardy, 1994).

Diagnosis of cerebral palsy is made by taking a complete case history, physical examination and ancillary examinations. According to Feldman, Haley and Coryell (1990) assessment of children with cerebral palsy should include a detailed case history including an account of gestation and peri-natal events, as well as an account of developmental milestones. In addition to the physical examination, assessment should be made of muscle tone, static balance, spinal alignment, range of motion of joints, and the presence of limb deformity. In addition, MRI scans, CT scans and cranial ultrasonography can be used to assess the extent of CNS damage.

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While there is no cure available for cerebral palsy, if appropriate healthcare is available, children affected by cerebral palsy without significant co-morbidities have normal-to-near-normal life expectancies (Koman et al, 2004). However, mortality is higher and lifespan is shorter in children with severe physical impairment, hydrocephalus, lack of basic functional skills, seizures and profound mental retardation.

2.1.2 International Perspectives on Cerebral Palsy

International literature reflects that in developed countries the prevalence rate of cerebral palsy is between 1.68 – 2.45 per 1000 live births (Hagber, Hagberg, Beckung, and Uvebrant, 2001; and Colver, Gibson, Hey, Jarvis, Mackie, and Richmond, 2000). These estimates translate into 15 000 to 20 000 children with cerebral palsy in Canada, and 150 000 in the United States (Ficher and Batshaw, 2003). These numbers are significant when one considers the financial, physical and psychological needs that children with cerebral palsy place on the caregivers, as well as when budgeting and planning for the appointment of healthcare workers. Of increasing concern is the evidence that the incidence of cerebral palsy is believed to be increasing as a result of modern technology

which is now able to save the lives of many premature and newborn infants whose nervous systems have suffered some insult or malformation (Koman, et al, 2004).

While there is no medical cure for cerebral palsy, international experts agree that early intervention and a treatment programme based on sound assessment and evaluation are the most important factors in helping a child to participate in as many fulfilling and enjoyable experiences as possible (Hardy, 1994; Mecham, 1996; and Pellegrino, 1997). Early intervention is essential because of the greater adaptability and plasticity of the infantile brain (Koman, et al, 2004). The team of professionals that should be involved in the management of cerebral palsy includes the parents, the paediatrician, nurse, speech-language therapist, audiologist, physiotherapist, occupational therapist, social worker and psychologist (Hardy, 1994). This holistic involvement is aimed at ensuring the formulation of the most appropriate programme for the individual. In addition to various forms of therapy, drugs and neurolytic procedures may be prescribed for muscular relaxation or where nerve impulses are blocked (Kuban and Leviton, 1994). In conjunction, orthopaedic surgery and neurosurgery are often required as well as prosthetic braces to control involuntary movement and support (Mecham, 1996).

According to Mecham (1996) the most important domains that require intervention in children with cerebral palsy are self-help skills, including feeding, dressing, washing and maintaining personal hygiene, and toilet training; as well as the development of cognitive skills.

Thus, successful intervention with children with cerebral palsy relies on early identification and a well-coordinated multidisciplinary approach. Various therapeutic options are available, including neuro-developmental therapy, patterning, paediatric massage, and constraint-induced therapy (Koman et al, 2004). Although the efficacy of these treatment regimes have been proven, they frequently rely on financial resources and post-graduate qualifications, which, in many areas, including South Africa, are largely unavailable. The following section will review cerebral palsy in South Africa and the

similarities and differences in etiology, identification and management of cerebral palsy in South Africa.

2.1.3 Cerebral Palsy in South Africa – Is there a difference?

Very little is currently known about the prevalence of childhood disability in developing countries (Cooper, 2002). This lack of information has implications for health, rehabilitation, welfare, and educational services. These implications need to be researched and addressed appropriately in order develop suitable rehabilitation services within the South African context. Schleichkorn (1993) provides the following reasons for our limited knowledge regarding incidence and prevalence of cerebral palsy:

- Many children are only diagnosed with cerebral palsy in childhood and are therefore exempt from being accounted for in the health statistics of newborn infants.
- The incidence of cerebral palsy is likely to vary according to geographical areas as a function of the quality of pre-, peri-, and post-natal care.
- There are several conditions present at birth of which abnormal tone is a component, but for which another diagnostic classification is felt to be more appropriate for care and treatment purposes.

While these are common areas of concern in compiling accurate and representative healthcare statistics, Schleichkorn (1993) fails to acknowledge the number of children born at home in rural areas which may contribute to the inaccuracy of statistics, as well as the level of stigma attached to disability. The Disabled People of South Africa (2002) reports that currently there are still many households who hide disabled family members in their homes, out of sight of the community as a means of escaping the stigma associated with disability. This is a harsh reminder of the level of shame associated with disability in South Africa, and is likely to be a factor associated with inaccurate statistics related to disability.

While mention has been made of the difficulty in determining the exact prevalence of cerebral palsy in South Africa, the World Health Organization report (WHO, 2005)

indicates that 10% of children in South Africa present with significant disability of neurogenic origin, while regional studies in South Africa (Couper, 2002; and Christianson et al, 2002) indicate a prevalence of cerebral palsy of between 1% and 8%.

National statistics on etiologies related to cerebral palsy do not exist. However, research conducted in Giyani, in north-eastern South Africa by Potterton (1996) revealed that in 32% of cases, cerebral palsy was due to post-natal causes, while 46% of cases were due to perinatal causes, and 22% of cases of cerebral palsy were due to unknown causes. The high percentage of post-natal causes is of concern, since these can potentially be prevented. A high percentage of the study sample who reported post-natal causes recalled that their children had suffered from gastroenteritis or meningitis, which are common illnesses in rural areas and if left untreated can lead to brain damage (Potterton, 1996). It was also found that Giyani has a high incidence of malnutrition among its children which can lead to brain dysfunction, especially if accompanied by dehydration (Harrison, 1991). Thus, when looking at cerebral palsy in the context of the South Africa it is important to take into account health issues that are specific to our country and can give rise to evolving cerebral palsy. A review of the literature reveals that, in addition to the causes mentioned above, cerebral palsy can potentially result from the following:

- Tuberculosis Meningitis

Tuberculosis (TB) was the most prevalent disease reported to health officials in South Africa in the decade 1990-2000 (Central Intelligence Agency, 2007), while tuberculosis meningitis (TB meningitis) is reported to be one of the major causes of neurological impairment among children under the age of six years in South Africa (Mahdi et al, 2000; and Hussey et al, 1997). Furthermore, it has been found that the neuro-developmental outcomes of TB meningitis are usually poor and the (possible) resultant cerebral palsy is usually severe in terms of sensory-motor and cognitive development (Levin, 2005). The control of TB in South Africa is extremely difficult mainly due to conditions of overcrowding and unsanitary living conditions, in addition to the inaccessibility of healthcare in rural areas (Hussey, et.al., 1997).

- Malaria

Statistics according to the central intelligence agency (2007) reports that malaria is ranked second in terms of disease prevalence in South Africa and is one of the most common etiologies of childhood mortality in Africa (WHO, 2005). The incidence of malaria is most common in the low-lying areas of the Limpopo province, Mpumulanga, and northeastern Kwa-Zulu Natal. Furthermore, a relationship has been established between HIV infected patients and severe cases of malaria, specifically cerebral malaria, (Grimwade et al, 2003), frequently resulting in cerebral palsy.

- Premature birth and low birth weight

Children born prematurely in rural hospitals very seldom have access to neonatal intensive care units (Cooper, 1998). In addition, these infants may not receive the specialized care that they require. Rural hospitals and clinics are frequently understaffed and very few doctors in these settings have experience in working with populations who have complex needs. For premature and low birth weight babies who do survive, their neuro-developmental complications may result in cerebral palsy.

Both Potterton (1996) and Irochu-omare (2004) recognized that the majority of therapists, particularly in state institutions are under-qualified for working with children with cerebral palsy. They recommended a need for Neuro-Developmental Therapy (NDT) techniques to be taught to therapists, therapy assistants, and CBR workers in order to provide them with sufficient knowledge and skills to manage children with complicated neurological conditions. Currently NDT courses are expensive and are therefore only accessible to affluent therapists, and thus the skills are not transferred to clients living in areas less accessible to private or tertiary healthcare. Additionally, a number of studies have reported that poor management and administration at healthcare centers result in poor quality of therapy and caregivers' expectations not being met, with many hospitals being understaffed and under-equipped, and some facilities lacking even basic commodities such as running water and electricity (Potterton, 1996).

Not only are barriers to healthcare experienced by patients, but also by therapists. The literature (Potterton, 1996; Irochu-Omare, 2004; and Kilonzo, 2004) reflects the following barriers experienced by therapists:

- Primary caregiver

In many cases children are brought to the hospital by a caregiver who is not the mother of the child (Potterton, 1996). This makes it difficult to obtain accurate details regarding the child's history. In addition, it is often found that there is not a constant person involved in the child's rehabilitation, which makes carryover of therapy home programmes somewhat ineffective.

- Cultural differences

Working cross-culturally can present as a major barrier to effective therapy. The western bio-medical model on which so much of the therapy is based is a foreign concept to the majority of patients, of whom many have little or no education (Potterton, 1996). Culture shapes people's attitudes and behaviours, and as a result affects the way in which people respond to challenges to their health. The decision to consult with a healthcare professional, particularly in rural areas is affected by, among other factors, access, education, age, prior experience, individual values, beliefs and judgement (Tollman and Kahn, 1999). Thus the question arises as to whether healthcare professionals are able to meet the needs of patients whose social and cultural beliefs and circumstances are so different from their own. Often problems, including miscommunication, distrust, delayed consultation, and passivity on the part of the patient affect the patient's chance of recovery. Herselman (2007) states that while these problems could be the result of the patient's experiences of poverty, lack of education, political issues, and lack of access to healthcare facilities, they could also be the result of the healthcare professional's lack of awareness and understanding of their patient's beliefs and social behaviours. For this reason, cognizance needs to be taken of cultural issues and the patient's worldview needs to be considered before one can even begin to discuss the pathogenesis of cerebral palsy. In addition, it is important to have a thorough understanding of cultural norms and

practices before giving a home programme. Traditional ways of caring for children are deeply ingrained and few caregivers will take kindly to being told to alter these practices by someone from another culture (Potterton, 1996).

- Language barriers

According to Penn (2007) communication challenges occur in all patient-practitioner interactions, but the challenges of these may be magnified in certain clinical encounters. South Africa is a diverse country with eleven official languages, and according to Penn (2007), 80% of clinical interactions takes place in the presence of cultural and linguistic barriers. As with working cross-culturally, it is difficult to work with a population with whom the therapist does not share a common language. This is particularly true in the South African context where hospitals do not employ interpreters and therapists frequently need to make use of other parents or hospital cleaners as translators and in this way confidentiality is compromised and much meaningful conversation is lost. Research indicates that the use of untrained persons as interpreters often results in omissions, substitutions, condensations and distortions of information resulting in a lack of understanding, both on the part of the clinician and the patient (Penn, 2007). The frequent inability of healthcare professionals to engage in conversation with their patients may reveal a lack of insight into the patient's customs and beliefs, and as a result, the healthcare provider may be unable to identify the root of the problem in the exchange of information. Herselman (2007) adds that where complex matters are discussed in layman's terms their meanings are often misunderstood which in turn may affect the nature of the interaction. In addition, other problems including fear, mistrust, delayed initial consultation, suspicion of medical recommendations, and failure to attend follow up appointments have implications for the clinician-patient relationship, and ultimately for recovery.

Thus there is much to be learned from examining cerebral palsy in relation to local contextual variables. Levin (2005) states that in South Africa, speech therapists working in the field of cerebral palsy bear a remarkable load. The dependence that children with cerebral palsy have on their caregivers necessitates family-centered intervention since

most children with cerebral palsy do not go to school and both the children and their caregivers receive very little, if any support from formalized institutions (Levin, 2005). As a result, therapists are faced with a complex population with many compound needs for which the speech-language therapist is frequently under-qualified. Additionally, in many state hospitals and primary healthcare clinics, the speech-language therapist does not have the luxury of working in a multidisciplinary team and therefore is required to address needs that traditionally lie beyond their scope of practice, such as accessing disability grants and training urinary continence, as well as disseminating condition-specific information, often in a language which is neither the first language of the patient or the therapist.

2.1.4 Role of the speech-language therapist in working with children with cerebral palsy

The speech-language therapist forms part of the multidisciplinary team. Common areas of concern in children with cerebral palsy include feeding difficulties, which may result in aspiration pneumonia, unintelligible speech, drooling, expressive and/or receptive language delay, and hearing impairments.

In terms of speech development, the speech-language therapist aims to promote functional communication such that the child can participate in social and scholastic activities. According to Hardy (1994) the distinguishing communication disorders of a person with cerebral palsy are dysarthria, which is a result of muscular weakness causing difficulty in generating the speech signal; respiratory system dysfunction, which affects lung volume needed to drive the vocal tract in order to produce sound; laryngeal dysfunction, which affects the closure and tension of the vocal folds needed to produce phonation; and velopharyngeal dysfunction resulting in hyponasality and difficulty producing consonants. The speech-language therapist thus works on improving oral muscle tone, and respiratory function and coordination in order to improve the expressive sound signal. As mentioned previously, many children with cerebral palsy may have concomitant problems such as drooling or facial grimacing which increase as the

demands of a task increase. These can also be targeted by the speech therapist by employing methods such as oral control, icing and brushing (Lewitt, 2004).

There is a general consensus that the language skills of children with cerebral palsy are delayed (Hardy, 1994). Delays in language development may be a result of mental impairment, limited speech production imposed by dysarthria, and limitations on the child's ability to respond as a result of neuro-motor impairment. Additionally, it is a recognised fact that children with cerebral palsy often tend to have hearing impairments (Hardy, 1994). This is particularly true for children with athetoid cerebral palsy who frequently present with a significant bilateral high frequency sensori-neural hearing impairment (Blackman, 1990). The cause of this high frequency hearing loss has been linked to an infiltration of bilirubin into the nervous system resulting in kernicterus (Blackman, 1990). Additionally, Young (1994) reports that sensori-neural hearing loss is more common in children with cerebral palsy than in the general population, even in subgroups other than those with athetoid cerebral palsy, suggesting that hearing loss in this population may be due to damage to portions of the brain's auditory system. Thus, the presence of a hearing impairment needs to be evaluated, and where necessary managed so as to promote effective communication, and a functional learning environment (Young, 1994).

For those children for whom the development of functional communication is unrealistic, there is the option of augmentative and alternative communication, including picture boards and computers (Beukelman and Mirenda, 1992). This however relies on a degree on cognitive ability, and in many instances private funding and access to electricity.

2.1.5 Current areas of research in cerebral palsy and implications for the speech-language therapist

Having reviewed the current literature regarding cerebral palsy, a number of themes have emerged in terms of areas of research. One common area of research is the area of assessment of quality of life and functional abilities of persons with cerebral palsy (Schneider, Gurucharri, Gutierrez, and Gaebler-Spira, 2001). In the past, research into the developmental framework of assessment dominated (Haley, 1994). This framework was based on the belief that interventions should be directed at helping children attain sequential developmental positions and move normally within them (Nelson, 1995). These assessments were abundant in their descriptive nature and their explanations of abnormality decidedly shaped therapeutic practice (Haley, 1994). Clinicians, however, realised that assessment needed to be tied more closely to function, rather than evaluating the child's ability to attain motor milestones. Thus the focus of research moved towards measuring function and the ability to complete activities of daily living at home and in the community (Haley, 1994; Nelson, 1995). More recently, studies have moved towards researching the condition not only in terms of physical functioning, but also in terms of the condition in relation to the body, the psyche and the way in which the person relates to society (Mweshi and Mpofu, 2001). This is in line with research conducted by medical anthropologist, Leavitt (1992) who notes that the medical approach to the management of cerebral palsy lacks a framework for understanding the dimensions of disablement and functioning at the level of the body, the person, and society as a whole.

Recently, several initiatives have focused attention on caregivers' health as an area requiring further research. A recent revision of the World Health Organization International Classification of Functioning, Disability, and Health framework stresses the environment as critical to health and well-being (WHO, 2005). This framework highlights the important relationship between the health of the caregiver and the health of the child. Additionally, there has been a shift in healthcare service delivery away from child-centered models that focus primarily on treating the disability, to family-centered models (Rosenbaum, King, Law, and Evans, 1998; and Viscardis, 1998). This shift recognizes the primary role of the family in child development, but may also serve to

increase the demands on family members by requiring them to be more active participants in the care of the child. This shift has also been recognized in studies conducted by Lambat (2004); Levin (2005); Potterton (1996); Mweshi and Mpofu (2001); Meyer and Moagi (2000); and Green (2003) who provide evidence that the management of cerebral palsy requires a family-centered approach.

A study conducted by Roberts and Lawton (2001) researched the care requirements of caregivers caring for severely disabled children under the age of 16 years in the United Kingdom. The authors reviewed 40 000 records of the Family Fund Trust where the children were registered so that they could obtain disability grants. These records were analysed quantitatively according to five activities of daily living (washing, dressing, feeding, nightly routine and ability to be self-occupied). While these findings confirmed that children with severe disabilities have considerable extra care needs and revealed that caregivers appreciate it when healthcare providers acknowledge the extra care they provide to disabled children, the quantitative nature of the study fails to recognise the personal experience of caring for a child with a disability. The personal experience significantly affects the outcomes of intervention as with most chronic conditions therapy extends beyond the therapy setting and into the natural environment of the patient.

Another study was conducted by Brehaut et al (2004) on the health of primary caregivers of children with cerebral palsy in Canada, which analysed the physical and psychological health of caregivers of children with cerebral palsy by issuing questionnaires and conducting face-to-face interviews. This study acknowledged that families are key participants in the process of establishing priorities and specific forms of care for their children with cerebral palsy. The results revealed that caregivers of children with cerebral palsy had lower incomes than that of the general population and listed ‘caring for their family’ as their primary activity. Locally a similar study was conducted by Amosun, Ikuesan, and Oloyede (1996) assessed the mental health of caregivers of disabled children. A total of 108 participants were assessed using the General Health Questionnaire. The results revealed that caregivers of disabled children were more predisposed to the stressful impact of caregiving which may contribute to psychiatric

morbidity. Thus the recommendation was made that caregivers of disabled children should be psychologically assessed on a regular basis.

Analysis of psychological health shows that caregivers of children with cerebral palsy were more predisposed to stress, emotional problems and cognitive problems, while they also showed a greater prevalence of physical ailments including back pain, asthma, headaches and gastro-intestinal problems than the average population. These results imply that healthcare professionals need to be aware of the relationship between childhood disability and caregiver's health and recommend that future research should be conducted on caregiver's perceptions of family-centred therapy. However, neither of the studies mentioned above undertook to delve into the nature of the psychological difficulties experienced by the caregivers, and thus the recommendations failed to provide concrete ways of improving the quality of life of persons caring for a child with cerebral palsy.

A study conducted by Paine (1999) analysed fifteen semi-structured interviews conducted with primary caregivers of children with disabilities in the United Kingdom. The study explored the type of information that caregivers had received regarding the child's condition, whom they had received this information from, and whether or not they found this information valuable. Results indicated that most information was received from professionals and caregivers reported that the information had assisted them in emotionally adjusting to the child's disability, accessing services and in managing difficult behaviours. Numerous studies have highlighted that information is vital to the empowerment of persons affected both directly and indirectly by disability. However, there is a paucity of information on the manner in which healthcare information is disseminated in South Africa and the way in which this information is interpreted by consumers of the healthcare service, particularly amongst the rural and illiterate populations of South Africa. Additionally, the nature of semi-structured interviews, as employed by Paine (1999) has limitations in that they frequently make use of closed-ended questions which prevent participants from voicing their opinions, concerns and experiences in their own words.

Locally, a number of studies have been conducted which have studied the survival of very low birth weight infants in South Africa (Cooper, Saloojee, Bolton, and Mokhachane, 1997; Hussey, et al, 1997; and Cooper, 2002;). These studies employed quantitative methods and focused on the medical system and the resultant survival rate of very low birth weight infants. The results show a significant decrease in mortality rates with the improvement of medical technology. This is consistent with international findings (Koman et al, 2004). However, these studies have not acknowledged the neurological outcomes of these very low birth weight infants or the parental experience of caring for these children. There is a scarcity of information of parental experiences of the healthcare system, the number of patients who default from the medical system post discharge and the reasons for this. Studies related to the nature in which condition-specific information is disseminated cross-culturally (Evans, 2000; Fisch, 2001; and Cilliers, 2005 as cited in Penn, 2007) revealed a wide variety of institutional language practices, with significant linguistic diversity and attitudes among clinicians, patients and persons brought into the clinical encounter to act as interpreters (for example, nurses, family members, cleaning staff and other patients). These studies revealed a wide variety of understandings in terms of the nature of a condition and the management thereof, which ultimately affects the effectiveness of the clinical encounter. Results of the studies mentioned above indicate that in order to improve communication in health settings in South Africa, healthcare settings need to establish consistent teams that deliver a specific service, and that efforts should be made to enlist the expertise of language specialists, both at treatment sites and in research in order to facilitate effective communication.

Based on the above, two major weaknesses were identified in current research on caring for a child with a disability. Firstly, most studies draw conclusions from relatively small, potentially biased clinic-based samples, and secondly the methodologies used in these studies is frequently quantitative, relying mostly on questionnaires or closed-ended questions and therefore does not explicitly represent the experience of caring for a child with a disability. This highlights the fact that the nature in which research is conducted is the pivotal point such that one obtains a true reflection on the nature of the impairment

and the effect that this has on the individual, the caregiver, the community, and society as a whole remains a contentious issue. This raises the issue of *how do we hear the client's voice?*

A study conducted by Glasscock (2002) in Orlando, in the United States of America used a convenience sample of fifteen mothers of children with spastic cerebral palsy between the ages of one and five years in order to describe the lived experience of caring for a child with cerebral palsy. The study employed phenomenological techniques and analysis of the transcripts revealed the following recurrent themes: caregiver burden, social/family support, woman's/mother's roles, and socio-economic difficulties. The study revealed the importance of family relationships, an interest in learning about cerebral palsy and improving their child's quality of life, the need for therapy and social services to assist them and their children.

A study conducted by Irochu-Omare (2004) researched caregivers' experiences of physiotherapy services at a hospital in Uganda. The study utilised focus group interviews with caregivers at the hospital, and results indicated that most caregivers were satisfied with the services they received at the hospital. However, they were dissatisfied with the information they were provided with regarding the child's diagnosis and prognosis, as well as the nature of interactions they had with the therapists. Additionally, caregivers were dissatisfied with transport services to and from the hospital, which accounted for the irrregularity of their attendance at the hospital.

The studies conducted by Glasscock (2002) and Irochu-omare (2004) highlight the significance of researching disability qualitatively by means of allowing the participants to tell their story as they have experienced it. Having reviewed the literature, there is a lack of such information obtained locally in South Africa within the disability sector, particularly related to childhood physical disability in rural areas. This raises concerns related to the nature of intervention that is provided to these populations since if we as healthcare professionals do not understand the cultural norms and practices of a given

community, nor the experience of caring for a child with a disability it is difficult to provide an appropriate and equitable service.

A way of overcoming this difficulty is to research the experiences of these communities making use of ethnographies. The word *ethnography* literally means to write about people (Hustler, 2001). The distinctive features revolve around the notion of people as meaning-makers, around an emphasis on how people interpret their worlds, and the need to understand the particular cultural worlds in which people live and how they construct and utilize these worlds. Ethnography is based on the premise that social behaviours cannot be reduced to predictable variables along the lines of natural sciences (Blumer, 1967); that people actively collaborate in the construction and maintenance of the cultural meanings which inform their actions; and that researchers therefore need to find ways of engaging with those meanings and processes.

Thus ethnographic research allows for insight into the intimate daily lives of participants and in this way allows the researcher to evaluate, for example, aspects related to healthcare delivery. In so doing, the researcher can explore how cultural beliefs and practices might impact on the individual's philosophy and practices related to health, illness and treatment, and in turn how the health professional's ethnocentricity might affect the perceptions of clients or other healthcare workers (Savage, 2000).

2.1.6 Conclusion

Cerebral palsy is one of the most common causes of severe disability in children caused by irreversible brain damage, before, during or after birth. It affects the motor, and often other systems controlled by the brain. As can be seen from the above, cerebral palsy is a complex medical condition, requiring early intervention and a multidisciplinary team approach. Over the past few years, there has been a shift from assessing affected units of function, such as muscle tone, speech, and feeding, individually, to assessing these as components of functional participation in terms of health-related quality of life (Schneider, Gutierrez, and Gaebler-Spira, 2001). This relates to areas of physical functioning, psychological issues, social functioning, impairment, symptoms and

disability, and how these issues affect the individual's ability to participate in everyday activities. According to Koman et al. (2004) current management models of cerebral palsy are client-centered and are focused on modification of spasticity, control of movement disorders and deformity, and reduction of discomfort. The availability of drugs and the ability to alter spasticity with surgical procedures, the development of techniques to strengthen and improve motor power, and the identification of surgical procedures to correct deformities have contributed to the provision of improved quality of life and improved self-esteem for those affected by cerebral palsy.

The nature of research into cerebral palsy has evolved over the years and currently much research focuses on the quality of the relationship between the child with cerebral palsy and the caregiver and the way in which the impairment inhibits social participation. However, the way in which this information is obtained remains contentious and a shift towards applying qualitative research methods, including ethnography has been noted in the literature (Hustler, 2001). This is particularly significant for the South African population where an extreme paucity of knowledge pertaining to cultural norms, practices, and experiences exists.

2.2 THE EXPERIENCE OF CAREGIVING AND COPING WITH DISABILITY

Parenting a child and attempting to provide a safe environment that fosters the physical, social and emotional growth is a complex task. In many instances families fall apart as a result of poor coping skills, lack of support structures, or in response to money struggles, addictions, abuse, health impairments, or plain unhappiness (Dickman and Gordon, 1985). It is therefore no surprise then that having a child with a disability can also drive a parent into a state of chronic stress or crisis. Disabling conditions tend to evoke strong emotional reactions in the affected individual, as well as in significant others in his or her environment. According to Lewis and Rosenblum (1974) these reactions are applicable across a broad range of disabilities and illnesses and are believed to be cross-cultural. These reactions are often manifestations of mourning the loss of an ideal or dream.

Grieving is described as the process of separating oneself from something significant that is lost, and is not necessarily a negative experience, as it can stimulate a re-evaluation of the individual's existential values (Ross and Deverell, 2004, p.32). However, if a person is, for whatever reason, unable to grieve they essentially cannot separate from the lost person or object. Essentially a person cannot grieve alone and successful grieving interactions depend on significant human interactions and support from numerous sources, extending from a spouse to friends, religious groups, a professional, the community or support organisations (Lewis and Rosenblum, 1974).

Kubler-Ross (1969) discusses the stages of grieving and points out that grieving is not a linear experience but that people may oscillate between stages of grieving for many years. Moreover, she highlights that acceptance is not necessarily inevitable. Some of the more common emotional reactions as identified by Kubler-Ross (1969) include the following:

- Shock and Disbelief

This is usually one of the initial reactions, and is common if the diagnosis is unexpected.

- Relief

Some patients, and parents alike, may experience a sense of relief once a diagnosis is made or when their fears are confirmed.

- Denial

This is another manifestation of grieving, particularly in the early stages, and may manifest in rejection of the diagnosis itself and 'shopping around' in search of an 'acceptable' diagnosis. This may result in the client 'arguing' with the clinician, and thereby creating a negative client-clinician partnership, or the client may not follow through on the clinician's recommendations and not cooperate with rehabilitation

procedures. Denial is frustrating for clinicians, but is a valuable defence mechanism that protects the psyche from the trauma that the affected person is not yet ready to deal with. In addition, denial is used to 'buy time' needed to find inner strength as well as the information and support needed to deal with the problem or impairment. Denial usually ceases once the person has attained the inner strength and external support to be able to deal with the trauma.

- Bargaining

Bargaining is characterised by 'fantasy thinking' whereby the affected person or family members may engage in bargaining within themselves, with God, or with their clinician, where they make promises to be ideal parents or withhold from certain behaviours if they can expect significant improvement in the affected person's condition.

- Guilt

Guilt can manifest in a number of ways. It can present where an individual has an actual theory about what has caused the impairment, such as a mother who contracted a disease during her pregnancy; or the belief that the impairment was a form or punishment for past misdeeds; or the belief that one gets what one deserves. Guilt is frequently linked to the belief that there is a cause of the impairment, which will cease once the person has been able to re-examine his or her existential beliefs and values.

- Depression

Depression is a normal and necessary part of the grieving process and allows individuals to separate from the dreams they have generated for a loved person. Common conceptions among those who are depressed are feelings of incompetence, and incapability since they are unable to influence an aspect so close and meaningful to them which they desperately want to alter.

- Anger

Anger is an integral part of grieving, and may be displaced onto the child with a disability, the spouse, siblings, other children or professionals. In some instances, anger may be translated into a 'death wish' where a parent or caregiver may fantasise about killing the child so that the situation will be over and everyone can get on with their lives.

- Anxiety

Anxiety is a commonly experienced emotion among parents upon receiving the diagnosis of disability. Anxiety may result from new responsibilities placed on them by the presence of the disabled child. The experience of anxiety may remain for many years and may resurface at different points in a person's life. The experience of anxiety is usually related to balancing the responsibility of welfare for the affected individual and maintaining an independent life of one's own.

- Acceptance and Coping

People move through the stages of grieving at different rates and the resurfacing of feelings and emotions associated with loss and grieving may occur at different times for different families.

While Lewis and Rosenblum (1974) state that the above-mentioned reactions to loss are applicable across a broad range of disabilities and illnesses and are believed to be cross-cultural, few studies have been done with the South African population to validate this. The literature reveals a lack of consensus with regard to the nature of grieving amongst non-westernised people. Spiegel and Moore (2004) claim that talking about death, dying, and the process of coping with loss still remain taboo subjects in many cultures, while

Eisenbruch (2004) reports that while people may react in similar ways in response to loss, cultural practices dictate how a person deals with or exhibits their grief. This has implications for the identification of persons in need of professional help and for counseling practices. However, the literature indicates agreement that bereavement is an inevitable part of life (Spiegel and Moore, 2004; Eisenbruch, 2004; Goldstein, 2004; and Palgi and Abramovitch, 1984). The authors report that people cope, or fail to cope, in culturally diverse ways. Thus, bereavement counseling is one of the hardest tasks for healthcare professionals to deal with, especially in cross-cultural encounters.

Based on the above, it is vital that parents have access to appropriate community resources and that effective methods of communication are employed among professionals and families for the amelioration of perceptions which may cause stress in families caring for a disabled child.

2.2.1 Experience of caring for a child with a disability

Many chronic conditions are surrounded by uncertainty. This uncertainty may begin at the time when an individual notices that something is wrong and may continue throughout the course of the condition. Many chronic conditions have a slow and insidious onset, first emerging in the form of vague symptoms, and diagnosis may only be made years later. During this time, the affected person may consult with healthcare professionals but often find that their complaints are dismissed as trivial or evidence of hypochondria (Kendall and Buys, 1998). Stanton (2002) reports that many parents felt that their reactions to being told that their child had a disability were influenced by the negative attitudes of healthcare professionals. Parents are usually overwhelmed at the prospect of providing special care for a child who is physically handicapped. They often feel at a loss in terms of how to cope and find that their immediate family and friends do not fully understand the problems and difficulties involved with raising a disabled child (Stanton, 2002).

In addition to the emotional aspects, the challenge of caring for a disabled child requires considerable resources including time and money. Studies have shown that caring for a child with a disability requires more time from the caregiver than when caring for an able-bodied child (Starmuch and Mortimer, 1982; Gowen, Johsnon-Martin, Goldman, and Appelbaum, 1989; and Kendall and Buys, 1998), and costs of medical treatment have been estimated to be 2.5 to 20 times higher than the average costs of caring for non-disabled children (Ireys, Anderson, Shaffer, and Neff, 1993). Potterton (1996) found that many parents of children with cerebral palsy in Giyani, South Africa, expressed regret that the traditional extended family was breaking down as they felt that this would have provided them with more support. This is significant particularly in the light of HIV/AIDS infection where a significant breakdown in the nuclear family and the traditional extended family has been noticed.

Ingstad (1999) points out that when families are unable to cope with the care of a disabled relative, it is usually the result of poverty and a lack of knowledge about what can be done to improve the situation, rather than the result of a lack of love or negative attitudes. This concurs with Kilonzo's (2004) findings which showed that most caregivers displayed a lack of understanding of the permanence of their child's condition. Another study done by Rumano (1994) in Zimbabwe found that lack of understanding and negative attitudes within the community coupled with the other roles that the family member has besides caring for the disabled person as being barriers to effective caregiving. This is common in South Africa where many people still hold the belief that if a child is born disabled it means that his/her mother did something 'evil' during her pregnancy (Potterton, 1996).

Kilonzo (2004) found that caregivers in his study felt stressed, overburdened and isolated by their roles. They often neglected their own needs, which impacted negatively on their physical and mental health. According to Schwarz and Roberts (2000) as cited in Kilonzo (2004) social support minimizes the adverse consequences of stressful situations and thus may contribute to helping the caregivers to cope with their roles. These findings concur with Thejane (1999) who found that lack of emotional and social support within the

community for families of children with disabilities were significant barriers to effective rehabilitation.

Wright (1988) found that the consequence of disability is not the reduction of a person's physical or mental capabilities, but rather the environmental and social system that are barriers to effective rehabilitation and integration of the individual into society. Both public policy and legislation can be significant barriers or enablers to the caregivers of disabled persons. Thus, while coping may prove to be a liberating experience, it may at the same time prove to be stressful. Therefore, a need can be identified for supporting and boosting caregivers coping efforts and this should be a major objective when planning for professional support. At this point it is vital to mention that in the planning and provision of such services, cognizance must be taken of the caregivers' cultural values and beliefs if they are to obtain maximum benefit from the support.

2.2.2 Effect of disability on the family

Chronic conditions can place a great deal of strain on the family due to the need for high levels of physical care and support, the emotional connotations of giving and receiving help, and changes in family roles and relationships. Typically, when people decide to have a child, there is great joy at the impending life they are bringing into the world (Ross and Deverell, 2004). That elation and hope for the future can come to a crashing halt when a baby is born with a disability. For many, this may be overwhelming and sorrow and grief begin to set in as the reality of lost hopes and dreams becomes apparent (Dickman and Gordan, 1985). In addition to the emotional problems that the parents have to deal with, they also have to cope with the attitudes of grandparents, relatives and friends. It is vital that the parents have access to appropriate information as well-meaning friends and relatives are likely to try and provide recommendations and reassurance, which may be inappropriate or incorrect. Often parents of newborns with disabilities are advised to institutionalise their baby or risk social exclusion and marital distress (McConachie, 1997). Parents may be concerned about social acceptance, and what the neighbours may think, while family members may claim that if the condition is

hereditary, the affected gene was not on their side of the family (Seltzer et al., 2001). A study involving caregivers of children with Down's Syndrome revealed that as many as 95% of the participants reported that the most hurtful aspect of raising a child with Down's Syndrome was that neighbours and friends would not allow their children to play with the child with Down's Syndrome, thus causing social isolation for the child (Vaccarino, 1996).

Due to the strong social stigma attached to physical and mental impairment, in many instances, the family may become isolated from their communities, and in these instances it is not uncommon for marital breakdown to occur (McConachie, 1997). Luterman (1984) reports that from the time a diagnosis is made, the father tends to receive most of the information about his child from the mother, and as a result, gradually begins to retreat into a secondary role because he feels less expert than his wife. Although he may be experiencing intense feelings of sorrow and failure, he may try to hide behind the façade of the male pillar of strength and provider. Whereas the father can retreat into this role, the mother is compelled to assume immediate responsibility of day-to-day care for the child. The gradual withdrawal of the father may evoke anger and resentment in the mother. Furthermore, the dependency of the child on the mother and the gradual restrictions on her activities can adversely affect the development of healthy family relationships. Inability to share their grief and disappointment can make parents become emotionally distant from one another. The father who finds his own needs unmet may direct his anger and resentment at his wife or the disabled child (Luterman, 1984). However, it must be acknowledged that this is a westernised view, and may not necessarily apply to all populations, particularly those in rural communities.

Caring for a child with a disability is time consuming, and this may place stress on the family. Siblings may react in a number of ways, including feelings of love, empathy, guilt, anger, support, resentment, and embarrassment. Burke (2004) describes the phenomenon of 'disability by association' where the experience of living with a sibling with a disability results in the other siblings being excluded from mainstream activities.

In addition to the child's disability affecting the immediate family, it also affects the grandparents. When a child's disability is first diagnosed, one of the main concerns is how the parents will convey this news to the grandparents and how this news will affect the parents' relationship with them (Hartman and Laird, 1987). According to Meadow (1980) extended family members may interact with the disabled child in two different ways. On the one hand, the disappointment and grief of the grandparents, especially if this is the first grandchild may add to the parents' feelings of guilt and despair. On the other hand, grandparents may provide additional support, both on an emotional and a physical level.

Whether relationships between the child with the disability, the parents, siblings, grandparents and extended family members are positive or negative depends on factors such as lifestyle, child-rearing practices, the type and severity of the disability, coping mechanisms utilised by the family, as well as the type and quality of support services available within the community (Burke, 2004).

2.2.3 Effects of gender on caregiving

Modern society is stratified in terms of social class and gender. These differences are entrenched in societal beliefs and standards, and as a result one's health cannot be considered immune to these differences. For this reason it is important that we examine discrepancies related to gender and caregiving in order to further our understanding of factors influencing cause and treatment of illness and disability. McLeod (1994) maintains that in Africa, many women are not only exploited at the level of production or labour, but also at the reproductive level in terms of making decisions regarding child-bearing and rearing. While such oppression of women may be exercised by individual men, the context in which this occurs is in a culture that is male dominant. These cultural attitudes can affect the degree of participation in health seeking behaviours and healthcare programmes. A factor which may further complicate the issue of gender is the belief that gender is not isolated from other influences, such as age, race and culture (Miller and Cafasso, 1992). In South Africa, women are cited as an 'at risk' group

(White Paper on an Integrated Disability Strategy, 1997) who are vulnerable and require additional support from both government and community establishments, while researchers and policy makers have increasingly cited gender-based violence and gender inequality as determinants of women's HIV risk (Dunkel et al. 2004).

Navaie-Waliser, Spriggs and Feldman (2002) report that the most consistent finding in caregiving research is that the majority of family caregivers are women. This dominance of women and the tendency to describe the caregiver role in terms of personal care activities highlights the societal image of caregiving as a largely feminine endeavour. Yet the extent to which women and men differ in their enactment of the caregiver role remains of high interest (Wallstein, 2000). Gender differences are believed to influence the amount and type of care provided, access to social resources that may alleviate caregiver stress, and appraisal of the caregiving experience (Navaie-Waliser, Spriggs and Feldman (2002). Miller and Cafasso (1992) reviewed the literature on gender and caregiving over the period 1980-1990. Their explanation of the bulk of caregiving being attributed to females was ascribed to theories of household labour, stress and coping frameworks, views of moral development, gender role expectations, adult development perspectives, networking attributes, and different opportunity costs for male and female caregivers. A study conducted by Saloviita, Italinna, and Leinonen (2003) revealed that mothers experienced burdens related to caring for a disabled child in terms of the child's behavioural difficulties, while fathers experienced burdens linked to social acceptance.

The stress/coping paradigm, as discussed by Dentinger and Clarkberg (2002) suggests that differences in levels of stress, psychosocial and environmental resources, as well as personal dispositions influence the outcomes of stressful situations. Thus, situation specific role demands, support resources, and personal dispositions influence the enactment of the caregiving role and the appraisal of caregiver distress. This suggests that the stress process is conditioned by attributes such as gender, age, and race, which in turn is associated with differential exposure to structural barriers and opportunities. Jewkes (2001) adds that poverty increases the risk for partner abuse through effects on conflict, women's power, and male identity. Violence is used as a strategy in conflict to resolve a

crisis of male identity, at times caused by poverty or an inability to control women. Additionally it is highlighted that women who are more empowered educationally, economically, and socially are most protected.

Additionally, the nature of gender influence on caregiving activities is influenced by gender-role socialisation (Wallstein, 2000), which involves aspects of sensitivity to relationships, nurturing behaviours, illness behaviours, and coping styles; as well as situational demands (Navaie-Waliser, Spriggs and Feldman 2002).

The above serves to suggest that certain concepts and variables explain why caregiving is predominantly a female-oriented activity. Although these perspectives are not mutually exclusive, they differ in their emphasis on the caregivers' previous socialisation and gender-linked personality traits versus behavioural responses to the caregiving situation. Thus stereotypical gender differences in the provision of caregiving tasks and expressions of burden may suggest areas in which residual elements of gender role socialisation influence caregivers' responses to caregiving.

2.2.4 Role of religion in caring for a child with a disability

A number of studies have examined the role of spirituality for patients with chronic diseases (Kendall, 1994; Fulton and Moore, 1995; Johnson and Spilka, 1991) and have found an increased reliance on spirituality as a coping mechanism. Crnic, Friedrich and Greenberg (1993) found that one's religious background and beliefs are significantly related to greater acceptance, positive adaptation, less stress and better coping strategies for caring for a disabled child. This has lead to the belief that spirituality may be an underused resource in the rehabilitation process (Underwood-Gordon, 1995). Also recognized is a need in the general area of disability literature for a conception of self, not based on the traditional medical view, but on a broader more holistic view that encompasses the self, spirit and society (Byrd, 1997; Fitzgerald, 1997).

Pfeiffer (2003) found that disability and spirituality are inter-related. Peck (1979) proposed that although people may perceive themselves as lacking in religion, everyone has explicit or implicit beliefs concerning how the world works. Whether people envisage a chaotic world devoid of a higher being in which events occur randomly, or a nurturing world guided by a higher power in which positive forces triumph, they develop a world view that colours their interpretation of life events.

The above is important in terms of reviewing the success of current therapy models. Boswell, Hamer and Knight (2001) thus recommend that recognition of a client's spirituality is taken into account in order to promote the rehabilitation process.

2.2.5 Conclusion

Disabling conditions pose a threat to the identity and self-concept of both the person with the condition, and the family members. One of the reasons for this is that the onset of a disabling condition necessitates a fundamental rethinking of the self-concept. According to Williams (1984) persons affected by disabling conditions must go through a process of 'narrative reconstruction' in which the individual's life story, morals, values and beliefs are reorganised in order to account for the onset of the illness. This identification of cause is part of the process of coming to terms with the condition, and finding an answer to the question "Why me?" In turn, this gives meaning and order to the individual's world. Williams (1984) adds that many people affected by disabling conditions are involved in a constant struggle to lead valued lives and maintain definitions of self that are positive. This balance can be difficult to achieve since cultural definitions of disability often tend to devalue the individual and interactions with others may constantly undermine his or her sense of self-worth. This loss of self-worth can result in a disabling condition for those affected by disability. However, much of the literature on the experience of caring for a child with a disability has been written in first world countries and thus the experience of caregivers living in rural South Africa may be very different. There is a need for culturally and contextually specific research to be carried out in order to develop and implement appropriate and effective intervention programmes.

2.3 CONTEXT, CULTURE AND DISABILITY

According to Draguns (1989) culture can be defined as pervasive social variables that determine what types of behaviour are acceptable and what is normal in a given society, including the beliefs, values, and knowledge held by a particular sector of society.

Concomitant with the established links between social class and health, as well as between gender and health is the realisation that many illnesses in modern society can be cured and in many instances both illness and disability can be prevented. Thus western society is characterised by widespread dissemination of information. This is possible mainly through the development of technology as much information is made available through print and television.

However, health promotion and disease prevention rely on people's levels of education, attitudes and behaviours, and the dissemination of information is only meaningful if it targets the underlying beliefs and attitudes which govern society's help-seeking and health-related behaviours.

This section will review attitudes towards health and disability in South Africa, as well as health and the current status of healthcare provision in South Africa. Finally it will provide an historical, social and geographical description of Tonga, and thus place this study in context.

2.3.1 Disability and healthcare as a sociological construct

Singer and Baer (1995) note that the medical system is a reflection of class, racial and ethnic relations, and gender relations in the larger society, and constitutes an arena of

struggle among those social divisions. It is further noted that whole worlds come together in a clinical encounter, and inevitably through the doctor-patient encounter and the expression given to underlying contradictions, medicine is established both as an arena of social conflict and as a structure of social control. This concept is expanded on by Taussig (1987) by pointing out that through the western bio-medical model of healthcare, the clinician-patient relationship is limited by the parameters of diagnosis and treatment, and behind this screen lies a social relationship of control that supports the dominant order. This gives rise to a false illusion of reciprocity in the clinician-patient relationship and the patient receives the message: "*Do not trust your senses, but leave the facts of physical matter to the doctor's control"* (Taussig, 1987, p.87). In this way the patient becomes both the subject and object and the term 'healthcare provider' comes to mean one who has the power to give health, thus disempowering the patient from making his or her own decisions and taking responsibility for their health-related uncertainties.

The relationship between poverty and disempowerment is a complex concept (White Paper on an Integrated National Disability Strategy, 1997). However, it is only when looking at the high levels of disempowerment found among people with disabilities that one is able to better understand the relationship between poverty, disability and exclusion (Disability Support Project, Lowveld Region of Mpumulanga, 2000).

People with disabilities are exposed to significant barriers in becoming economically independent. This is related both to fears, myths and stereotypes related to the inabilities of people with disabilities, as well as a lack of access to basic facilities, such as healthcare, education and transport. As a result, disabled entrepreneurs and local organizations are at a disadvantage due to their low skills and education levels and the fact that they are often not as mobile as their able-bodied counterparts (Disability Support Project, 2000). Many development functionaries do not realize the need for systematic efforts to prepare disabled persons adequately for participation in skills development and other poverty alleviation programmes. The inclusion of social and economic rights into the South African constitution reflects the understanding that dignity, freedom and equality are not just about the absence of civil and political violations, but that the

transformation of current society into one in which there will be human dignity, freedom and equality, lies at the heart of our new constitutional order (South African Constitution, p.6-25). The challenge therefore facing therapists in the healthcare sector in South Africa is to transform the human, economic and social rights in the constitution into tools of empowerment and mobilization in the hands of the poor living in the rural areas of our country.

2.3.2 Disability in post-apartheid South Africa

Many national policies have changed and new ones have been implemented in South Africa since the 1994 elections. For many South African citizens, the 1994 elections symbolized the end of the apartheid regime and the end of an era of marginalization. Today much emphasis is placed on establishing a culture of rights, and new healthcare policies are being promoted through the media and legislature. In addition, access to basic healthcare and social support is now a right of all South African citizens and many of the new healthcare policies promote the role of the community in service provision and resource promotion. As a result the term 'community' is now a politically recognized term.

The South African healthcare system has historically taken on a medical approach. While new policies are based on the social model of intervention, this approach is not always evident in practice. Young (1982) discusses how many medical practices develop and persist because they are useful - not for the consumers of the service - but for other people and for reasons unconnected with curing and healing. In addition, Taussig (1987) points out that social restrictions are intimately related. Thus healthcare sciences can be used for political goals in a large number of interconnected ways. Taussig (1987) adds that healthcare often takes the political edge off the social problems that the system as a whole produces, without necessitating deep changes in the system itself.

It has been found that the racial categorization of problems related to health is deeply entrenched in the societal and professional consciousness and in the discourse of healthcare professionals (Abrums, 2000). This is problematic where healthcare

professionals and researchers are taught by other professionals who utilize the traditional medical approach to disability, and the focus of their teaching material is related to statistical information, combined with their own clinical experiences, personal histories, fears and stereotypes. This in turn impacts on their teaching and caregiving activities and the clinical judgments they make and hand down to their students (Abrums, 2000)

2.3.3 HIV as a complicating factor in South Africa

The extent of the HIV pandemic in South Africa is now common knowledge. According to Rehle and Shisana (2003), South Africa is recorded to have the largest number of persons living with HIV/AIDS in the world. Estimates obtained from pregnant women who attend antenatal clinics in the public sector indicate that the HIV/AIDS epidemic has been increasing rapidly since 1991, particularly among those aged 20-24 years and 25-29 years, while it has been indicated that sub-Saharan Africa accounts for 70% of global HIV infection and that there are approximately 1800 new infections occurring daily in South Africa (Rehle and Shisana, 2003). In 2004 it was estimated that five million people became infected with HIV, of which 800 000 were children. Of these five million infections, 3.5million were in sub-Saharan Africa, bringing the total number of people infected with HIV to approximately 28.5 million, and it is estimated that there are currently 11 million children orphaned by HIV in this region (UNAIDS, 2005).

The Nelson Mandela/HSRC study of HIV/AIDS (2002) selected a general sample of people from each geographical, racial and social group. Results indicated that HIV is generalized in the South African population leaving no race, sex, age, province or locality unaffected. Based on the results of this study it is estimated that approximately 11.4% of the South African population over the age of 2 years is infected with HIV, with prevalence highest in Africans (12.9%), followed by whites (6.2%), Coloureds (6.1%), and Indians (1.6%). Females had a prevalence of 12.8% while males had a prevalence of 9.5%. HIV prevalence among adults aged 15-49 years was 15.6% with 17.7% of women and 12.8% of men in this age group. Among Africans aged 15-49 years a prevalence of 18.4% was found. The epidemic was highest in people living in urban informal

settlements (21.3%) compared to those living in urban formal settlements (12.1%) and those living in rural settlements (8.7%).

Based on a sample of more than 16 000 women attending antenatal clinics across South Africa in 2003, it was estimated that 27.9% of pregnant women were HIV positive (Department of Health HIV and Syphilis Sero-Prevalence Study, 2003). The highest prevalence rate is estimated to be between the ages of 25–29 years. Based on this antenatal data, the study estimates that at the end of 2003, 5.6 million South Africans were HIV positive, of whom 55% were female. According to the figures obtained in the study approximately 22.8% of all South African citizens were HIV positive, with Mpumulanga having an HIV prevalence rate of 30.8% (Department of Health HIV and Syphilis Sero-Prevalence Study, 2003).

Mhalu (2000) describes the major facilitators of HIV transmission in sub-Saharan Africa. These include:

- The ignorance of the population
- Poverty and poor healthcare
- Social, demographic and cultural conditions that result in the predominance of one gender, e.g. the military, migrant labour and truck drivers. In such situations some males share sexual favours of a limited number of available women.
- The high prevalence of sexually transmitted diseases and tuberculosis which increase the rate of transmission and replication rate of the virus
- The biological necessity of heterosexual intercourse for procreation
- Lack of education and open discussion among the youth as a result of the mystification of sexuality.

Allowed to spread in this rampant fashion, HIV/AIDS weakens the capacity of households, communities, institutions and nations to cope with the social and economic effects of the epidemic. This cycle is dynamic and vicious. Choices and opportunities, the hallmarks of successful human development (WHO, 2005) shrink as the epidemic gains a foothold in an environment of inequality and exclusion. Negative development and

HIV/AIDS lock into a dynamic relationship whereby one feeds on the other. Typically it is the poor who are edged further towards the margins of exclusion, and as HIV prevalence levels rise, poverty deepens. A complex interplay occurs between such negative development and the spread of HIV/AIDS. The epidemic flourishes, particularly among communities that are deprived of the elementary benefits of successful development, such as education, healthcare, and employment (World Summit on Sustainable Development, 2002).

According to Kalipeni (2000), although urban areas lead in terms of rate of infection, the disease is spreading rapidly in the rural areas propelled by rural-urban linkages, and the disadvantaged position of rural areas in terms of knowledge about the disease. The pace of the anti-retroviral therapy (ART) programme rollout in South Africa has been criticized by many for the length of time it took to begin providing treatment to those who need it (Stein, Lewin and Fairall, 2007). In addition to withholding medication from those who need it, Schiller (1992) raises the concern that testing for HIV without providing treatment and the construction of HIV/AIDS risk groups has compounded the AIDS crisis in the following ways:

- It has lead to misunderstandings about who is at risk and who is not, resulting in an increased spread of the disease.
- It has lead to stigmatization and marginalization of people with HIV.
- By concentrating on the disease itself without noting that the disease is proliferating under the conditions of unemployment and poverty, the government has failed to identify factors contributing to the spread of HIV.

Extrapolating from the above, sexism, racism and other oppressions have created forces on people's beliefs about the risks of HIV and AIDS and on their perceived power to address risks that in reality are enmeshed in social, cultural and economic problems. This is in turn related to disability in that disabled persons and their families are marginalized groups. South Africa is faced with a growing number of children who are HIV positive, and it is estimated that by 2010 10% of the population will be orphans (WHO, 2005). Currently South Africa is estimated to have 660 000 HIV orphans (WHO, 2005), while

many children live in households with sick and dying family members and thus suffer the effects of AIDS (UNAIDS, 2004). At present, data does not exist on the number of children with cerebral palsy who are HIV positive (Levin, 2005), but given the dynamics of the disease and the rapid spread of the disease in South Africa, these numbers are presumed to be high.

2.3.4 Traditional healing and disability in South Africa

Within any given society there are numerous groups or individuals who can offer ways of explaining, diagnosing and treating ill health (Gilbert, Selikow, and Walker, 2002). Reis (1992) points out that causality beliefs determine the way in which both lay and professional people explain, treat and handle disability and consequently how their explanatory models and illness beliefs develop.

Within traditional medicine, the primary concern is why a disability has been caused, while in modern medicine, the primary concern is how the disability has been caused (Mweshi and Mpofu, 2001). According to Foster and Anderson (1978) in traditional communities, a naturalistic cause of disability is explained in impersonal systemic terms. This implies that disability may be caused by purposeful interventions of an agent, who may be a supernatural being such as a ghost, ancestor or evil spirit; or a human being, such as a jealous neighbour, a witch or sorcerer. However, Reis (1992) heeds that causality belief is not a static thought system, but a dynamic process that reflects changes in society. In terms of traditional medicine, the concepts of illness and disease are different, where 'illness' refers '*to the patient's subjective interpretation of sickness in line with their health belief system'*, while 'disease' refers to '*the physiological or psychological process malfunctioning of the body which manifests in specific symptoms as recognized by the medical profession'* (Herselman, 2007, p.62). Therefore when a patient consults with a medical professional, van Deventer (2007) states that part of the consultation should be aimed at understanding the 'illness' as opposed to the 'disease', and this is strongly influenced by the patient's world view. Van Deventer (2007) points out that where there are unexplored and unacknowledged differences between the models

held by healthcare practitioners and patients, there is frequently more patient dissatisfaction and poorer outcomes.

Identifying the cause of an illness may be an initial step in a coping strategy. According to Herselman (2007) in African cultures causation may be natural or supernatural. Within natural causation, it is believed that certain conditions, such as aging or common influenza are a process of cause and effect or may be influenced by chance. Supernatural causation includes belief in ancestor spirits or witchcraft and sorcery. Therefore misfortune can be ascribed to a consequence of neglected duties owing to the ancestors where sickness becomes a symbolic form of communication; or malicious activities of someone in the community reflecting tensions resulting from competition over scarce resources (Ashworth, 2005; and Herselman, 2007). These beliefs shape the patient's behaviours and attitudes and therefore a comprehensive understanding of the patient's worldview is necessary in order to holistically assess and manage a medical condition.

A review of the literature reveals that approximately 80% of the South African population seeks the services of traditional healers for various signs and symptoms of disease and illness (Ross and Deverell, 2004; Lambat, 2004; and Struthers, 2002). Various studies conducted among a variety of South African populations have indicated that disability is frequently attributed to evil spirits, disharmony among the ancestors, or spells cast on the mother of the disabled child (Lambat, 2004; Ross and Dagher, 2003; Foster and Anderson, 1978). It has also been found that many African people consult with traditional and western medical professionals concurrently, in hope that traditional healers will attempt to restore spiritual harmony, while western healthcare professionals will address the physical symptoms (Struthers, 2002). Although the South African government has made attempts at bridging the gap between traditional and western healthcare professionals, at this point there exists very little communication and co-operation between the two schools of thought (Levin, 2005).

2.3.5 The complex relationship between poverty and disability

South Africa is an upper-middle income country, but is also a country of stark contrasts (Woodlard, 2002). The extreme inequality evident in South Africa means that one sees destitution, hunger and over-crowding side by side with affluence. In a report prepared by Woolard (2002), she reports the following:

South Africa has a per capita GNP of USD 3690 p.a. (in 1998 dollars), yet:

- 15% of adults are illiterate
- 9.2% of children under five years are malnourished
- Life expectancy fell from 62 years in 1990 to 48 years in 1999 as a consequence of HIV/AIDS
- Infant mortality rate is 45 per 1000 live births
- Maternal mortality rate is 230 per 100 000 live births
- Of the 44 million people living in the country in 2000, approximately 8 million were surviving on less than the international dollar a day poverty line, and 18 million were surviving on less than 2 dollars per day
- 37% of households survived on less than R1000 per month in 2002
- 60% of the poor do not receive social grants
- Health expenditure is 7% of the GNP but less than half of this is public spending

Today South Africa is an emerging market with an abundant supply of natural resources and well-developed sectors, including financial, legal and communication (Saunders, 2001). Although South Africa is one of the richest and economically most important countries on the African continent, its socio-political history has resulted in marked

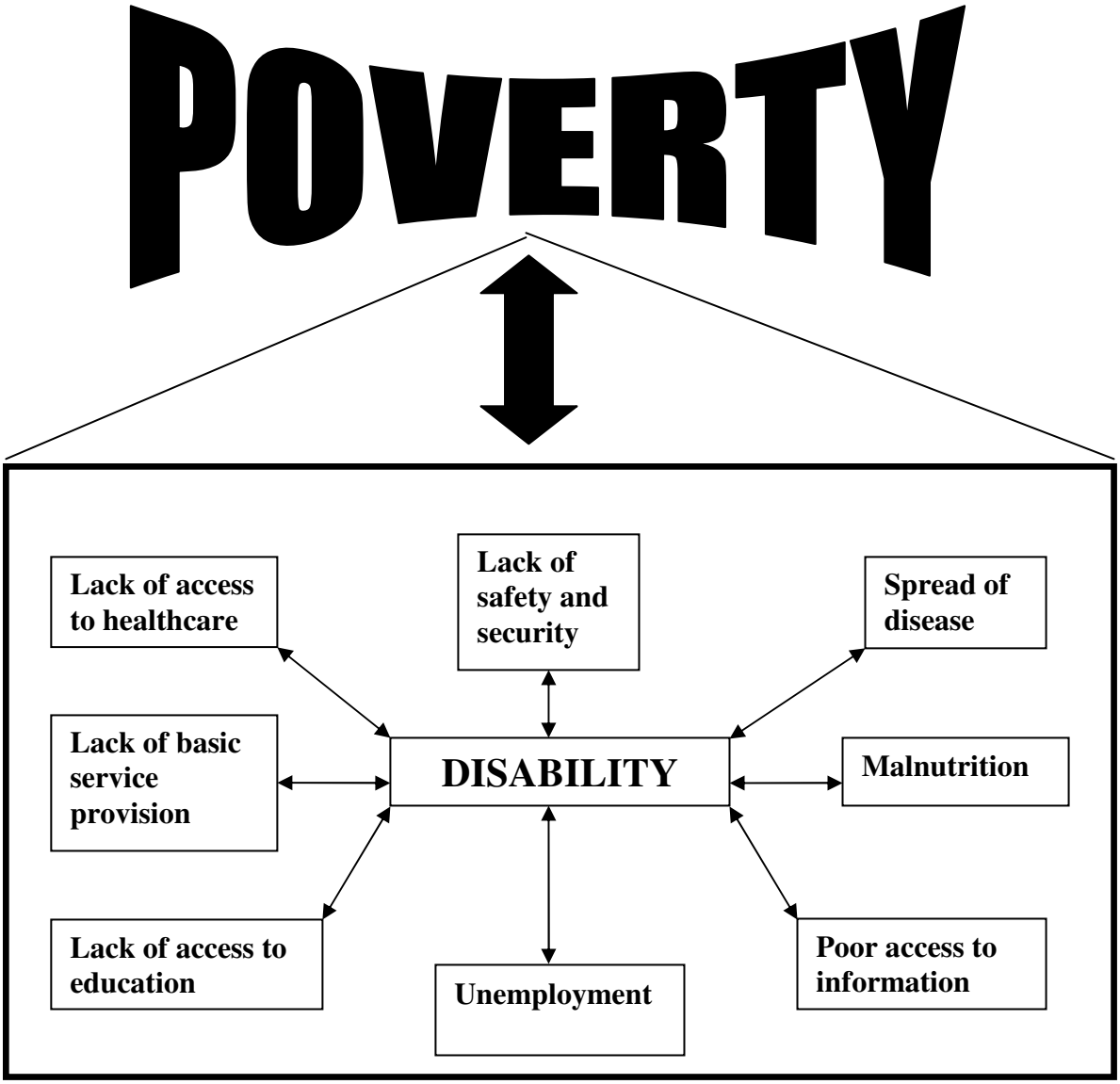
disparities, particularly in the areas of healthcare and education (Levin, 2004). As a result, South Africa is plagued, particularly in rural areas with high birth rates, low levels of literacy, high rates of unemployment, and largely uncontrolled spread of disease and disability. Anderson and Phohole (2003) report a strong relationship between disability and socio-economic status, while Hutcherson (1991) noted a correlation between poverty, educational level, nutrition, and the prevalence of disability. In addition, it is reported that children in poor families are at risk of acquiring chronic health problems and disabilities, and caring for these children can impose substantial costs to their families. Globally it is reported that there are about 140 million disabled children of whom 97% are found in poor countries where rehabilitation services are either lacking or inadequate (Hurst, 1997). Furthermore, Hurst (1997) found that of the total number of disabled children globally, approximately 98% of them lack education and 90% will not survive beyond five years. This has huge implications for healthcare workers working in the field of child health, both from a research and a practical point of view.

Helander (1984) reports that in developing countries people with disabilities are largely without access to or knowledge of the most basic health and social services. In South Africa, as a result of the structure of health and rehabilitation services under the apartheid regime, there has been a lack of implementation of primary healthcare service provision and an inequitable provision of services in terms of accessibility, appropriateness and funding, particularly across the variables of race, class, gender and level of urbanisation (Kwa-Zulu Natal Department of Health, 1997).

According to Young (2004), socio-economic variables which contribute to disease exposure and healthcare access place children at risk for cerebral palsy in South Africa, while poverty plays a pivotal role in predisposing neonates to conditions which may result in cerebral palsy (Levin, 2005). Mothers, particularly in rural areas, often do not have access to prenatal care, are exposed to the spread of infectious diseases, such as TB, and do not take in sufficient nutrition (Young, 2004). In many poor communities in South Africa, mothers do not have access to running water, live in unsanitary conditions and experience high levels of stress related to poverty (Bhorat, Poswell, and Naidoo, 2006).

Furthermore, health literacy is poor (Nutbeam, 2000) because most mothers, particularly in rural areas have received limited, if any education and therefore do not have access to, or the ability to interpret and use information for healthcare.

Model 1 below provides a visual description of the pervasive nature of poverty. It describes how limited access to basic service provision, healthcare, safety and security, information and education; as well as the spread of disease; malnutrition; overcrowding and unsanitary living conditions; and unemployment reciprocally contribute to disability, and how all of these factors are over-ridden by poverty.



Model 1: Diagram depicting the pervasive nature of poverty

Based on model 1 above, it is evident that while poverty pervades all aspects of life for persons affected by disability, it also creates a vicious cycle whereby disability renders people vulnerable to the effects of poverty, while at the same time poverty renders people vulnerable to disability. Additionally, a reciprocal relationship exists whereby having a disability predisposes a person to lack of access to healthcare, education, information; unemployment; malnutrition; spread of disease; lack of basic service provision; and poor provision of safety and security. Yet, by not having access to these basic rights creates a bias in terms of developing a disability or having a child with a disability. This is explained in sections 2.1.2 and 2.1.3 which addresses the causes of cerebral palsy both internationally and in South Africa.

The Disabled People of South Africa have identified the key forms of exclusion responsible for the cumulative disadvantage of persons with disabilities as being poverty, unemployment and social isolation (DPSA Annual report, 2005). This is consistent with both national and international literature (Anderson and Phohole, 2003; Bhorat, Poswell, and Naidoo, 2006; Cooper, 2002; Dowdall, 1991; Helander, 1984; and Kalipeni, 2000), which recognises poverty as an overriding factor that cuts across all the disciplines within the realm of social science. Despite the presence of diverse literature, poverty remains a difficult concept to define. Central to the complexity of this definition is the fact that poverty is a sensitive issue because of its political nature. Defining poverty involves examining social conditions and inequalities within a given society. In the process, the examination classifies populations within a society and either implicitly or explicitly explains the distribution of power over wealth. However, this kind of research is becoming increasingly necessary as understanding poverty at a national level is essential for raising awareness and concern about national development (Bhagwangee and Stewart, 1999).

The United Nations Development Programme (UNDP, 1998) states that a key indicator in poverty is the degree to which people are excluded from accessing basic goods and

services. Poor people do not have sufficient income to purchase goods. In addition, they live in under-developed areas where there is a lack of sanitation, water, electricity, health services, job opportunities, and education and recreational facilities. Furthermore, poor people face a greater risk of disability (Anderson and Phohole, 2003). The birth of a disabled child or the occurrence of disability within a family often places heavy demands on family morale, thrusting it deeper into poverty. This means that there is a higher proportion of disabled people among the very poor, but also that there is an increase in families living in poverty as a result of disability (White Paper on an Integrated National Disability Strategy, 1997).

Poverty levels among people with disabilities in South Africa are high. Data collected as part of the Mpumulanga Province Community Based Rehabilitation (CBR) Disability Support Project in the Lowveld district of Mpumulanga province between August 1999 and July 2000 among 907 predominantly rural African households with disabled family members revealed the following:

- 38% of families have no regular monthly cash income
- 49% of families rely on R530 or less income per month
- 11% of families have a regular monthly income of between R531 and R1199
- 2% of families have a regular monthly income of between R1200 and R1999
- None of the 907 families had a monthly income exceeding R3000
- 82% of disabled school-age children do not attend school

The disparity in poverty levels between people with disabilities and the general population has been attributed to the following factors (Disability Support Programme, 2000):

- Uncoordinated implementation of poverty alleviation programmes

- Failure of poverty alleviation programmes to specifically identify disabled persons as a target group, resulting in local or partial exclusion of persons with disabilities.

As a means to try and curb the poverty experienced by marginalized communities, social welfare grants are available to South African citizens, including child support grants, care dependency grants, disability grants and old-age pensions. It has been found that people who receive social security benefits in South Africa tend to be totally dependent on them for their survival (White Paper on an Integrated National Disability Strategy, 1997), while the majority of people with disabilities receive no grant at all (Ka Toni, 2003; and Woolard, 2002). This, compounded by the fact that 99% of disabled people are excluded from employment on the open labour market (Ka Toni, 2003), for various reasons, ranging from inadequate education, to inaccessible transport, to generally high levels of poverty nationwide, to name but a few, continues to reinforce the cycle of disability and poverty.

In rural areas, one of the biggest barriers to accessing quality healthcare is poverty. The relationship between disability and poverty is complex and multifaceted. Being born with a disability increases the chances that one will be poor because of the unfair discrimination that those with disabilities encounter (Ka Toni, 2003). It has already been ascertained that the majority of the world's disabled population come from developing countries, and this exacerbates most disabled persons' efforts to free themselves from poverty. Additionally, where people with disabilities have been explicitly targeted for poverty alleviation, they still face tremendous difficulties in being recognized as a group with entitlements, and a group whose needs should be addressed on their terms and not on the terms dictated by others (Disability Support Programme, 2000).

2.3.6 Tonga: A historical, social and cultural geography

Tonga, the geographic location of this study, falls within the Nkomazi Municipality in Mpumulanga province. Nkomazi forms the eastern section of the Lowveld area and is

located approximately 350km east of Gauteng, consisting of a wedge of land between the Kruger National Park in the north, Mozambique in the East, Swaziland in the South, and the Mbombela and Umjindi Municipalities on the west. Nkomazi is made up of two areas with vastly different characteristics in terms of economic and social development. The study area of Tonga falls into the Kangwane region in the south, and has a typical rural under-developed character where tribulations associated with poverty, massive unemployment and general lack of development exist (Nkomazi IDP, 2003). Tonga is situated approximately 30km northwest of the Mananga border post into Swaziland and approximately 40km west of the Mozambiquan border. The closest towns are Malelane, which lies approximately 45km northwest of Tonga, and Komatipoort, which lies approximately 60km northeast of Tonga. Tonga has been described in the Nkomazi Spatial Development Framework (2003) as one of the poverty pockets of South Africa. Approximately 350 000 people live in approximately 45 dysfunctional, informal settlements. The majority of these 350 000 people are black SiSwati speaking residents.

According to the Nkomazi Spatial Development Framework (2003) the last national election reflected that almost 90% of the adult population's political persuasion is to the African National Congress (ANC). There is very little land ownership as all land belongs to the State. People have informal land rights via deeds of grant, permits to occupy and plots purchased from the traditional authorities. All informal land rights are protected by law. Some settlements in the area are in the process of being formalized and these people will soon have title deed ownership of their properties. However, not all traditional authorities are receptive to the process of formalization. The process is therefore slow and much conflict is experienced. All settlements are growing at a rapid rate and in the absence of proper planning the settlements are expanding in an uncontrolled manner. Urban sprawl is rife and places stress on existing infrastructure and has the effect of sustaining the current state of underdevelopment (Nkomazi Spatial Development Framework, 2003).

Economically, Tonga has always served a dormitory function, meaning that the people commuted from the area to their place of work (Nkomazi Spatial Development

Framework, 2003). There is very little investment or economic development in the area and the inhabitants have to travel long distances for consumer goods. Businesses in other settlements are mostly represented by small general dealers, liquor stores and spaza stores. Informal small-scale industrial businesses such as car repair shops, exhaust repairs, tyre sale and fitment, and welding shops are found in all settlements. These business facilities do not sufficiently meet the needs of the consumers and it may be expected that the demand for consumer articles may increase dramatically as the economic situation of the people improves (Nkomazi Spatial Development Framework, 2003). Extensive farming development has taken place recently and many previously disadvantaged farmers have been settled on irrigated farms. However, this process is hampered by a lack of water for irrigation purposes and it has been recommended that the development of farmers should take place on farms with existing water quotas (Nkomazi Spatial Development Framework, 2003).

Social and community facilities are divided into the entities of sport, cemeteries, bus shelters, pensioner services, disabled facilities and community halls. Recreation facilities are provided in the form of two libraries (one at Langeloop and one at Kamhlushwa). No public parks exist in the settlements. Some formal sport facilities exist but they are in a state of disrepair. There are numerous informal soccer fields that are regularly used. Some sites of archeological and/or historical importance exist, the most well known of which is the Samora Machel Monument. Almost all cemeteries are informal. Bus shelters are widely unavailable or are of an insufficient standard. There are grave concerns about the conditions that pensioners have to endure on pension payout days, as there is a lack of water, sanitation, and shelter. Very little provision is made for the disabled, at both public and council buildings, community halls are available in some settlements but most of the infrastructure needs upgrading and there is a general lack of equipment and furniture (Nkomazi Spatial Development Framework, 2003). Community and social facilities are insufficient and this dramatically lowers the quality of life for the people residing in the Tonga settlement. The upgrading of social facilities is ongoing but requires immense investment to be brought up to acceptable levels.

There is a general low incidence of crime in the Nkomazi region, which is a praiseworthy achievement, considering the general poverty and unemployment in the area (Nkomazi IDP, 2003). The judicial system is insufficient and no correctional facility exists in the region, and emergency services are insufficient. There is a lack of information within the communities, which leads to frustration and distrust and hampers effective policing (Nkomazi IDP, 2003). Access to appropriate and relevant information can play a critical role in empowerment and therefore in the poverty alleviation process. Information and training materials that do exist on disability related issues are however seldom available in accessible languages to rural communities, thereby excluding the poorest group within the disability sector from championing their own development. Others tend to make decisions about the lives of people with disabilities and decide even very basic things for them, and as a result people become disempowered because of their living conditions, making them even poorer. Subsequently they become malnourished, are exposed to unhealthy living conditions and are frequently exposed to violence. This is particularly true for women and children with disabilities who frequently experience high levels of violence and abuse due to the fact that they are often confined to their homes (Disability Support Project, 2000).

Environmental degradation is taking place in alarming proportions in the Tonga area and is attributed to a number of factors, including the under-provision of municipal services, the extent of urban sprawl and unsustainable subsistence farming methods. These factors have their cause in the general state of poverty that the people find themselves in and the solution lies firstly in the careful regulation and mitigation of the unsustainable use of natural resources and secondly in the economic upliftment of the people (Nkomazi Spatial Development Framework, 2003).

Table 1 below provides a summary of the community profile for the Nkomazi region as determined by the Nkomazi Spatial Development Programme (2003):

Table 1: Community profile for Tonga

Employment	40% of the economically active population are unemployed
Income Level	73% households bring in less than R2000 per month
Dependency Ratio	1:8
Household Density	6 person per household
Population Distribution	50% population under 17 years old
Population Growth Rate	20-30% per annum
Water Provision	41% households have water supplied in their houses 14% households have access to an outside tap
Sanitation	55% households make use of the urine diversion VIP sanitation system 20% households make use of pit latrines 7% households make use of chemical toilets 5% households have access to flush toilets 13% households have no sanitation at all
Electricity	60% households have access to electricity
Roads	40% tarred with internal roads almost inaccessible
Health	2 x 24-hour hospitals functioning at a primary healthcare level 1 x 24-hour clinic 27 x day clinics 6 x home-based care initiatives
Education	32% of the population have no formal education 113 primary schools 40 secondary schools 3 combined schools 45 adult education centres Teacher : pupil ratio of 1 : 54
Literacy Levels	24% of the population are illiterate
Community/Social Facilities	2 libraries Informal soccer fields Informal cemeteries only

According to the Nkomazi IDP Executive Summary (2003), the priority issues of the people residing in the Nkomazi municipality are:

- Engineering service: water
- Engineering service: sanitation
- Engineering service: electricity
- Engineering service: roads and storm water drains
- Engineering service: solid waste
- Effective local government
- Economic development
- Land ownership and housing
- Health
- Social service
- Education
- Social and community facilities
- Safety and security
- Communication and information
- Environmental conservation

2.3.7 Conclusion

Healthcare in South Africa is both affected and defined by our history of apartheid, the previous implementation of the medical model of healthcare; poverty; HIV/AIDS; and the interplay of traditional healing and western medical models. Access to appropriate and relevant information can play a critical role in the empowerment of communities and therefore, also in the poverty alleviation process. Information and training materials that do exist on disability related issues are seldom available in accessible languages to rural communities, thereby excluding the poorest group within the disability sector from championing their own development. Others tend to make decisions about the lives of people with disabilities and decide even very basic things for them, and as a result people become disabled because of their living conditions, making them even poorer. Subsequently they become malnourished, are exposed to unhealthy living conditions and are frequently exposed to violence. This is particularly true for women and children with

disabilities who frequently experience high levels of violence and abuse due to the fact that they are often confined to their homes (Disability Support Project, 2000).

Based on the historical, cultural and social demography of Tonga, it is clear that the Nkomazi region is heavily burdened with the effects of poverty, HIV/AIDS, lack of municipal services, reduced levels of education and literacy, and disability.

According to ethnographic research by Ezzy (2000); Kalipeni (2000); Schilder, Kennedy, and Goldstone (2001); and MacLachlan (1997), patients, particularly in rural areas, seeking healthcare are affected by poverty, stigma surrounding the disorder, and negative attitudes of healthcare workers, while Patton and Westby (1992) assert that a description and understanding of the social environment or context is essential for an overall understanding of what is to be observed.

This study strives to acquire an understanding of the experience of caring for a child with cerebral palsy in Tonga and in this way aims to provide a cultural perspective of cerebral palsy by reviewing the socio-political perspectives of disability, and highlighting the limitations of the medical model. It strives to emphasize the relevance of context and of obtaining cultural specific information in order to development of appropriate intervention strategies. By employing qualitative methods of research, including participant observations and narrative interviews this study aims to obtain a comprehensive understanding of the barriers experienced by caregivers in caring for a child with cerebral palsy in a rural area and in so doing to improve on current healthcare policies and refine the role of the speech-language therapist working in primary healthcare.

CHAPTER 3
Methodology



Image 4: Research mediator conducting a narrative interview

3.1 AIMS

The aim of this study was to describe the experiences of caregivers caring for children with cerebral palsy in Tonga, Mpumalanga.

The study had the following specific objectives:

1. To develop a better professional understanding of socio-cultural processes in the context of Tonga and to better understand what it means to look after a child with cerebral palsy in a rural area.
2. To identify the needs of caregivers and persons with cerebral palsy living in Tonga and thus to better define the role of the speech-language pathologist working in rural contexts.
3. To apply qualitative methods of research, including ethnography, as a potential tool for obtaining a better understanding of cerebral palsy in the South African context.

3.2 RESEARCH DESIGN

As this study set out to construct an ethnography of what it is like to care for a child with cerebral palsy in Tonga, and to identify the challenges facing caregivers of children with cerebral palsy, no explicit research question or hypothesis was put forward. Instead a flexible design was employed underpinned by naturalistic observation to enable an understanding of the social behaviors and thought processes of the participants. For this reason, qualitative methods were used in order to place an emphasis on understanding the individual's life experiences through closely examining people's words and actions in order to understand the situation as experienced by the participants (Maykut and Morehouse, 1994). Qualitative methodology is effective in such a study as it allows for the description of problematic moments in the individual's life (Denzin and Lincoln, 1994).

In order to establish a valid concept regarding the experiences of caregivers caring for a child with cerebral palsy in Tonga, a triangulation of methods was employed (McNeill,

1990), including narrative interviews, participant observation and researcher and research mediator observations. These research methods were used in an attempt to strengthen the validity of empirical evidence by reliance on more than one approach (Bulmer, 1991, p.45)

3.3 ACCESS TO SETTING AND PARTICIPANTS

As discussed in Chapter 1, I was employed at Tonga Hospital as a community service speech and hearing therapist over the period extending from 1 January to 31 December 2003. Living in Tonga I was able to immerse myself within the community, and as a result I experienced many of the frustrations that the locals experience, including poor provision of municipal services, poor conditions of the roads and limited access between the hospital and many of the homes in the community, as well as the frustration of traveling long distances in order to acquire products essential for the sustenance of life. Over the year, I spent a great deal of time communicating with the tribal elders in order to gain access to the community and visiting the homes of local residents in order to obtain an understanding of the needs of the patients and to deliver a basic rehabilitation service. This experience provided me with a degree of understanding of the way of life within the community, the beliefs and cultural practices, as well as the support structures and roles of various members of the community.

Direct access to participants was gained by obtaining permission to access clients through the Community Based Rehabilitation Worker (CBRW) who has regular contact with disabled persons. The CBRW was identified as the best person to act as a mediator in the study because, among other reasons as discussed below, she has access to both clients who attend the hospital and those that do not and it was hoped that this would provide a more complete concept of what it means to care for a child with cerebral palsy in Tonga.

3.4 RESEARCH MEDIATOR

The community based rehabilitation worker (CBRW) based in Tonga was appointed as research mediator and provided the researcher with access to the community. The selection of the CBRW was based on the following reasons:

- The CBRW is a Siswati speaking person. During her year of compulsory community service, the researcher worked with the CBRW, whereby the CBRW helped with translating and the researcher helped the CBRW with identifying and accessing persons with various disabilities. In addition, during my year of community service, I provided the CBRW with informal translating skills.
- In her capacity as CBRW for Tonga, the research mediator knows many of the members of the community personally and already had a relationship with many of the disabled persons and caregivers of disabled children residing in the Tonga vicinity. Therefore she had already established a relationship of understanding and trust in the community prior to the research study.
- The CBRW is a disabled person confined to a wheelchair. She therefore has a good understanding of disability and caregivers of disabled children and it was predicted that they would feel more comfortable discussing their experiences with her due to the fact that they could communicate in the same language and the CBRW was able to empathize in a way that the researcher was unable to.
- The CBRW had received formal training on disability and counseling, organized by the Mpumulanga Department of Health.
- Aside from working on a professional level with the CBRW, during her community service year, I as researcher had already cultivated a relationship of friendship and trust with the CBRW. The CBRW provided a unique and instrumental outlook on the community as a whole and the needs of individuals within the community. By aiming to carry out a study that emphasized the need to develop a cultural sensitivity in a community whose cultural beliefs and practices were largely foreign to me, it was vital to make use of the skills of a mediator with whom both the community and I had an established relationship of trust.

The following table provides a summary of the profile of the CBRW:

Table 2: Profile of CBRW

Gender	Female
Age	41 years
Nationality	South African
Home language	SiSwati
Other languages spoken	English, Afrikaans, Zulu, Shona
Disability	Polio as a child, now confined to a wheelchair
Highest academic qualification	Grade 11
Work experience	Employed by Disabled People of South Africa (DPSA) since 1998 as a community based rehabilitation consultant (CBRC) in the Nkomazi East region. Main duties include: • Identifying persons with disabilities or those caring for disabled persons within the community • Peer counseling • Liaising with Department of Health and Department of Social Welfare
Training received through DPSA	• Disability and HIV (2003) • Human Rights (2004) • Counseling in the community (2005)

Primary roles that the CBRW was required to fulfill for the purpose of the study included:

- Helping the researcher to identify possible participants for the study.
- Accompanying the researcher to the homes of the participants

- Carrying out the individual interviews with the participants, using the guiding questions as a basis for discussion.

The CBRW was reimbursed for her time on an hourly basis based on the University of the Witwatersrand guidelines for paying research assistants.

3.4.1 Training of Research Mediator

During the researcher's initial visit to Tonga in March 2006, the CBRW was provided with a full orientation regarding the interview and the underlying concepts to be discussed. This was done at Tonga Hospital as this was accessible to both the researcher and the CBRW. Orientation to the study and review of the guiding questions for the narrative interviews were done in one of the consulting rooms in the rehabilitation department, and took approximately 3 hours. From time to time the researcher summarized what had been discussed or reworded it in order to ensure that the CBRW had grasped the nature of the study. In addition, the CBRW provided the researcher with feedback from a cultural point of view regarding the themes to be probed and the wording of questions, as well as the order for proposed discussion. Minor changes were made in order to make the interview more culturally sensitive. A pilot interview between the CBRW and a caregiver of a child with cerebral palsy was conducted for the CBRW to gain practice in carrying out a narrative interview and she was given the opportunity to clarify any concerns she had regarding the interview with the researcher. The interview was transcribed and translated in Johannesburg and minor changes were made in relation to the order of discussion prior to the onset of data collection. The CBRW was encouraged to begin implementing the narrative framework of interviewing ahead of the study, as the guiding questions were not specific to cerebral palsy.

On the day prior to data collection the researcher reviewed the nature of the study as well as phrasing of narrative questions with the CBRW. The pilot study was reviewed by both researcher and CBRW and a discussion evolved regarding which strengths and weaknesses of the interview questions and the reasons behind possible shortfalls. Once again minor alterations in relation to wording of questions were made.

3.4.2 Working in a Mediated Language Context

One cannot ignore the language barriers between the researcher and the community and the inherent limitations that this placed on the study. While it would have been optimal to conduct the research in Siswati, the notion of gaining sufficient competence in the language to communicate efficiently and effectively was not a realistic option. As an alternative, the CBRW was used as a cultural broker and conducted all interviews, and thus the researcher remained the sole observer.

3.5 PARTICIPANTS

The study set out to interview three female primary caregivers caring for children with cerebral palsy in Tonga, Mpumulanga. At the initial visit to Tonga in March 2006, the researcher requested that the CBRW ask any interested parties who would be willing to participate in the study to visit the hospital on a given date so that the researcher could explain the objectives for the study, the nature of participation, and to obtain informed consent. (Caregivers were reimbursed for their traveling costs as they did not have appointments for treatment at the hospital on that day).

In the original proposal, the following criteria were put forward for participation in the study:

- The child should be between the age of 4 and 6 years since it is generally at this age that caregivers become increasingly concerned about the nature of the disability and its implications for school placement. In addition, by the age of 4-6 years, the significance and severity of the disability becomes apparent and consequently the load on the caregiver is increased.
- The child must present with a communication impairment
- The child must present with a feeding impairment
- The child must be dependent in activities of daily living (ADL) tasks, e.g. bathing, dressing, toileting, feeding.

However, based on the underlying principles of ethnography, as well as an overwhelming interest to participate in the study, predetermined categories for inclusion in the study were not implemented with the exception that the participants needed to be caring for a child with cerebral palsy. The naturalistic character of the study aimed to capture the reality of everyday experiences in the participants' home environment.

Twelve caregivers attended the information meeting at the hospital and all twelve agreed that the study was of importance to them and that they would like to participate. By the time the researcher conducted her second visit to Tonga in order to begin data collection, three other caregivers of children with cerebral palsy had approached the CBRW and requested to be involved in the study (they had heard about the study through other caregivers who lived in the same vicinity who were participating in the study). This was taken to be a significant indicator of the level of determination of the caregivers to empower and to actively engage in disability awareness. Thus in an attempt to acknowledge the caregivers' attempts to assert themselves, an in the interestes of enriching the research material, it was decided that all interested parties would be interviewed.

3.5.1 Sample Size and Sampling Strategy

A sample size of fifteen children with cerebral palsy was employed and a total of twenty-seven interviews with caregivers were conducted. Convenience sampling was employed in terms of the participants' proximity to Tonga and the ability to access the participants' homes in a car. The CBRW identified eight children with cerebral palsy that she knows of whose homes are inaccessible by car. This in itself has huge implications for these caregivers' experiences of caring for a child with a disability, as well as for healthcare professionals, and other stakeholders, such as municipal services, in terms of providing an equitable and accessible service for all.

While convenience sampling presents the possibility of bias in terms of the participants' chance in being included in the study and their access to services, the nature of the study strived to obtain an ethnographic account of the experience of caring for a child with

cerebral palsy in rural area and was not limited by variables and therefore results were not affected by this sampling strategy. However, since the study aimed to obtain a personal account, both common and new themes arose, but results cannot not be generalized for each and every person caring for a child with cerebral palsy in a rural area.

3.5.2 Demographics of Participants

The following table provides a summary of the caregivers who were interviewed over the course of the study:

Table 3: Participants interviewed in study

MOTHERS	FATHERS	GRANDMOTHERS	OTHER
12	3	7	1 Grandfather 1 Aunt 1 Step-mother 1 Male cousin 1 Male neighbour

While twenty-seven interviews were conducted in total, the main focus of the study was placed on the primary caregiver and their experience of caring for a child with cerebral palsy. A total of ten mothers, one father, two grandmothers, one cousin and one aunt were identified as primary caregivers. The majority of primary caregivers were mothers, with an average age of twenty-five years, with the youngest mother being twenty years old and the oldest mother being thirty-seven years old. The average age of children with cerebral palsy in the study was five years, with the youngest child being eight months and the oldest child being fourteen years. In order to preserve the participants' rights to privacy and confidentiality, the physical location of where they live has been withheld. However, in order to place the study in context, mention is made of the villages visited in where interviews were conducted. These included Naas, Tsambokhulo, Mangweni, Steenbok, Block A, Block B, Mzinti, and Managa. The following table provides a

summary of the profile of the primary caregivers and their children who participated in the study:

Table 4: Profile of primary caregivers and children in study

Gender of Caregiver	**Age of Caregiver**	**Relationship to Child**	**Age of Child**
Female	24	Mother	3
Male	38	Father	6
Female	24	Mother	4
Female	25	Mother	3
Female	28	Mother	4
Female	48	Grandmother	11 months
Female	23	Mother	8 months
Female	22	Mother	4
Female	37	Mother	14
Female	20	Mother	2
Female	28	Aunt	4
Male	20	Cousin	7
Female	65	Grandmother	12
Female	21	Mother	4
Female	26	Mother	6

Due to the personal nature of the study and the methodology, one cannot ignore the effects of the environment, living conditions, poverty, accessibility and services on the caregivers' experiences of caring for a child with cerebral palsy. Below is a summary of the demographics of the living conditions of the participants:

Table 5: Demographics of participants

	Distance of home from Road	Electricity	Water	No. of People in House	Sanitation	Grant Recipient	Other Financial Support	Support Structure	Father Involved
1	500m	yes	Jojo resevoir	23	Long-drop 15m from house	no	Father pays maintenance and Grandfather's pension	Family and community	Maintenance only
2	2km	no	No – walks 3km	4	On neighbour's property	no	Mother's boyfriend (R300 per month)	None	No
3	4km	no	Water point on property	3	None	Disability grant	Father pays maintenance	Boyfriend	Maintenance only
4	1.5km	Yes	Running water in house	7	Long-drop 5m from house	Child support grant	Mother's cousin	Both parents, family and neighbours	Yes
5	1km	Yes	Running water in house	16	Long-drop 5m from house	Disability grant	Father employed and Grandfather's pension	Parents, family and neighbours	Yes
6	1km	Yes	Running water in house	16	Long-drop 5m from house	Disability grant	Grandfather's pension	Parents, family and neighbours	Yes
7	On tar road	yes	Jojo reservoir	8	Long-drop 5m from house	No	Gogo's pension	Gogo and family	No
8	5km	no	no	14	Long-drop 100m from house	Child support grant	Gogo's pension	Gogo	No
9	10km	Yes	Water point on property	11	Long-drop behind house	Disability grant	Father is employed	Family and community	Yes
10	45km	No	Water point on property	5	Long-drop behind house	No	Gogo's pension	Gogo	No
11	50km	Yes	No	8	Long-drop 100m from house	No	Live off land	Father and step-mother	Yes
12	45km	no	no	5	None	No	Father is employed	Male cousin and neighbour	Yes
13	15km	yes	Water point on property	17	Long-drop	Disability grant	Uncle	Aunt	Yes
14	8km	Yes	Water point on property	13	Long-drop	Disability grant	Father is employed	Extended family and neighbour	Yes
15	8km	Yes	Water point on property	3	Long-drop	Disability grant	Father is employed	Mother's family and neighbour	yes

3.6 PILOT STUDY

A pilot study involving several mother-child dyads was conducted in Johannesburg using caregivers of children with cerebral palsy attending the Johannesburg Hospital cerebral palsy therapy groups prior to the data collection stage of the study. This was done in order to validate the techniques employed in the study and to inform the researcher of any changes and additions that needed to be made to the interview guiding questions, as well as to determine whether the methodology, sampling, instruments and analysis techniques were adequate and appropriate.

Interview data obtained in the pilot study was analyzed using theoretical coding as described by Strauss and Corbin (1990) and the following themes from the raw data which were useful in validating the guiding questions and in the analysis of the eventual data that emerged:

- Perceived stigma within the community
- Caregiver's sense of being ostracized from the rest of the community
- Traditional beliefs surrounding cerebral palsy and their interplay with Western medicine
- Role of religion
- Role of gender within the community
- Importance of peer support

3.7 ETHICS

Permission to conduct the study was applied for to the University of the Witwatersrand Ethics committee prior to commencement of the study (Clearance Certificate Protocol number 51101).

Signed consent to act as research mediator was obtained from the CBRW (Appendix 3). This included aims and nature of the study and the roles of the participants, the CBRW and the researcher in the study. It also stated that participation is entirely voluntary, although once agreed upon, a contract was signed including working conditions and payment. A separate section on confidentiality was included on the consent form.

Separate consent forms were formulated for the participants to participate in the study (Appendix 5) and for the interviews to be digitally recorded (Appendix 6). These were available in Siswati since this is the first language of the participants, and included the aims and nature of the study. In addition, it was clarified that participation was entirely voluntary and that biographical data and interviews would be treated with confidentiality. Furthermore, consent forms were phrased in a manner made easily comprehensible and free of academic jargon. Consent forms were available in written form but due to the lack of literacy in the area, explanation of the study and consent was given verbally by the research mediator and consent to participate was mainly given verbally, since both mediator and participants spoke the same language. Where possible a signature was obtained as a means of signed consent.

Furthermore, in the management and presentation of the data, the following steps were taken to preserve the confidentiality and legal status of the participants:

- Identifying information pertaining to the geographical location was removed from the demographic information.
- Data in the results and discussion section was not linked to participant numbers.
- Transcripts in appendices 14 – 41 are presented in a random order, unlinked to the order in which participants were interviewed, and all identifying information has been removed.

3.8 REFERRAL PROTOCOL

It was acknowledged that the nature of the interview may give rise to emotional responses on the part of the caregivers or that questions may arise surrounding schooling for the child with cerebral palsy or accessing social grants.

Prior to the stage of data collection, the department of social work at Tonga hospital (Appendix 13) and the department of special educational needs (Appendix 11) were contacted in order to set up a formal referral protocol so that issues which potentially could surface during the process of data collection could be dealt with efficiently and effectively.

While most interviews did elicit an emotional response, none warranted immediate referral to the social work department at the hospital. Some queries arose regarding disability grants and child support grants. These participants were referred to the department of social services. This conforms with the obligations of conducting an ethnography where the ethnographer is no longer an outside observer, but becomes a participant of the situation (McNeill, 1990). Thus the ethnographer carries the obligation of bearing witness to the observations and providing a system of support where necessary.

3.9 METHOD OF DATA COLLELCTION

As discussed previously, a triangulation of methods was employed as the research design, data was collected in the following ways:

- Observation and field notes as described by Flick (2002) were recorded in the home of the child and caregiver
- Unstructured, open-ended, face-to-face individual interviews as described by Patton (2002). These focused on the experiences of caring for a child with cerebral palsy in Tonga (Appendix 1). This took place over a number of hours in the home of the caregiver and child.
- Personal reflections of the researcher and research mediator as recommended by Crepeau (1997) and Primeau (2003).

Consistent with the nature of ethnography, the areas that were probed were of a personal interest to me as the researcher, and my personal identification both as a speech therapist

and as a feminist also situated the study. However, the themes probed were evidence-based and included the following:

3.9.1 Personal experience of caring for a child with cerebral palsy

The rationale for this was that the primary aim of the study was to establish and describe the experience of caring for a child with cerebral palsy. In addition to this, Runciman (2003) found that caregivers of physically disabled children experienced social, emotional and financial difficulties, while Salas-Porance, Erikson and Reed, (2000) found that disability represented a stumbling block to community support. Emotional difficulties associated in caring for a child with a disability have also been reported by Levin (2004), Mweshi and Mpofu (2001) and Potterton (1996). This indicates a clear need to establish the experiences of caring for a child with cerebral palsy and identify the implications for intervention.

3.9.2 Poverty

The living conditions in Tonga are not conducive to bringing up a disabled child as there is a severe lack of provision of basic services, such as provision of water and electricity, poor roads and lack of access to healthcare facilities. For this reason, I decided to investigate the perceived effect that poverty has on a caregiver's experience of caring for a disabled child. In addition, Hutcherson, (1991) found a correlation between poverty, educational level, nutrition, gender and disability, while Meyers et al., (1998) reported that children from poor families are at higher risk for disability.

3.9.3 Gender dynamics

It is a known fact that in rural areas, men migrate to the cities in search of work, leaving women and children in the homelands (Cancian and Oliker, 1998). This results in many women-headed households where the responsibility for looking after the children, tending the crops, and fetching water and firewood rests on the shoulders of the woman. The existence of a child who has special needs would obviously add to this responsibility.

These reports concur with the findings of Peat (1997); Tamm (1999); and Chernesky & Gutheil (2002), who found that most caregivers in all societies are family members, most of whom are women, who have to balance this role with other domestic responsibilities. This led to the decision to investigate the role of gender in caring for a disabled child in Tonga, and the feelings associated with gender roles in this regard.

3.9.4 Cultural beliefs and practices in relation to cerebral palsy

Living in a multicultural society such as South Africa, it is vitally important that cognizance is taken of the individual's cultural beliefs and practices if one is going to be effective in therapy. The role of culture is enormous, and the impact thereof cannot be ignored. Mweshi and Mpofu (2001) reported that 47% of caregivers living in the Cape Flats felt that culture and beliefs affect child rearing practices. In addition, Byrd (1997); Fitzgerald (1997); and Fulton and Moore (1995) found that the role of spirituality in the lives of those affected both directly and indirectly by disability has received an increase in recognition over the last two decades.

3.9.5 Personal experiences of western management of cerebral palsy at hospital level

The way in which the participants have experienced western medicine up to this point forms the basis for this study. While it is important to understand the above themes, if we as western healthcare professionals are to redefine our role in primary healthcare, to improve service delivery and ultimately to inform policy makers it is imperative that we invesitgate both the nature of the services currently being provided and the patients' experiences of these services. Kalipeni (2004) reports that patients often have poor access to healthcare facilities, and when they do reach such facilities they are often treated with disrespect. This concurs with the findings of Irochu-omare (2004) who reported that rehabilitation staff were frequently rude and abrupt when addressing patients, while Potterton (1996) found that there was a significant breakdown in communication between patients and therapists. These reports need to be validated within the context of Tonga, and the findings will be used in an attempt to improve on service delivery and to advise policy makers.

The open-ended unstructured nature of the interview allowed the caregivers to recount their experiences and perceptions in their own words and terminology and ensured that all relevant topics were covered and could be used to facilitate the analysis of raw data (Patton, 2002). One of the main advantages of this method was the flexibility, spontaneity and responsiveness with which the interviewer was able to probe and question certain areas of interest as they unfolded in the various interviews.

3.10 DATA COLLECTION SCHEDULE

Data collection took place between March and May 2006. Originally it was proposed that the researcher would make three trips to Tonga. The initial trip was planned to train the CBRW, obtain informed consent from the hospital for using their patients, and to meet possible participants, explain the nature of the study and to obtain informed consent for participation in the study. The aim of the second visit was to observe caregivers in their home environment and to compile ethnographies for each of the participants. The purpose of the third visit was to conduct the narrative interviews in the homes of the caregivers. However, after the initial visit (26-29 March 2006) it was decided to amend the data collection schedule and instead of visiting the site on two separate occasions (4 days each) it was decided to combine those two visits into one longer visit (10 days). The rationale behind this amendment was two-fold. Firstly the number of participants was far more than the researcher had anticipated and therefore due to time constraints it was impossible to spend a minimum of a full day with each participant, and secondly the CBRW advised the researcher to compile the ethnography and carry out the interviews at the same time to avoid participants being away from home or unable to set aside time to be interviewed. Thus the amended data collection schedule took on the following form:

Table 6: Data Collection Schedule

MONTH	LENGTH OF VISIT	PURPOSE OF VISIT
26 – 29 March 2006	4 days	-Discuss the nature of the study with CBRW -Train CBRW in terms of carrying out narrative interviews -Make necessary amendment to the guiding questions to be used in the interview -Identify participants -Explain purpose of study to participants -Obtained informed consent from Tonga Hospital, CBRW, Participants -Review statistics at Tonga hospital in terms of prevalence of cerebral palsy -Discuss current management of cerebral palsy at Tonga
28 April – 7 May 2006	10 days	-Observation of caregivers in home environment -Compile ethnographies for each of the participants in their home environment (done by researcher while CBRW carried out interviews – each interview took two-and-a-half to three hours to complete) -Carry out individual narrative interviews with participants in their homes (done by CBRW)

3.11 PROCEDURES

The following research methods and procedures were adopted for the purpose of the study:

3.11.1 Participant Observation

During my year in Tonga, I frequently played the role of participant observer since I was unable to communicate with members of the community in their own language. In this way I became familiar with the culture, beliefs and practices within the community, as well as the unwritten rules of communication within the Swazi culture. While this provided me with invaluable information, for the purpose of this study I returned to the setting in order to develop a better understanding of the experience of caring for a child with cerebral palsy in Tonga and ultimately to better define the role of the speech language therapist in rural areas.

Hinds, Chaves and Cypress (1992. p.61) describe the role of the healthcare professional as *'to understand human beings and to help create conditions that promote healthy and meaningful life experiences'*. This implies that a researcher's efforts to understand are facilitated by the ability to attach meaning and impart understanding to clients in a manner that helps them to experience this meaning in their lives. Thus participant observation allowed me to gain insight into the lives of both children living with cerebral palsy and their caregivers and to begin to formulate a professional understanding of the role of the speech-language pathologist working in rural areas.

Overing and Rapport (2003) describe the process of participant observation as an interactive one, where the researcher is both an observer, and an interactant of the field of events under observation. In this study a number of hours were spent observing the daily routine, the living conditions and the interactions of children with cerebral palsy, their caregivers and other persons living in the home and/or community. Due to the fact that I

as researcher took on the role of participant observer, interpretation of the information obtained was a product of its means of acquisition (Overing and Rapport, 2003).

Ethnography allows for an understanding of behaviour related to health and illness in the context in which the behaviour occurs and in turn allows for the understanding of cerebral palsy from an emic point of view. Consequently this allows for a better understanding of the implications of caring for a child with cerebral palsy in a rural area.

3.11.2 Narrative Interviews

Penn (2000) suggests that the story of an illness is a vital point of intersection among many disciplines and provides an interesting range of perspectives on the condition as well as on diagnostic and therapeutic regimens. The interviewer has the potential to transform the interview situation into a situation where the interviewer and the respondent are co-equals who engage in a conversation about mutually relevant, and often biographical, critical issues. For this reason, the study employed a narrative, storytelling framework to change the interview into an important tool for both applied action research and clinical research.

Since a rigid geometric structure was not used for fear of overlooking the narrative and thus mis-interpreting the caregiver's personal life experience, Flick's (2002) approach to using 'guiding questions' was employed. This focus was used as it aids decisions surrounding methodology, case and material selection, conceptualization of interview schedules and interpretation of data (Flick, 2002). By conducting open-ended interviews I aimed to obtain information about the perception of cerebral palsy in Tonga and to gain insight into the experiences of caring for a child with cerebral palsy in a rural area. The open-ended nature of the interview in the home of the caregiver allowed me to gain insight into the cultural model of disability and based on the themes that surfaced during the study new dimensions on the experience of caring for a child with cerebral palsy became evident. This in turn will be used to guide the profession of speech-language pathology in developing appropriate tools for assessment and management of cerebral palsy in rural areas.

Due to the fact that the CBRW had received in-depth training on conducting narrative interviews, the researcher was not present at the time of the interview, but rather sat some distance away and conducted and took field notes of each participant's home environment. By not being present at the interview, the researcher aimed to put the participant at ease and minimize the possibility of sensing that he/she was being judged by the researcher, and in this way the researcher hoped that the participant would give an honest and detailed narrative description of caring for a child with cerebral palsy in Tonga.

3.11.3 Reflections of Researcher and Research Mediator

According to Primeau (2003), reflexivity is a qualitative research strategy that addresses our subjectivity as researchers related to people and events that we encounter in the field. In addition, reflexivity also addresses the subjective nature of the research account as a narrative and enhances the quality of research through its ability to extend our understanding of how our positions and interests as researchers affect all stages of the research process (Crepeau, 1997).

Ahern (1999) states that reflexive accounts are meant to demonstrate our awareness of our biographies, assumptions and personal values, and to provide a context in which our analysis and interpretation of data can be understood. In this way the research displays multiple levels of consciousness, connecting the personal to the cultural. Initially it was proposed that both researcher and research mediator should journal their reflections of the research process after each encounter with each participant since Wheeler and Macdonald (2000) report that writing about a topic or event is important because it forces the author to organize his or her thoughts, ideas and facts and enables him or her to elaborate on those ideas to a deeper level of understanding thus causing the writer to engage the material directly.

This, however, was not carried out in the manner it was planned for two reasons. Firstly, the data collection process was very time consuming, with the research mediator carrying

out on average, three interviews per day, with each interview lasting between two-and-a-half and three hours each. As a result, the research mediator did not have time to journal between each interview. In addition, while the research mediator has a good command of spoken English, her command of written English is not quite as accomplished and therefore it was difficult for her to put her thoughts down in writing.

As a result, the researcher journalled her thoughts and observations, while for the research mediator, instead of journaling, immediately after each interview the researcher and research mediator sat together to review and discuss the proceedings, the responses obtained, and the nature of the themes which emerged during the interview, and both the researcher and the CBRW's emotional responses to the interviews. Additionally, the research mediator's responses provided the researcher with insight into what had been gained from a personal point of view and whether the research mediator would be able to implement new techniques or be aware of new themes or aspects of daily life and as a result, implement new methods and techniques into her daily work after completion of the study.

3.12 RECORDING OF DATA

Observations were recorded in the form of detailed field notes. Flick (2002) refers to field notes as the classic medium of documentation in ethnography since observations become results by their documentation in text. Field notes were taken down during and immediately after fieldwork contacts and contained descriptive accounts of observed events and processes as well as the researcher's impressions, analyses and interpretations as events unfolded, as recommended by Flick (2002). Field notes were also used to document interviews and included information such as where the interview took place, who was present and non-verbal cues as observed by the researcher.

Interviews were recorded on a Sanyo digital audio-recorder. This was done in order to increase the accuracy of data collected and to allow the interviewer to be fully attentive to the interviewee instead of attempting to produce verbatim transcripts during the interview

(Patton, 2002). In this way an attempt was made to establish a natural conversational environment.

3.13 MANAGEMENT OF DATA

Once the interviews had been recorded, they were transcribed verbatim into written form.

Since the researcher is not first language SiSwati speaking, a University of the Witwatersrand fourth year Speech and Hearing Therapy student whose first language is Siswati was identified and employed to transcribe and translate the interviews into English before analysis of data began.

Criteria for the assistant included:

- First language SiSwati
- English proficiency at a grade 12 higher grade level

3.13.1 Validity

In order to increase the trustworthiness of the study findings, the researcher and research mediator met immediately after each interview to discuss the proceedings and the themes which emerged. In addition, detailed field notes were critiqued and compared to the comments made by the participants to ensure that what the researcher recorded was a true version of what had occurred.

Once data had been transcribed and analysis was complete, a percentage of the transcribed interviews and a percentage of the analyzed interviews and ethnographies were handed to a Professor from the University of the Witwatersrand Anthropology Department in order to ensure that what the researcher had observed and the nature of the recording was true and valid.

In order to ensure validity of transcripts, a second translator was employed to verify the Siswati transcripts and English translations in order to ensure reliability of these transcripts. The second translator was a third year Social Work student from the

University of the Witwatersrand, and she fulfilled the same criteria stipulated for the above-mentioned assistant.

3.14 DATA ANALYSIS

Once the interviews had been transcribed and translated, data remained unstructured and not coded across a limited set of predetermined categories so as to avoid the over-simplification and deconstruction of data. Instead, by allowing data to remain unstructured the true complexity of the situation was given the opportunity to emerge. Thus as researcher, I made an overt attempt to avoid following a specific procedure at the point of data analysis, but rather used it as a time of sense-making of themes and issues that surfaced during the process of data collection. Analysis of qualitative data involves examining the meaning of people's words, actions and inductively deriving the research findings from the data (Maykut and Morehouse, 1994). Through thorough repeated reading of the transcripts and detailed field notes the emerging ideas and themes were coded and grouped together into categories into the following categories:

- Personal Experience of Cerebral Palsy
- Poverty
- Gender Dynamics
- Cultural Beliefs and Practices in relation to Cerebral Palsy
- Experience of western medicine at hospital level

The themes of the interviews and ethnographies were explored and analyzed, while new themes and categories were further explored. These themes were viewed individually in the context of Tonga and in relation to the individual participant's narratives. The emerging themes were then viewed in relation to each other and in relation to the experience of caring for a child with Cerebral Palsy in Tonga.

Theoretical coding, as described by Strauss and Corbin (1990), allowed for such flexibility. By using theoretical coding, concepts were identified within the data and

developed in terms of how they may be understood in relation to observed events or phenomena as well as in relation to theory.

CHAPTER 4
Results and General Discussion



Image 5: Research Mediator interviewing a *gogo* at her home

This chapter will explore the narratives obtained from participants, the reflections of the research mediator and my own responses as participant observer. Due to the personal nature of the study, many of the narratives obtained, as well as the settings in which interviews took place evoked an emotional response from the participants, the research mediator and from me. However, the nature of the study allows for such responses and in turn further helps to define the role of the speech therapist working in rural areas. This will be discussed in more detail in chapter 7. The transcripts of the stories are reproduced in full in appendices 14 – 41. The order in which the narratives appear has been randomised so as to protect the participants and maintain confidentiality.

The decision to employ narrative interviews as recommended by Penn (2000); Flick (2000); and Minister (1991) proved to be very successful. This is evident from the rich narratives obtained which revealed important personal perspectives on caring for a child with a disability. These would have been impossible to obtain from more structured interviews with closed-ended questions (Abrums, 2001). Eliciting data by means of narrative interviews allowed the participants to give a personal detailed account of their experience of caring for a child with cerebral palsy. According to Greenhalgh and Hurwitz (1999 p.48) *"we dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, gossip, learn, hate and love by narrative. Episodes of sickness are important milestones in the enacted narratives of patient's lives. Thus not only do we live by narrative, but we fall ill, get better, get worse, stay the same and finally die by narrative too"*. The narrative interviews were therefore able to provide meaning, context and perspective for the patient's predicament and responses. In addition, they were used to define how, why and in what way the child and the family had been affected by the disability. The study of narrative therefore offers a possibility of developing an understanding that cannot be arrived at by any other means.

By means of discussing each interview directly after it had been conducted, the researcher and research mediator were able to evaluate the proceedings, the responses obtained and in turn our responses to the participants, and the nature of the themes which emerged during the interview. Additionally, the research mediator's responses provided

the researcher with insight into community life in Tonga, and the importance of the intricate relationships within the community which proved to be central to the experience of cerebral palsy. This will be discussed in detail in chapter 5.

As discussed in chapter 3, the following themes were probed:

- Personal experience of caring for a child with cerebral palsy
- Poverty
- Gender dynamics
- Cultural beliefs and practices in relation to cerebral palsy
- Personal experiences of western management of cerebral palsy at hospital level

Writing anthropological accounts such as this one necessarily involves a power relationship. My account is a dialogue in which the participants were not only caregivers caring for a child with cerebral palsy, but also a body of scholarly theory that defined certain statements as important, others as irrelevant, and in turn provided analytical categories. This is my account. I have taken the participants' stories, my own observations and both my own and the research mediator's thoughts and perspectives in order to reach this point where I am able to provide an account. I make no claims to be speaking for the people of Tonga, with whom I have worked and spent time. I have borne witness to their lives and I have tried to understand as far as I could *what* things look like from their perspective. In asking *why* they look like this, I have tried to put this into a theoretical perspective in order to advise policy makers and hopefully bring about change to this marginalized community.

The observations and results will now be discussed in detail according to the way in which I, the participant observer recorded them. An in depth review and discussion of the emergent themes will now be discussed:

4.1 PERSONAL EXPERIENCE OF CEREBRAL PALSY

> *"Being told that one's child has a disability may well be the most severe shock that one may experience in a normal lifetime full of trying experience."* (Evans, 1983, p.84).

According to Sithole (2003), a child with a disability is usually unexpected and more often than not, an undesirable member of the family because of the heavy demands he or she places on the family. When caring for a normal child problems may arise, but when caring for a disabled child these problems are profound because they have emotional, physical and financial implications. This notion is elaborated on by Paul (1981) and Purse (1981) who state that the caregiver of a disabled child has to deal with feelings of guilt, failure, doubt, resentment, and protectiveness all jumbled together with love, while simultaneously having to cope with excessive caregiving demands imposed by a child with special needs. This was evident from the caregivers' narratives obtained in this study.

According to Kramer and Kipnis (1995), the characteristics of the caregiver and the care receiver and the context of the caregiving situation potentially play a central role in understanding all other aspects of the caregiver's experience. These contextual variables are conceptualized to determine the types of caregiver activities the individual is engaged in, the type of resources available to manage these responsibilities, the appraisal of gain or strain and ultimately the well-being of the caregiver. Within the theme of 'Personal Experience of Cerebral palsy" a number of themes emerged, which will now be discussed in more detail. At times it was difficult to separate the discussion of certain personal experiences and for this reason some of the themes have been grouped together.

4.1.1 Acceptance Issues

Of the twenty-seven participants interviewed twenty-two reported that they had accepted their child's condition, while five reported that they had not come to terms with having a disabled child. Interestingly it was the *gogos* who appeared to have an easier time accepting the disability, with only one out of seven gogos reporting that she has still not come to terms with the child's condition.

A combination of positive and negative responses was obtained in response to acceptance. Some of the positive included:

- ***"It took me a while to understand. I just prayed and said he is my blessing from God. It was very painful though."***
- ***"(The child's) father did not have any problem with him being disabled".***
- When asked how the neighbors respond to the disabled child the *gogo* replied ***"They like him like any other child"***.
- Another *gogo* responded by saying ***"I take all of these children as my own".***

Some of the comments made by participants who felt that they have not yet accepted the child's disability included:

- ***"(The child's) father's mother doesn't want (the child). She is ashamed of her".***
- ***"I have not seen any of the neighbors who like (the child)".***
- ***"I don't think (the child's) mother has accepted that he is disabled because she doesn't show care or love for (the child) at all. She doesn't want (the child) to touch her and when he cries she just leaves him there without caring".***
- ***"He has no relationship with his granny and I don't know why she dislikes (the child). I think she needs counseling to help her and then stop disliking the child".***

I found the theme of acceptance interesting as from pure observation there was no evidence of non-acceptance as all of the children appeared to be well looked after, and were treated with great dignity. This was evident from the fact that all the children were clean and well dressed, and at times where caregivers were observed feeding the child

with cerebral palsy this was done with tenderness, care and patience. When the issue of acceptance was discussed with the research mediator she said, ***"For some of these people it is very difficult. They do not have help and they do not have money and there is nobody to help them care for the child but what must they do? This is the child that God has given them."*** I found this an interesting response as it embodied many of the responses obtained from the participants. Based on the narratives, it seemed as though the participants did not question the difficulties imposed on their lives by caring for a child with a disability in a severely under-resourced area. In addition, none of the participants assigned blame to the fact that their child was disabled as a result of, for example, poor nutrition or lack of access to healthcare. This may be as a result of lack of formal education or lack of access to the media, but more than that, it appears that disability was accepted by both the participants and the research mediator as 'an act of God'. Contrary to this, the participants' reports of how the community reacts to their children was not always indicative of acceptance, but rather of isolation and marginalization. None of the participants had found that acceptance was an easy point to reach and most described a period of mourning of the loss of a normal child and the loss of a dream. Throughout the interview it appeared that the use of narrative as a means of eliciting data was comforting to the participants as they were, possibly for the first time, given a chance to tell their story as they had experienced it – not from a medical point of view but from a personal point of view.

4.1.2 Support

Brody (1985) states that whether the primary caregiver assumes the responsibility of caring voluntarily or is assigned this role by the family members, he or she is more vulnerable to burden by virtue of the responsibilities assumed. According to Brody's research (1985) most caregivers will assume the responsibilities not by choice but because there is no alternative. I found that this linked to the issues surrounding acceptance, as well as the research mediator's comment ***"…but what can they do?"***

From the narratives, it appeared that only eight of the fifteen participating families had a good support structure. The remaining seven participants either had very little or no

support structure. In Kilonzo's study (2004), which looked at caregivers' experiences of community based rehabilitation in Botswana, he found that caregivers were overburdened and isolated by their roles. They often neglected their own needs, which impacted negatively on their physical and mental health. According to Schwarz and Roberts (2000), social support minimizes the adverse consequences of stressful situations and thus may contribute to helping the caregivers to cope with their roles. These findings concur with those of Thejane (1999) who found that lack of emotional and social support from the community for families of children with disabilities posed significant barriers to effective rehabilitation.

Some of the comments from the participants with good support structures included:

- ***"We stayed together because we love each other and we both love (the child) very much."***
- ***"I believe that God made us strong through everything in such a way that even after (the child's) disability He kept us together".***
- When asked about the first time the mother took the child to the hospital, she replied ***"We were all going together with (the child) because at that time she couldn't walk".***

Some of the comments from participants with little or no support structure included:

- When asked who cares for the child if the mother is not around, she replied ***"It's me but if I am not around there is no one".***
- ***"…no one is able to help look after him – they complain that he cannot even say when he wants to go to the toilet and that he is just an inconvenience".***

I found this very distressing because apart from having poor access to services, financial stability, and having to care for a disabled child, not having emotional support seems unbearable. The theme of 'Poor Support' was closely linked to 'Sense of Abandonment and Isolation', which also emerged as a common theme.

Ingstad (1999) points out that when families are unable to cope with the care of a disabled relative, it is usually the result of poverty and a lack of knowledge about what can be done to improve the situation, rather than the result of a lack of love or negative attitudes. This concurs with Kilonzo (2004)'s findings which showed that most caregivers displayed a lack of understanding of the permanence of their child's condition. Another study conducted in Zimbabwe by Rumano (1994) found that lack of understanding and negative attitudes within the community may result in an inability to cope with the burden of caring for a disabled child. However, this study revealed that in addition, the inability to cope with a disabled child was also related to stigma and superstition surrounding disability.

Seven caregivers in this study felt that they had become isolated from their community as a result of caring for a disabled child, while six participants reported that they had experienced a sense of abandonment by the other parent or by the community. Some of the comments made included:

- ***"We broke up because of the child because I got the baby when I was 7 months pregnant. He chased me away. He said he didn't want the baby because it was so tiny. He said I must go home or I must kill the baby."***
- ***"The difficulty of losing a person who claimed to love me because of the baby we had is also painful".***
- ***They also told me they don't want (the child) back in their house and that I should keep her forever. They said they don't want a disabled child."***

While this is not a unique experience and has been reported many times in the literature (Gath, 1977; Sabbeth and Leventhal, 1984; Potterton, 1986; Anderson and Phohole, 2001), both the research mediator and I were saddened by hearing these comments as this was clear evidence of a fragmented community. This made me want to do something to make it all better, but upon reflection I realized I am unable to change the intricacies of human relationships. What I am able to do, however, is to listen to the stories of my participants, to empathize with them, and to bear witness in such a way that I may make a small contribution to their quality of life.

The sense of isolation, in turn was strongly linked to 'The experience of being gossiped about and ridiculed in the community', which also emerged as a common theme. Three participants reported that the members of the community gossip about them and openly ridicule them. Some comments included:

- ***"I really would appreciate some help, but those few that do care to help also say bad things about my son."***
- ***"They just laugh at me saying my child is disabled".***

Both the research mediator and I found these issues difficult to deal with as they represented very real evidence of human pain and suffering and both of us remarked that we felt quite depressed by what had been said. However, after discussing the nature of the comments and the way in which the narratives were told by the participants, my response to these narratives changed somewhat from depression to a sense of hope. The fact that these women were surviving in such adverse conditions was quite beyond me. Their physical and emotional strength and their ability to hope for a better future despite the marginalization which they have experienced gave me hope that it is possible to empower these members of the community in such a way that they may be able to educate and support other members of the community.

4.1.3 Sense of Disappointment

Sixteen participants reported a sense of sadness related to bearing, bringing up and caring for a disabled child. Some of the comments included:

- ***"I was very disappointed since it was my first-born. I expected that since she was my first-born she would be everything I ever wanted from a child".***
- ***"It is difficult to see other children walk and yours cannot."***
- ***"It is very painful because I did not ask for a disabled child".***

The experience of disappointment is an international response and is consistent with the findings of Sabbeth and Leventhal (1984), Gath (1977) and Abrums (2001). Both the research assistant and I felt that we could understand and empathize with these

participants. The fact that the research assistant – a disabled women herself – was able to empathize with the participants was for me, yet another indication that she fulfills a very important role in the community. Not only is she able to fully understand the implications of disability in Tonga, but she is sensitive and supportive and empowering. This made me realize that if we as healthcare professionals are going to improve service provision in rural areas and marginalized communities we cannot do this without the assistance and guidance of the CBRs and without empowering members of the community themselves to initiate change.

4.1.4 Experience of Depression

The narratives revealed nine instances of what appear to be symptoms of depression (Kubler-Ross, 1969) where participants reported instances of isolating themselves, emotional lability, anger, bargaining and weight loss in response to being informed of their child's disability. This is consistent with a longitudinal study carried out in Britain by Wade, Legh-Smith and Hewer (1996) who found that 11-13% of caregivers caring for a disabled family member showed signs of significant depression, while Gath (1977) and Romans-Clarkson, Clarkson and Ditmer (1986) found that parents of disabled children were more prone to depression, mood lability and the tendency to feel tired than the parents of children without disabilities. This was evident in the following narratives:

- ***At first I felt terrible. I lost weight and I used to spend time alone thinking about (the child's) disability, but after two years I accepted the situation as it is and I regained weight.***
- ***We can't even resolve things like adults. She is always upset without reason. She doesn't even communicate what is wrong. She just becomes angry and upset without reason".***
- ***"It took me a whole year to accept. During that time I was just crying all the time."***
- ***"It took me nine years to accept her disability. From time to time I still become upset".***

4.1.5 Experience of Guilt

Two mothers exhibited an overriding sense of guilt towards the child with cerebral palsy. A comment made in relation to this included:

"There is nothing I can do. I just keep telling him that I am sorry".

The above is consistent with results obtained from other studies (Leavitt, 1992; Pimm, 1996; Mweshi and Mpofu, 2001) which found that one of the frequently cited reactions to the diagnosis of disability is guilt. While only two caregivers overtly reported experiencing a sense of guilt I found this significant. I related this to Abrums' (2000) study where she states that often the simplest statements are the most profound, and the reports of the experience of guilt are indicators of the need for consistent support for those caring for a disabled child.

4.1.6 Sense of Desperation

Two caregivers reported a sense of desperation. Their narratives included:

- ***"I left (the child) with his father because I didn't know what to do with him because he was very sick and no one was able to help him so I came to his father for help…I always thought about him. My father said I should leave him here until he gets better".***
- ***"When (the child's) granny is here she usually says bad things about the child. She even said she wishes this situation would be over. I don't know what she meant about the situation being over or maybe she wishes (the child) to die. I don't know".***

Once again I found these harrowing personal accounts difficult to deal with as they are a harsh reminder of the extent of shame and desperation attached to disability amongst some of our people. The research assistant also reported that she was deeply upset by these comments but not surprised by them. She reported that when counseling parents, they frequently make reference to the fact that family members or members of their

community have recommended leaving the child at the hospital where someone else will care for the child, or in more severe instances, parents are pressurized into abandoning babies in desolate areas. When asked how she deals with such reports, the research assistant reported that she counsels the parents and anyone else who is around for many hours and may go back to visit these clients everyday in their homes for days or weeks. However, the concept of desperation among caregivers of persons with a disability is not a new concept. Amosun, Ikuesan, and Oloyede (1996) report instances of caregivers trying to 'do away' with their disabled children. This is an indication that healthcare professionals need to enquire about formal and informal support systems within the community as part of the intervention process.

4.1.7 Conclusion

From the above there is clear evidence of the emotional pain and suffering attached to disability in South Africa. The narratives highlight that the caregivers of children with cerebral palsy require assistance in managing the successive day-to-day problems of caring for a child with a disability and maintaining a sense of normality in everyday family life. There is a clear need for information about the child's condition and for education on handling a child with a disability. This is consistent with the needs of parents caring for a child with a disability internationally (Paul, 1981; Purse, 1981; McCormack, 1978; and Power and Del Orto, 1981). In addition, the participants in this study demonstrated a need for support and access to community resources, including medical, financial and social support, but most of all they need to become empowered leaders within the community.

4.2 EFFECTS AND EXPERIENCES OF POVERTY

Over 250 years ago, Olwen Hufton (as cited by Ngwisha, 2003), wrote *"The approach to the study of poverty must be predominantly qualitative not quantitative. There is no such thing as a graph of human suffering"*. However, the word 'poverty' means different things to different people, and it is one's value judgment that determines the kind of definition one is likely to give to this social phenomenon. While this study did not set out to study poverty per se, poverty emerged as an overriding factor. It was something that I, as a participant observer found difficult to deal with, as the living conditions were so foreign from those to which I am accustomed.

In rural areas, one of the biggest barriers to accessing quality healthcare is poverty (Anderson and Phohole, 2003). The relationship between disability and poverty is complex and multifaceted. Being born with a disability increases the chances that one will be poor because of the unfair discrimination that those with disabilities encounter (DPSA Annual Report, 2005). It has already been ascertained that the majority of the world's disabled population come from developing countries, and this exacerbates most disabled persons' efforts to free themselves from poverty.

Most of the narratives discussed in this section were obtained from mothers. Looking at the demographics of Tonga it is clear to see that this is one of the most under-serviced and poverty stricken areas of South Africa. As a result I had expected much discussion surrounding this topic and complaints regarding the accessibility of services, the provision of water and electricity, the conditions of the roads and long distances walked each day in order to collect water, firewood and food. However, I was surprised to find that none of the participants complained in any way! There were reports of difficulties encountered but these were merely mentioned as part of life, not as a complaint. It is difficult to understand why this is so and I believe that there is no clear-cut answer. At this point I feel that it is important to mention that poverty is relative and while I experienced shock and disbelief at some of the harsh living conditions of some of the participants, for them this was merely everyday life. Part of the reason for the participants not complaining could be ascribed to the fact that as a result of poor roads, lack of

transport and a lack of regular or sustainable income, many of the participants had never been into a town and therefore did not know of any different form of lifestyle. In addition, most of the participants were illiterate and had received very little, if any formal education. In addition to this, the lack of provision of basic services such as electricity and the degree of poverty meant that few people have access to media such as television, and in the participants' houses only a few were noted to have transistor radios. This implies that possible media attempts to relay messages regarding basic rights would be futile. However, paramount to this was the comment that the research mediator had made in response to the issue of acceptance of disability, which embodied many of the participants' responses to various points of discussion ***"…but what can they do?"*** These responses once again indicated to me that many of the participants felt disempowered to change their situation.

The central themes that arose while discussing the issues surrounding poverty included the provision of grants, the payment of maintenance by fathers who had abandoned the family, the fact that a large number of households are still living off old age pensions, the expense of equipment, poor nutrition as a result of not being able to afford a balanced diet, inability of mothers to work as their children with cerebral palsy require 24 hour care, and the inaccessibility of the hospital. These will now be discussed in more detail:

4.2.1 Grants

While every child with cerebral palsy in this study would have been eligible for a disability grant, only seven of the children were receiving disability grants. Two of the caregivers were receiving child support grants, while six children were not receiving any form of government grant, of which one child was a Mozambiquan citizen and therefore not eligible for a South African grant. One child had been receiving a grant which had been stopped as the mother was reportedly using the grant for her own interests and she had abandoned the child. There appeared to be a lot of confusion regarding grants and which children were eligible for a disability grant. This was evident in the following cases:

- One mother reported that her child is receiving a disability grant, but she wanted to know whether she was also eligible for a care-in-aid grant.
- Another mother reported ***"I tried to apply for a disability grant but I haven't got my reply yet. They told me at the hospital that the child won't get a disability grant until she is 7 years old, so I went to the pension office and they gave me a child support grant form that I filled and sent back. I thought that the child dependent form is the same as the child disability grant."***
- ***"I don't have the right information on how to apply for a disability grant"***.

Although less than half of the participants reported that they were receiving grants, I found the above responses to be positive as they showed that information about rights is slowly filtering through the communities. This is likely to be due to the fact that the therapists at Tonga hospital advocate disability grants and assessments for all social support is done at the hospital, all clinics, and at pension pay points. Something I found particularly effective was the way in which the research mediator conveyed information regarding grants. Based on review of the interview transcripts, the research mediator was able to provide basic information regarding grants but always made a plan to follow up on the participant's query. In addition, when she did not have an answer she promised to find out whatever the participant was querying and to give feedback at their next hospital appointment.

4.2.2 Pensions

Of the fifteen participants interviewed, six were supported by a gogo or nkulu's pension. This is consistent with the findings of Meyer and Moagi (2000) who investigated the needs of mothers caring for children with disabilities in Winterveldt, in the Northern Province of South Africa. In some instances I found that the gogos and nkulus actually felt that it was their responsibility to use their pension money to care for their children and grandchildren. One gogo reported **"*When he got sick I knew it was my duty to take him to all the medical professionals for help using my pension funds.*"** I found this response amazing, given that the gogo was supporting an entire household on her pension. This alerted me to the role of kinship within this community. Maverick (1966)

reports that within Swazi culture, the grandparents are instrumental in teaching and bring up the young. In addition, he reports that should a child fall ill he or she is often sent to live with the maternal grandparent until health returns. While this was not explicitly reported in any of the narratives, there was evidence that this practice may still exist today.

4.2.3 Expense of equipment

Two caregivers, both of whom were mothers, reported that they were unable to afford equipment which would help to improve their child's functioning. One of these mothers was a Mozambiquan refugee and her child did not have a South African birth certificate, meaning that he was not eligible to receive free assistive devices from the hospital. This mother reported ***"I think a walking ring or something similar but I can't afford one myself. The child does not have a South African birth certificate so he does not get the Government grant".***

The second mother who reported that she was unable to afford equipment was the same mother who did not have the appropriate information about how to apply for a disability grant. Due to the fact that her child has a South African birth certificate, he should receive assistive devices free of charge through the local state hospital. However, it appeared as though she felt there should be more that she should be able to do to help her child. From having personal experience of working in the area of childhood disability in the government sector, it appears to be a common belief that parents feel that if they had more money their child would be better off. This concurs with the findings of Irochu-omare (2004) who found that parents participating in her study felt that affluent patients were able to chart improvement in the children since they are able to afford assistive devices. Unfortunately this is true. While the National Rehabilitation Policy (2000) states that assistive devices must be made available to all persons requiring them within the public sector, the reality is that there are long waiting lists and healthcare budgets for assistive devices are often used up within a few months. Thus patients requiring these assistive devices are placed on a waiting list, and consequently, while waiting to receive these devices may develop secondary complications such as bedsores or contractures.

4.2.4 Poor nutrition

Two mothers reported that they were not able to afford appropriate nutrition for their children. When asked what type of food the child eats, the mother replied ***"He really manages with everything he is given even though he could have a much better diet if I could afford it"***. The second mother also reported that she thought that her child would show more improvement if she was able to provide him with a balanced diet. It surprised me that these caregivers were so well informed in terms of the importance of a good diet, given their lack of formal education, living circumstances and access to the media.

4.2.5 Inability to work

Five of the mothers of the children with cerebral palsy felt that they were unable to go out in search of work as their children required constant care and they felt they were unable to leave the child with anyone else while they went out to work. One mother reported ***"I always have to take him everywhere I go because no one is able to help look after him – they complain that he cannot even say when he wants to go to the toilet and that he is just an inconvenience".*** Another mother reported ***"(The child) needs a lot of my attention",*** while yet another mother reported ***"When I am away for any reason I get back and find (the child) refusing to eat because I am not there. She will only eat if I am there"***. One caregiver reported ***"Neighbours take (the child) if I am here at home otherwise I don't want them to take her because (the child) needs constant care".***

From the above it appears to me that although children with cerebral palsy do have very specific needs, the mothers of these children do not trust others to take care of them as they would a non-disabled child and thus isolate themselves further from society. These reports are confirmed by Johnson and Deitz (1985) who found that mothers with physically handicapped children had difficulty getting away from home in order to participate in social activities. This was evident through observation of the general community, where it was seen that toddlers were frequently left in the care of other young children. At times, children as young as four or five years were seen carrying babies on their backs and caring for them (feeding and dressing them). This is consistent with the findings of Kuper (1963). She reports that once a child can walk and has been

weaned, the child is expected to be independent and interact with his or her peers. Thus, should the mother go out to work in the fields or gather firewood or fetch water, the child is left in the care of children nor much older than him- or herself, who play with the child, sing to the child, discipline and teach him/her the rules of behavior. However, at each of the fifteen homes we visited, the child with cerebral palsy was always in the care of a mother or grandmother. The implication of this is that children with cerebral palsy may never learn to walk or to feed themselves and thus remain the responsibility of their mother (or primary caregiver) and while they are not given the opportunity to interact with their peers in the same way that a normally developing child does, their caregivers become even more isolated from the general community.

4.2.6 Inaccessibility of hospital

Atman (1981), Hahn (1983) and Wright (1988) found that the consequence of disability is not the reduction of a person's physical or mental capabilities, but rather the environmental and social system that are barriers to effective rehabilitation and integration of the individual into society. This was confirmed by the study.

Transport remains a major barrier to health services for people living in rural areas (Anderson and Phohole, 2003). Common complaints among caregivers of children with cerebral palsy include long distances which people have to travel, combined with expensive, unreliable transport, making regular follow-up visits difficult to achieve. Kilonzo (2004) reported that caregivers identified lack of transport and lack of understanding on the behalf of taxi and bus drivers (regarding transporting disabled children and wheelchairs) as problems which made coping with caregiving roles difficult.

Three mothers who participated in the study said that they felt that the hospital was inaccessible. One mother who lived in a home barely accessible by car reported **"W*hen I need to go to the hospital it is a mission because I need to find a person with a car to take (the child) to the hospital".*** Another mother who lived 45km off the tar road in an area where there is no public transport and whose only source of income was R180 child

support grant reported ***"I loan money from people, usually R50 to take him to the hospital or clinic".***

4.2.7 Conclusion

From the above it is clear to see that paramount to the experience of caring for a child with cerebral palsy is the experience of poverty. Not only do these caregivers experience the emotional effects of caring for a child with cerebral palsy, but they also have to deal with the physical and economic effects. While general progress has been made in South Africa in terms of addressing the inequalities of the past, it is evident that change has been slow in reaching the people who are most destitute and those who need it most. Unfortunately change cannot be uni-dimensional. Change needs to take all stakeholders into account and address physical, social and emotional needs simultaneously (White Paper on an Integrated National Disability Strategy, 1997). This obviously holds implications for the role of the speech-language therapist in a rural community and will be discussed in more detail in chapter 7.

4.3 GENDER DYNAMICS

> *"The business of womanhood is a heavy burden," she said. How could it not be? Aren't we the ones who bear the children? When it is like that you can't just decide today I want to do this. Tomorrow I want to do that. When there are sacrifices to be made you are the one who has to make them…but what will help you is to carry your burdens with strength."* (Dangarember, 1988, p.10).

The above quote taken from a rural Swazi woman captures the interlocking systems of oppression (Collins, 2000). Collins suggests that a gender-centered approach to the study of social structures helps to reveal the nature of a particular society's systems of oppression and therefore the nature of the society itself. However, I found that gender dynamics can be a sensitive issue and as the study progressed it became apparent that studying the gender dynamics involved in caring for a disabled child could have been a study in itself. As researcher, I found this a difficult topic to broach as by questioning gender dynamics and roles, not only was I questioning culture, but I was also questioning the intimate life of the family. The nature of this theme was different from the other themes as it was extremely personal. While, the personal experience of cerebral palsy, poverty, traditional beliefs and practices, and the experience of western medicine looked at external factors (i.e. within the community, provision of state services, etc) the role of gender was considered an internal factor. In addition, particular attention had to be paid to the way in which questions were posed so as to not appear judgmental. The research mediator played a pivotal role in this section of the study as she shared the same culture as the participants and prior to the study she had established a relationship of trust with the community. Upon reflection of the transcripts I felt that it would have been interesting to have a male cultural broker interviewing the male participants and to compare the responses obtained as the narratives may have differed based on the culturally specific pragmatics of social interaction. Having said this, many remarkable narratives were obtained. Unfortunately due to the fact that I was not part of the interview process it was not possible to probe certain issues and comments that were made in

relation to gender dynamics. It would also have been interesting to analyze the non-verbal cues in relation to this topic.

Of the participants interviewed in the study, twelve of the children were cared for primarily by their mothers, while two children were cared for primarily by a grandmother, and one by a father. Some of the themes that emerged in relation to gender dynamics and the experience of caring for a child with cerebral palsy included:

4.3.1 Involvement/Lack of Involvement of the Father

At all of the fifteen homes that we visited, and observing the community as a whole I noticed a distinct absence of men and I was unable to establish exactly why this was so. This phenomenon can partly be explained by Cancian and Oliker (1998), who report that in rural areas, often, directly as a result of poverty, men become migrant workers, and relocate to the cities in search of work, resulting in many households being headed by women. This has implications for support within the family, both on an emotional level and on a physical level for running the home and carrying out chores, growing and harvesting crops and caring for the disabled child. The African culture, like in most other societies, assumes caring is a basic duty of women (Cancian and Oliker, 1998). This role exacerbates an already existing exclusion of women from social and economic activities, and therefore brings about conflict between the needs of two disadvantaged groups – the children with disabilities and the women who are caring for them.

Of the fifteen families who participated in the study, nine of the fathers lived with the family and were actively involved in the child's upbringing, two paid maintenance regularly, and four did not have any contact with the child.

In situations where the father was not involved, this put obvious strain on the caregiver who was taking care of the child both from an emotional and a financial point of view. Some of the comments made by the female primary caregivers in instances where the father was not involved included:

- ***"We do not have any relationship since he denied the child after he was born. It is easy for him to say that he does not love the baby because he is disabled".***
- ***"One day we had a fight and the father told me that he knows (the child) is not his son because they have never had a disabled person in their family".***

I found these comments terribly sad, but I also found myself questioning their validity. I do believe that a man may claim that a disabled child cannot be his child because he has no history of disability in his family, especially with a disorder such as cerebral palsy, where in rural areas the cause of disability is often claimed to be unknown (see section below entitled 'Cultural Beliefs and Practices'). However, I do wonder what the men in questions would reveal in their narratives. Do they truly believe that the baby in front of them is not their child? Do they question themselves and their actions? Can they walk away and not turn back? At night when they are unable to sleep does this decision torment them? I wonder…

In situations where the father was involved in the child's upbringing, there appeared to be significant commitment to the development of the child and in the decision making regarding treatment. Some of the comments obtained in this regard included:

- (When asked about the father's acceptance of the child's disability) ***"He didn't say or do anything. He just told us to accept (the child) as he is and as a gift from God".***
- Yet another mother reported ***"He says nothing, he just loves his son."***
- ***"(The child's) father did not have any problem with him being disabled".***

I found this level of acceptance both encouraging and disturbing. Acceptance would obviously mean a more positive quality of life for all involved. However, this non-questioning acceptance drew me back to the research mediator's comment ***"…but what can they do?"*** which points strongly in the direction of a lack of empowerment and knowledge to change or improve the situation.

4.3.2 Children who had been abandoned by one or more parent

Of the fifteen children with cerebral palsy, seven had been abandoned by one or more family member. Of these seven children, five had been abandoned by their father and the father's family (once again indicating the role and power of the paternal family), two had been disowned by their mother, one of whom was now cared for by her grandmother, and the other child was now in the care of his father. The fact that most of the children were cared for by women is consistent with the findings of Boswell, Knight and Hamer (2001) who found that women with disabilities tended to view the disability as an integral part of themselves and this often precipitated or demanded a search for personal growth or spiritual meaning. Comments that arose from this discussion included:

- ***"We broke up after the birth of (the child) because of bad influence from his mother".***
- ***"While I was living with his family (the child) got sick. I then decided to leave and come back home because the father's mother was saying that (the child) is not her son's boy".***
- ***"(The child's) father's mother doesn't want (the child). She is ashamed of her".***

As can be seen from the above, kinship issues arose here and it appeared that in many instances the paternal grandmother had enormous power over her son's relationships and would make the decision regarding her son's involvement with the child. This is explained by Kuper (1963) whose perspectives on kinship, although produced over forty years ago, suggests that while the father bears the legal authority within the family, mothers share in more indulgent relationships, with Swazi men openly expressing their affection and appreciation, as well as respect for their mother. This is expanded on by the Swazi belief that 'The desires of men are satisfied by women but the satisfaction of women come through their children" (Kuper, 1963).

Based on the above, the following questions arose in my mind:

- Do the men's perceptions of disability in urban African settings differ from those in rural settings?

- Does the white man's perception of disability differ from that of the black man? By this I mean what is it that influences our perceptions on disability? Culture? Education? Money? Wealth? Knowledge? Exposure?

4.3.3 Conclusion

As mentioned previously, the study of gender and gender roles is a delicate issue and needs to be investigated with a great deal of integrity and sensitivity, and relies strongly on a developed sense of trust between the researcher and the participant. Based on the studies of Hilda Kuper (1963) and the Swazi gender reviews of the 1970's and 1990's (Palmer and Parsons, 1992) it is demonstrated that women and children dominate the Swazi culture as a result of men migrating to the cities in search of work, that there exists a close relationship amongst women and children within the Swazi nation. Thus if we are to improve the living conditions and quality of life it is important to develop and ensure the implementation of policies that place women and children at their centre such that they can become empowered to initiate change. However, in addition to this I believe that it is vital to capitalize on the involvement of men and to include them in bringing about change.

4.4 CULTURAL BELIEFS AND PRACTICES

Reis (1992) points out that causality and beliefs determine the way both lay people and professionals explain, treat and handle disability, and this consequently impacts on their explanatory models and illness beliefs. This is elaborated on by Foster and Anderson (1978) who state that within traditional medicine, the primary concern is *why* a disability has been caused, while in modern medicine the focus is on *how* the disability came about.

Once again some vitally important themes arose which assisted me in understanding the cultural model of cerebral palsy. The research mediator once more played a pivotal role in obtaining this information, and the decision to use narrative interviews in order to potentially minimize the cultural barriers which would have existed in a more structured interview setting (Penn, 2000) proved to be efficient. Not only does the research assistant represent the personal experiences of both disabled people and their caregivers, but she is also a confidante and a cultural broker in the confusing representation of illness and disability in an area which is predominantly rural both in terms of the provision of services and in dealing with disability. Although she clearly belongs to the Western model of understanding disability, the research assistant has grown up with and lives within a community where disability is frequently ascribed to witchcraft. As a result it is believed that the community was more comfortable discussing their beliefs with the research assistant than with one of the white western therapists who would not have even been able to hold a conversation in a common language.

While a number of interesting points were raised by the participants and most of the participants spoke openly, it is important to bear in mind that the participants knew that both the researcher and the research mediator had connections with Tonga hospital and that some healthcare professions frown upon traditional healers. It is thus possible that certain viewpoints were withheld or that the participants told us ‘what we wanted to hear’.

When discussing cultural beliefs and practices the following themes emerged:

4.4.1Visits to Traditional Healers

Ten of the fifteen families participating in the study had taken the child with cerebral palsy to a traditional healer. The responses obtained and the experiences of traditional medicine were quite varied, although not one participant reported noticing any improvement in the child's condition after consulting with a traditional healer. Something which became apparent during the course of the study was the fact that the *gogos* and *nkulus* were always consulted first before any action was taken in terms of managing the child's disability. It appeared that for the most part it was the *gogos* and *nkulus* who recommended going to the traditional healers, while the parents of the child were happier with western medicine. This raised the question as to what role the traditional healer would have in the South African healthcare context twenty years from now. In many instances, traditional healers and western healthcare practioners were consulted concurrently. This concurs with Lambat (2004)'s findings which indicated that parents of children with cerebral palsy felt that traditional healers may be able to 'see' something that that western doctors are unable to 'see'. Loveday (2001, p.57) explains this by stating *"most Africans believe in an immediate and an ultimate cause for disease and misfortune"*.

While the above research findings provide interesting results which do appear to concur with the findings in this study, Swartz (1998) warns that there is a danger of seeing the world neatly divided into the western world and the non-western world and that these creations reflect neither the diversity of beliefs that people hold, nor the commonalities that exist across different groups of people. Thus, comments and beliefs cannot be generalized as there is much individual variation.

Some of the responses that were obtained in relation to visits to traditional healers included the following:

- ***"They promised to heal (the child) but since then I haven't seen any improvements so I decided to stop going to any traditional healers".***

- A mother and father of a child with cerebral palsy reported that they have taken the child to traditional healers and were told that the disability is a result of evil at home and ***"they cannot manage it"***.

A common belief in the cause of cerebral palsy as explained by the traditional healers was "evil spirits at home". This concurs with Struthers (2002) findings which indicated that witchcraft was frequently attributed to the cause of disability among people living on the Cape Flats in South Africa. In addition, both Lambat (2004) and Ross and Dagher (2003) found that disability was frequently attributed to evil spirits. Surprisingly Lambat (2004) found that only 10% of her study attributed cerebral palsy to the influence of evil spirits. This could possibly be due to the fact that the study was carried out in an urban area where the participants have relatively easy access to healthcare and the media. Some of the responses obtained from the participants in this study included the following:

- ***"They said it is witchcraft and evil spirit. They then gave us herbs to chase the evil spirits away, but we haven't seen any improvement in the child's condition".***
- ***"They said there is a misunderstanding between the elders of the mother's and father's family".***

As can be seen from the above, those participants who believe in evil spirits causing disability view the disabled person as the victim, the object of aggression, or the bearer of punishment directed specifically against him or her (Foster and Anderson, 1978). However, Reis (1992) heeds that causality beliefs are not a static thought system, but a dynamic process that reflects changes in society. This implies that these persons may experience stigma related to disability both from a traditional or cultural perspective, but also from a western perspective.

4.4.2 Umuthi as a Cause of Disability

Translated into English, 'umuthi' can mean either 'medicine' or 'poison', and refers to substances fabricated with an expert hand, designed to achieve either healing or illness (Ashworth, 2005). There are reportedly no limits to the uses of 'muthi' and witches are

able to cause every kind of ailment under the sun. Dangerous substances deployed as 'muthi' can enter the body through the mouth in the form of food or drink, through the lungs, through the skin, or through sexual contact, so anyone who puts their body in contact with other persons or substances needs to be careful (Hammond-Tooke, 1970).

Fifteen of the twenty-seven participants interviewed, most of whom were gogos or nkulus, believed that 'umuthi' was the cause of disability. This appeared to be the most common belief in the cause of disability and many of the participants reported that this was also the belief that their neighbors and the wider community held. Some of the responses obtained included:

- Five out of seven of the *gogos* said that they believed that disability was caused by umuthi. One *gogo* reported ***"Anyway, I heard elders saying that if a child is disabled it is because of cross dressing of males and females within the house or young people dressing in older people's clothes. So they say all this cross dressing causes confusion within the family and can lead to disability.***
- ***"I think that there was a problem while I was giving birth to him. Traditionally we call it umuthi".*** I found this to be an interesting comment as it alluded to both the western and the traditional model of medicine.

From the above it is clear that those affected by disability in this context have both created their own meaning and understood that this creation was influenced by the world around them.

4.4.3 Disability as a Result of Birthing Difficulties

Seven of the participants interviewed believed in an alternate/medical cause of cerebral palsy. This is a larger percentage than in other studies conducted in South Africa (Lambat, 2004; Mweshi and Mpofu, 2001). The reason behind this is unclear, however, this may be due to the fact that all of the participants who report a medical cause are patients at Tonga hospital and may have had the western model of cerebral palsy explained to them. In addition, it is possible that the participants did not actually believe that cerebral palsy is caused by medical factors but were telling us 'what we wanted to

hear'. Of these seven participants who believed in an alternate cause of disability, two of them concurrently believed in umuthi. Some of these beliefs included:

- One gogo reported ***"…because she was born disabled, I believe she got her disability in her mothers' womb".***
- A mother reported ***"As soon as I knew I was pregnant my family-in-law took me into their home. I then gave birth at their home. (The child) was born one month early, so she had a breathing problem. I then took her to the hospital and had to stay for 1 week because at that time she was not even crying. She only cried after two weeks".***

However, Scheper-Hughes (1990) warns that patients may respond to the doctor's explanation of disability or illness by shifting his or her explanatory model of illness towards that of the doctor in order to make a working alliance possible, and thus these comments must be interpreted with caution.

4.4.4 Unknown Cause of Disability

Ten participants cited an unknown cause of disability. Of these ten participants, two concurrently believed in umuthi and one believed in an alternate cause of disability. The belief in two concurrent causes of disability (usually one related to medical problems and one related to cultural beliefs) was also found by Mweshi and Mpofu (2001) who studied parents' perceptions on the causes of cerebral palsy in the Western Cape area of South Africa. The reason behind more than one belief was not ascertained but can be linked to education and access to medical perspectives. Some of the responses obtained in this study included:

- ***"I don't know. At the hospital they told me she was affected and that is what I believe now".***
- ***"I used to believe that it is because of cross-dressing of males and females within the house or young people dressing in older people's clothes, so they say this causes confusion in the family and leads to disability. Now I have confirmed that it's not that, it's something else that I don't understand"***.

- One neighbor that was interviewed reported ***"Since I was a child I was told that disability is because of the parents not respecting a mourning period and sleep together before the mourning period is over. They then say this causes disability on the born child that was conceived during a period of mourning".***

I found this attributed cause of disability dreadful as the guilt that the parents of this child must have had to endure over the years must be unbearable. This belief, however, is validated by Loveday (2001) who reports that in African belief systems, ancestors can punish their people by sending illness and misfortune if people do not listen to their wise counsel, if certain social norms and taboos are violated and if culturally prescribed practices and rites are neglected or incorrectly performed. In addition, Boyce and Paterson (2002) found that some South African cultures attribute disability to punishment for past misdeeds. However, once again, this must be interpreted with caution as heeded by Swartz (1998).

4.4.5 Disability viewed within the realm of spirituality

Consistent with a study conducted by Mweshi and Mpofu (2001), seven participants spoke about disability in terms of religion and stated that they had accepted the children with cerebral palsy as a religious blessing. This concurs with other studies conducted in South Africa related to cerebral palsy (Lambat, 2004) and stroke (Bham, 2003). None of the participants viewed disability itself as a religious blessing, but rather stated they accepted the children for what they were as gifts from God. In addition to this, three participants clearly stated that the church played a fundamental role in their life and in helping them to cope with caring for a child with cerebral palsy. The use of religious metaphors in order to support those caring for patients with chronic conditions have been reported by Stein, Lewin and Fairall, (2007); Lewin, (2004); and Leydon, (2000). This relates to Boswell, Knight and Hamer's (2001) findings which suggested a reciprocal relationship between disability and spirituality which involved an ongoing and recurring personal process which led to revision of the participants' beliefs. In this study, the diagnosis of disability was typically followed by a period of questioning and openness to alternative understandings which culminated in changes or refinements in their

perceptions of the world, themselves and disability. Some of the comments made in the study exploring the experience of cerebral palsy included:

- ***"I don't know. I just think (the child) is my gift from God and God is tempting me to see if I can rise above this challenge.***
- ***"We believe God knows what he is doing"***
- One of the *gogo's* main concern appeared to be who would care for the child should she be unable to do so. She reported ***"It is something I think about everyday. I always pray that God will bring a solution to this problem because there is no one I trust to take good care of (the child) the way I do.***
- ***"There is only one woman from the church who comes near her. She comes and prays for her recovery".***
- ***"I also took him to XXX Church and that's where he became better through our prayers. He started crawling and walking again before I took him to physiotherapy training at the hospital".***
- ***"I cried and I prayed to God to help me and to help (the child) to be strong so that he will be able to walk again".***

This is consistent with Abrums (2000) findings which showed that for members of the church in her study, no matter what happened to one in life, they encouraged each other to count their blessings. This lead the participants of Abrums' study to believe that the essential meaning of the body is a beautiful gift from God and that only God has power over the body.

4.4.6 Conclusion

From the above it became evident to me that it is impossible to ignore the individual beliefs of the participants in order to understand their perceptions regarding disability and their reactions to life experiences. This has implications for intervention, and gives rise to the possibility that spirituality may be an underused resource in the rehabilitation (Underwood-Gordon, Peters, Bijur and Fuhrer, 1997). The implication of this for healthcare professionals working in the area of disability is that there is a need to view the conception of 'self' not based on the traditional medical view but rather upon a

broader, more holistic view that encompasses the self, spirit, and society if we are to attempt to understand the experience of disability and take this into account when developing policies and planning intervention.

4.5 EXPERIENCE OF WESTERN MEDICINE

This theme forms the basis of my argument in terms of the role of the speech-language therapist working in a rural setting. While it is important to know and understand the personal experience of cerebral palsy, the effects of poverty and gender dynamics, and the influence of cultural beliefs and practices, it is important that we also evaluate our services. If we as western healthcare professionals are to redefine our role in primary healthcare, improve service delivery and ultimately inform policy makers, it is imperative that we look at both the nature of the services currently being provided and the patient's experiences of these services.

At the time of data collection, the Tonga Hospital Rehabilitation department consisted of five physiotherapists (one chief, three juniors and one community service therapist), three occupational therapists (all of whom were community service therapists), one physiotherapy assistant, and one occupational therapy assistant. There is currently no speech therapist. The current nature of service provision to children with cerebral palsy and their families is a monthly group therapy session at Tonga hospital. The procedure is that patients are required to fetch their hospital files from the administration desk at the hospital before they will be seen by any healthcare professional. Once they have their file they proceed to the rehabilitation department, where the group takes place, starting at 9am. The group is run by the physiotherapy and occupational therapy assistants (both of whom are locals and thus speak Siswati), and the community based rehabilitation worker (CBRW). The assistants were both trained at the University of the Witwatersrand and have five and nine years experience respectively. The group sessions are designed by the physio- and occupational therapists and then passed on to the assistants to implement. The nature of the group is such that each parent has the opportunity to tell the group of any progress that the child has made over the month and to ask any questions. Once each

parent has had such an opportunity, a group discussion will take place about a commonly experienced problem, such as toileting, play, handling techniques, etc., where the parents will be given specific strategies to improve the child's skills in the area under discussion. This normally takes one hour. After the discussion, each child and parent is consulted individually for between twenty minutes and one hour, depending on their needs and the number of persons attending the clinic on that specific day. Progress is reviewed and each parent is given new exercises, strategies or techniques to try at home. If assistive devices are to be issued it is done during this time. Individual consultations are normally done by the physio- and occupational therapists, with the assistance of the assistants, and where necessary referrals are made to the dietician who will see the patients immediately.

The therapists at Tonga Hospital also provide services at nine clinics in the Nkomazi East district. Patients who are unable to attend the monthly sessions at the hospital can receive monthly therapy at their nearest clinic on an individual basis. However, there are fewer resources at the clinic so therapy is not as effective at the hospital. In addition, assistive devices are only issued from the hospital as specific measurements need to be taken and adjustments need to be made.

Of the fifteen children with cerebral palsy, only nine regularly attended the hospital. Of the six who did not attend the hospital regularly three reported that the hospital was inaccessible, while one mother reported that she needs to borrow R50 every time she takes the child to the hospital, so she only manages to go when neighbors are prepared to loan her money. Two of the participants said that they had no reason for not taking the child to the hospital for therapy.

There was a mixture of positive and negative feedback was given relating to the experience of western medicine, although on the whole most patients appeared to have had a positive experience.

Positive Experiences:

4.5.1 Improvement in Child's Condition

Sixteen of the participants interviewed reported that they have noticed improvement in the child's condition since they started attending the hospital, while twelve of the participants actually voiced the fact that they had faith in western medicine. One nkulu reported that at the hospital ***"they checked the baby's bones and said they were not strong enough. They gave us exercises to improve the strength. It looked promising".*** He added that they were informed that the mother reported that she is happy with the hospital because her child received a chair and at physiotherapy he is given exercises and is learning how to sit alone.

Another mother reported that she had taken her child to traditional healers who confirmed that the child was not developing appropriately because of 'umuthi'. She said ***"They gave me medicine but it did not work. After the traditional medication did not work I chose to stick to western ways which seemed more effective".*** When asked what kind of treatment she was given at the hospital she said ***"I got there and they took the child to the gym which I thought was helpful. They gave me reassurance that his situation would get better which sounded promising. The gym sessions are helping a lot and the people in the hospital are very helpful. It is much simpler".***

One of the most significant responses, which embodies the essence of our job as therapists was ***"I have gained a lot of knowledge because all this time I have been sitting with my child telling him that I love him without teaching him anything that will help him. At the hospital they taught me to teach (the child) so many things like how to wash and dress himself independently and other things that will help (the child) to be more independent."*** From personal experience as a therapist who worked in this community, this comment touched the core of my being. I remember thinking so much of the time that the work I was doing was insignificant and wondering what the point was, especially when international literature (Cooper and Sandler, 1997; Young, 2004; Sandrum, Logan, Wallace and Spencer, 2005) states that in order to chart significant

improvement in neurologically impaired children, intensive treatment is necessary. Yet listening to this mother's narrative encapsulates what I, along with my colleagues during our community service year were striving to attain: this child had gained a measure of independence, and in so doing he was being prepared both physically and emotionally to contribute significantly to his community.

4.5.2 Emotional Support

Three participants reported that one of the reasons they kept returning to the hospital even though accessibility was difficult for them was because of the emotional and peer support that they receive at the hospital. Although only three participants actually cited this as a reason for attending the hospital, many of the participants alluded to it. The need for support concurs with the findings of Mweshi and Mpofu (2001). Some of the responses obtained included:

- ***"It took me three years to accept. All this time I have been looking for alternative to help (the child) to get better. However, in all my hospital visits I have seen many people there that are disabled like (the child) and that made me to accept and put things into perspective".***
- ***Also to see other disabled children at the hospital helped very much because I was able to see and compare (the child's) condition, and what I have realized is that (the child) is less disabled than any other children I have seen at the hospital".***
- ***"It is very difficult dealing with the changes I have had to go through to accommodate my baby. Most of the time I just let it pass but I deal better with it when I go to the clinic and find other women with children with the same problems. It feels good to know that I am not alone".***

These references to peer support are important for us as speech-language therapists to acknowledge as they have huge implications for us in terms of refining our role in service provision in the community. It is important to remember that with significant neurological impairment, compounded by living conditions which do not allow the patient easy or regular access to healthcare facilities, and inexperienced therapists who do

not have advanced training in working with such conditions, it may not be possible to achieve full or even partial recovery. However, it is easily achievable to set up information centres and support groups and in this way empower members of the community to stand up for their rights and the rights of their children.

4.5.3 Helpfulness and Friendliness of the Staff

Four participants reported that the staff at the hospital are helpful and friendly. Individual reports included:

- ***"They are always understanding and sympathetic. There is one doctor, I think he is from Cuba or anywhere in Africa. That doctor always gives me advice about what I should do and about life in general".***
- ***"…very sympathetic and understanding. They always help with everything I need."***

It is concerning that only four participants reported that the staff were helpful and friendly. However, one must bear in mind that this was an open-ended discussion and just because the participants did not comment on friendliness does not mean that they did not experience it. However, Irochu-omare (2004) also found that caregivers reported hospital staff to be rude and unfriendly. This is an important aspect, because if the staff are viewed as friendly and helpful it is likely that parents will make an effort to return for therapy and feel comfortable in the therapy session to participate and ask questions. Conversely, if the staff are viewed as unfriendly and unhelpful it is likely that the parents will not buy in to the therapy process which will have physical, emotional and financial implications for the child, the caregivers and society as a whole.

<u>Negative Experiences:</u>

4.5.4 Problematic Filing Process

Thirteen out of the fifteen participants interviewed, complained about the filing and adminsitration system at the hospital and reported that at times they wait in a queue for hours at a time before receiving their file. This has also been reported by Kalipeni (2004) and was seen as a cause of poor follow up by patients for subsequent consultations. This

seems ludicrous when the hospital itself is so inaccessible, and when the patients eventually get to the hospital they have to queue for hours to obtain their file. As a result a number of the participants reported that they look like late comers when they get to the rehabilitation unit, and this would obviously mean when attending group therapy they would miss out on part of the group. Some of the complaints included:

- ***"It's the filing system that takes very long and by the time you get to the gym it's already late. It takes more than 2 hours to get a file".***
- ***"I often stay there for 2 to 3 hours waiting for a file and the nurses sending me everywhere."***

4.5.5 Poor Communication between Therapists and Caregivers

Six participants reported that they had problems with the way that therapists communicate with them. This has enormous implications which need to be addressed urgently within this particular healthcare setting, but also at an undergraduate level in general. While it is possible that some therapists are rude and inconsiderate, it must also be acknowledged that working within a language barrier is likely to give rise to miscommunications, and poses a major threat to the rapport between the therapists and the caregiver as well as the efficacy of therapy.

Working with a population with whom you do not share a common language is extremely difficult. This is particularly true in the South African context where hospitals do not employ interpreters and therapists frequently need to make use of other parents or hospital cleaners as translators and in this way much meaningful conversation is lost. In addition to language barriers, working cross-culturally can be a major barrier to effective therapy. The western bio-medical model on which so much of the therapy is based is a foreign concept to the majority of patients, many of whom have little or no education (Potterton, 1996). Cognizance needs to be taken of cultural issues and the patient's worldview needs to be considered (Penn, 2000) before one can even begin to discuss the pathogenesis of cerebral palsy. In addition, it is important to have a thorough understanding of cultural norms and practices before giving a home program. Traditional

ways of caring for children are deeply ingrained and few caregivers will take kindly to being told to alter these practices by someone from another culture.

Some of the negative comments included:

- ***"I always ask for a wheelchair and no-one is helping"***.
- ***"I want to know why the physiotherapists don't listen to what we need. Because one day I told them that (the child) can sit independently and now I want something that will help strengthen her leg and feet muscles so that she will be able to walk. They told me that what I am asking is something they will see later".***
- Another caregiver said that she had been told that her child needs an orthotic shoe. In response the research assistant asked, if since the mother visits the hospital frequently why she has not asked one of the therapists about such a shoe. The mother replied ***"I told them. It was 3 of us who wanted those shoes. They told us to write our names on the waiting list in 2004 because these shoes were not available at the time. So we have been waiting without any reply from anyone."***

Upon analysis of these comments it appears that although there certainly is an element of poor communication, a sense of disempowerment among the caregivers emerges strongly. This can be related to Abrums (2000) findings which revealed that a sense of mistrust and unease among patients could be related to the fact that patient's impressions of the doctor's words or actions did not correspond with their belief systems or understanding about what was going on between the clinician and the patient. However, I found myself questioning why the caregivers did not demand an answer to why the child has not yet received a wheelchair or an orthotic shoe, and the only answer I can come up with is that they do not feel empowered enough to do so. Although the issues surrounding disempowerment form a major and ongoing project within the disability sector (White Paper on Integrated National Disability Strategy, 1997) it is an area that needs to be addressed within the Tonga community. This paradigm that 'the doctor knows best' extending from the medical model of disability which views disability as a health and

welfare issue has invaded all areas of society (White Paper on Integrated National Disability Strategy, 1997). The WHO (1981) states that CBR activities should encompass the principles of power-sharing and decision-making. However, the research assistant reported that the empowerment of persons with disabilities and their families is one the most difficult areas of her work as empowerment is not a uni-dimensional construct and involves among other things, poverty, gender dynamics, level of education and exposure.

In addition to reports of poor communication within the therapy sessions, it was also noted that many caregivers displayed a lack of understanding regarding the nature and chronicity of their child's condition. This confirms the findings of Kilonzo (2004). While most parents appreciated the benefits of exercising their children regularly, most caregivers did not know the types of disabilities that their children had, nor did they understand why they were exercising their children other than because the physiotherapist had told them to do so, i.e. they were performing duties as instructed by rehabilitation workers. In this study, two of the participants appeared unhappy since the therapists don't give them any medication to improve the child's condition. This indicates that the caregivers are not fully informed about the nature of cerebral palsy and therefore one can only think that the efficacy of therapy is reduced. One can understand that rural people attending the hospital would assume that a condition such as cerebral palsy should be treated with medication, and therefore this highlights the need for healthcare professionals to develop their communication skills, as well as to develop resources and to train and involve the CBRWs in the counseling and family intervention in families caring for children with cerebral palsy.

Two of the complaints voiced when asked what the caregiver had gained from attending the hospital included:

- ***"I gained nothing except they showed me exercises. They don't give me any medication to assist (the child) with his condition".***
- ***"I've gained nothing. Most of the time when I go to the hospital they just ask me about (the child's) condition and don't give me any medications."***

4.5.6 Negative Attitudes of Nurses

Crawford (1994) demonstrates how societal beliefs of a community affect how the members of that community construct beliefs about who becomes ill and who remains healthy and how this serves to marginalize an already marginalized community. In turn, Crawford demonstrates how the language of health has come to signify those who were responsible from those who were irresponsible, those who were respectful from those who were disreputable, those who were safe from those who were not, and ultimately those who have the right to rule from those who need supervision, guidance or reincarnation. This gives rise to a social distancing from the 'unhealthy' – a further stereotyping from an already stigmatized group. In this way the sick are not only made responsible for their illness, but they are also made different. This was evident in some of the participants' reports of interactions with nursing staff at Tonga hospital. Six participants reported that the nurses' attitudes at the hospital and at the clinics were negative and this made it difficult for them to access the treatment that they required. Their comments included:

- ***"What I have found to be a problem is the nurses listening skills. When I try to explain to them about the child's condition they try to disagree with me thinking that I am lying or something".***
- ***"At the clinic the nurses don't know how to talk to people. (The child) has asthma and she sometimes doesn't get the help she needs at the required time because of the nurses' attitude. Sometimes we get to the hospital at 9am and only get helped at around 6pm".***

4.5.7 Conclusion

The above discussion reveals many aspects related to caring for a child with cerebral palsy in Tonga. It demonstrates both positive and negative factors as experienced by the caregivers in Tonga. It highlights a number of successes, both on the part of the healthcare professionals, and the caregivers. It demonstrates the needs, wants, desires and dreams of the community. It reveals the effects of apartheid; thirteen years post freedom in South Africa. It is a depiction of both a disempowered and fragmented community, as well as a representation of the strength and power and capability of a marginalized

community in standing together and supporting each other. It shows huge discrepancies in the provision of basic services and healthcare. It reveals that an understanding of societal constructs regarding disability in a given culture is crucial to the development of strategies in meeting the needs of people. But mostly it represents a need to be heard. Here in the middle of nowhere, surrounded by the lowveld plains, imposing mountains, and scattered mud huts I experienced a moment of truth. So often, healthcare professionals graduate with ambitions of sainthood but are very quickly disillusioned. In this desolate setting I realized that giving patients what they want can be deeply unsettling. I am not talking about actual speech therapy, or issuing of assistive devices, or filling out disability grant forms – I am talking about a much deeper need – the need to be understood and empowered.

Chapter 5 will attempt to provide a construct for speech-language therapists, as well as other healthcare professionals to address this need. It will delve into the premise that in rural South Africa it takes more than a single caregiver to raise a child, it takes an entire village, and for this reason it is imperative that when taking into consideration the rehabilitation of a child with disability, such as cerebral palsy, the context in which this child exists and the community as a whole are taken into account. That is to say both the marginalized persons and those who undertake to marginalize are acknowledged. The next chapter will address the concept of *'ubuntu'* and how it relates to both the social and the physical aspects of rehabilitation, and will endeavor to redefine the role of the speech-language therapist working within a rural context, and will make recommendations for the development and implementation of healthcare policies.

CHAPTER 5
General Discussion and Implications



Image 6: Home of a child with cerebral palsy, 50km off the tar road

> *The civility of a country is judged by how it treats its children, its persons with disabilities, and its poor and elderly citizens* (Albrecht, 1997, p.45).

As discussed in chapter 4, the results of this study highlighted many areas, but mostly it highlighted the participants' need to tell their stories and to be heard. This has huge implications for us as healthcare professionals implementing public policy in, among other contexts, primary healthcare. If we are to deliver a service which is effective and efficient, we need to review and evaluate healthcare policies, review and evaluate the implementation of healthcare in context, and we need to listen to our patients as they, as consumers of this service, are the ones best able to inform us of our successes and defeats, and indicate the reasons behind these.

Most importantly, in developing and implementing healthcare policies, we need to review the context in which we are working. Thus, in terms of reviewing context we need to look at the physical context, such as the provision of basic services, as well as the emotional and psychological contexts, i.e. how the consumer exists within a family unit, a community, society and the country at large, and which factors influence this existence. Central to this need is the question of *how* these contexts will be observed such that a true reflection is obtained. The use of narrative interviews and participant observation used in this study allowed for such observation to take place. According to Crehan (1997), the primary value of fieldwork based on participant observation is that it provides a certain kind of insight that is difficult to obtain in any other way. It is not living in a place and watching its daily life ebb and flow around you that enables you to capture its totality or its essence; but it is observing life in context and listening to people's life stories that makes the difference. That is not to say that the participant observer is ever a neutral presence. In fact the contrary is true, and as a white, educated person from the city, I could not help but be an alien presence. Therefore by my very presence I have to acknowledge that I altered the reality of what I was observing.

However, through my observations I realized that fieldwork involves the struggle to discover the questions that I did not ask, but those which the participants 'heard' and their responses to these situations. According to Crehan (1997) it is often these unasked questions, which reveal how reality appears from the informants' vantage point.

In this study two unspoken themes emerged. These will now be discussed in more detail:

5.1 DISEMPOWERMENT AND MARGINALIZATION

While some participants reported positive experiences and others reported negative experiences, the single most important aspect which shone through in this study was the notion of disempowerment, and the resultant experience of marginalization. This was evident throughout the themes that were probed, and resonated throughout both the narratives and the field note observations. It ranged from the non-questioning acceptance of disability to the experience of desperation where caregivers admitted to "***…wishing the situation would be over"***. Disempowerment was evident in the caregivers' lack of knowledge about which grants their children were eligible to receive, to the passive attitudes of the caregivers in waiting for four years for their child to receive an orthotic shoe, or waiting for assistive devices, such as wheelchairs without demanding an answer as to why their children were still on the waiting list. A sense of passivity was also noted in the reports of problematic filing processes as reported by thirteen out of fifteen participants. Although they reported this difficulty to the research mediator it seems as though no one had actually lodged a complaint or taken it up with hospital management. The reports of negative attitudes of nurses and poor communication between therapists and parents were also worrying. However, there were no reports of taking this up with the person or department involved and it appears as though the participants had accepted this, 'without questioning' just as they had accepted 'everything else' without questioning. The concept of ***"…but what can they do?"*** as voiced by the research assistant was evident in many of the narratives, and sadly, I do not believe that the people of Tonga realize just how disempowered they are and it is believed, partly for this reason, that they did not complain, or expect more from service providers.

However, findings of passivity concur with the findings of Abrums (2001). The participants in Abrums' study reported that encounters with healthcare providers were generally '*an exercise in frustration, fraught with wasted time and at worst occasions for humiliation and a basic sense of dislocation about the validity of one's own impressions'* (p.102). However, none of her participants refused to go to the doctor – they wanted to trust those in whom they had entrusted themselves and their children. Nevertheless, it was found that they resisted passively by averting their gaze, refusing to answer questions and resisted actively with loud storytelling and complaining when among friends. This seemingly common passivity can be partly linked to the historical 'medical approach' to disability where disability was viewed as a health and welfare issue where the focus of 'caring' for disabled persons fell on society and thus, persons with disabilities were controlled by non-disabled persons. The philosophy behind the medical model was not that disabled people were hated or feared, but that they were pitied and helped as part of the 'deserving poor' (White Paper on an Integrated National Disability Strategy, 1997). As a result, people with disabilities very seldom had any say in the aims, objectives and management of these organizations, thus resulting in dependence and exclusion from social, political and economic rights.

5.2 FEAR

A second 'unspoken' theme which emerged was that of fear. Some of the examples of fear were overtly obvious, such as where caregivers reported not feeling comfortable leaving their child in anyone else's care as the child has special needs and requires fulltime attention. The notion of fear was also obvious where a gogo reported (in response to being asked who would care for the child if something were to happen to her) ***"It is something I worry about everyday. I always pray that God will bring a solution to this problem because there is no one I trust to take good care of (the child) the way I do."*** However, in addition to these examples of fear, an underlying, more sinister representation was observed both through the nature in which comments were made and also by observing the interactions of the caregiver and child. These brought on a realization for me that many caregivers, at the back of their mind were thinking *"What will happen if this child dies? What will happen to me?"* Although no caregivers overtly

spoke about this it appeared to be a thought underlying much of what was said and done. My observations of the participants' living conditions and interactions, both with the research assistant and with me, was that these caregivers had given up everything to care for this child. They had stood up to their families and communities and refused to follow instructions or recommendations given to them, such as "***He said he didn't want the baby because it was so tiny. He said I must go home or I must kill the baby"***, and ***"If it was according to them I would have taken (the child) and give him away or throw him in the dustbin".*** In making a stand as demonstrated above, these caregivers have overtly chosen the child with cerebral palsy over and above their families and communities, and in so doing have isolated and marginalized themselves. However, underlying the caregivers' narratives and actions appeared to be a concern that *'should the child die, what will happen to me? I will have no-one.'* This too may account for the reason why parents were reluctant to leave their children with other people as a result of a real fear that if the parent is not there the child may die. Once again, this is not a new theme and has been reported in the literature, mostly in relation to mothers' fear of death in chronically ill children (Florian and Mikulincer, 1997; Hoelter, 1979; and Winnicott, 1974). Natterson and Knudson (1960) found that fatal illness constituted death threats for parents, while Solomon, Greenberg and Pyszczynski (2000) report instances of paralyzing fear in response to considering a child's death. In addition, Solomon, Greenberg and Pyszczynski (2000) found that cultural worldviews serve the fundamental psychological function of providing the basis for death transcendence.

Thus, as therapists we need to be sensitive to both the spoken and the unspoken needs of our patients, and once again the use of narrative interviews and participant observation allows for this. Over and above the participants' narratives, was the role of the community and how the community can either enable or disable the caregivers' ability to care for a child with a disability and for themselves. This highlights the concept of *'ubuntu'* and the need for us as healthcare professionals to understand this concept and to take heed of it when planning intervention programmes.

Ubuntu comes from the Zulu language and underpins the very communal nature of African society and by extension, its ethics (Mbigi and Maree, 1995). *Ubuntu* is a philosophy of life representing one's personal existence, humaneness and morality, where solidarity is the central element to survival within the community (Teffu, 1994). Thus, the well-being of the individual and his or her interests are possible through the community whereby the community becomes a web of relationships. This is well expressed in the Zulu saying, *Umuntu ngumuntu ngabantu*, meaning "You are a person through others" (Teffu, 1994). In other words, the well-being of the individual and his/her interest is possible through the community. As an ethical principle, *Ubuntu* places a high value on sound human relations, and instances of, for example, cruelty, murder, cheating or stealing may be viewed as sufficient to warrant ostracizing the individual through public censure (i.e. for the shameful or immoral act). Therefore, in a sense the act of ostracizing the individual serves as some kind of a form of deterrent punishment. (Murithi, 2006). While the essence of African culture is community oriented, I found this reference to ostracizing individuals from the community interesting as this was the experience of many of the participants. Thus it would appear that within the general community, cerebral palsy is viewed as a form of punishment for some misdeed, and in response to this, the community as a whole ostracizes families with cerebral palsied children.

Practically, what this means in terms of service delivery is that if the concept of *ubuntu* is consciously harnessed, it has the power to bring about increased harmony within society, promoting a new patriotism among the members of our rainbow nation. Communal living is a tradition that has always been upheld among African families, and therefore in order to fully realize the spirit of ubuntu, it is crucial to engage members of our communities in dialogue.

Based on the discussion of findings in this study, the question regarding the physical role of the speech therapist working in rural areas remains to be answered. Only one of the twenty-seven participants remarked that the fact that her child cannot speak increases the level of burden on care. It is thus vitally important for us as speech therapists to take cognizance of this and to evaluate the role that we play in service delivery in rural areas.

However, at the same time it is important to view all narratives in context and the toll that daily life takes on the caregivers cannot be ignored. This implies that perhaps the physical concerns regarding where the next meal will come from, as well as the physical activities of collecting water and firewood are of a more immediate concern than the fact that the child cannot speak. In addition, in eight of the fifteen households there were numerous people around to care for the child, thus taking away from the immediate concern regarding speech.

This does not mean that there is no role for the speech-language therapist in rural areas, but implies that perhaps we need to remove ourselves from the traditional role of the speech therapist and be more forthcoming in advocating the rights of marginalized communities. This can be addressed in the following ways:

5.3 ADVOCATING HUMAN RIGHTS

Caregivers of children with disabilities need to be empowered to demand both their own and their children's rights to a safe and healthy lifestyle, and to education. Klaber, Moffet and Richardson (1997) insist that patient empowerment should be recognized as an important aspect of healthcare and can only be achieved through good communication and the provision of appropriate information provided regularly over a period of time. However, empowerment is not a short-term goal and may take years to implement. Empowerment does not involve bringing in external sources, such as UNAID or Doctors without Borders (although these organizations provide a wonderful service within context). Pfeiffer (2003) warns that development aid systems contribute to the process of structural violence in many ways, either by growing income inequality and land concentration, or by reinforcing a condescending attitude towards marginalized communities. David Werner, author of Disabled Village Children (1934) states that 'planning is a continuous learning process that responds to the changing needs, difficulties and possibilities within a community. Werner recommends that a bottom-up approach be practiced since a program organized by those it serves decentralizes and redistributes power, and thus people who have been powerless begin to find strength through unity. In developing such a program, a facilitator needs to be appointed. It seems

almost futile for the facilitator to be someone like a speech-language therapist who does not have a complete understanding of the community. Instead it would be better for the therapist to advocate the rights of the marginalized community and to empower a member of the community to facilitate this program, such that with time the project will be run by members of the community who were previously marginalized. The act of taking ownership of such a project is an important factor in the process of empowerment.

5.4 SETTING UP SUPPORT GROUPS

According to Levin (2005), parental support is the cornerstone of intervention. This concurs with the findings of this study, where some caregivers reported that their primary reason for attending the hospital was to meet and engage with caregivers whose situations were similar to their own. The value of support groups is immeasurable (Kurtz, 1997), and what is particularly appealing from a therapist's point of view is that support groups can be run in any setting without any specific expertise. As has been noted in previous studies (Houston, Cooper, and Ford, 2002) and Stevenson and Coles, (1993), the setting up of a support group frequently relies on a facilitator and/or an outside person. Thus the setting up of support groups often falls on the shoulders of a therapist working in the community. However, if this is done successfully, with time the support group can be run by the very members of the community who saw the need and benefited from such a source of support originally.

While support groups for physically disabled persons in rural areas are frequently established and run by hospital or community therapists, it is essential to recognize the role of caregivers in healthcare and rehabilitation. This is elaborated on by Crawford (1981) who states that a basic prerequisite for development is the capacity of society to use its own resources to sustain itself.

5.5 TRAINING HEALTHCARE PROFESSIONALS ON CROSS-CULTURAL COMMUNICATION

Central to the training of healthcare professionals on cross-cultural communication and the importance of clear communication, is the need to fully implement and advocate the social model of disability. The social model is based on the belief that the circumstances of people with disabilities and their families, and the discrimination that they face are socially created phenomena and have little to do with the impairments of disabled people (White Paper on an Integrated National Disability Strategy, 1997). The disability rights movement therefore believes that the 'cure' to the 'problem' of disability lies in restructuring society (DPSA, 2001). Penn (2000) argues that the area of narrative medicine is particularly useful as a cross-cultural focal point as it minimizes the cultural barriers which may exist in more structured clinical interview settings. Clinicians need to be exposed to and gain competence in communicating with patients from different cultures in such a way that they are able to reflect a sensitivity to cultural and linguistic influences such that the clinician is able to maximize the flow of information and optimize clinical effectiveness. In response to this, Penn (2000) reports the following skills which are necessary when working in a multi-cultural setting:

1. Knowledge: Knowledge of languages used in the country, socio-political aspects, and language policy.
   Basic understanding of cultural aspects of the culture one is working in.

2. Skills: Practice in interviewing skills
   Practice working with and without an interpreter or translator
   Practice using various interview techniques
   Experience in receiving a case history as opposed to taking one.
   Creating time and opportunity for narratives to emerge.

3. Values: Understanding where you as a clinician are coming from (historically, geographically, family, and the biases you hold).
   Respect for the role and function of the patient and co-workers.

Thus these are the skills that need to be transferred to students, new graduates, and other professionals working in multicultural settings. The knowledge, skills and values are invaluable to the success of the clinical encounter.

5.6 EDUCATING THE COMMUNITY

Community development has the potential to become a tool that may alleviate negative perceptions by assisting the persons affected by these perceptions to influence their future. The inclusion of those affected by disability is therefore a key component of any system endeavoring to raise awareness of disability within a community.

The Disabled People of South Africa (DPSA) has found that one of the greatest hurdles facing disabled people and their families are negative attitudes of society (DPSA, 2001). This concurs with the findings in this study. It is these attitudes that lead to the social exclusion and marginalization of people with disabilities. It has been found that negative attitudes are continuously reinforced since disability is viewed by society as a 'problem' and persons with disabilities and their families are viewed as helpless and dependent, in constant need of help, or as tragic victims (DPSA, 2001).

However, the changing of attitudes is not something that happens automatically or spontaneously. Attitude changing is a complex process which involves moving in a series of stages from one set of attitudes to another, and is influenced by cultural beliefs and practices (White Paper on an Integrated National Disability Strategy, 1997). The process of educating the community and thus initiating a process of attitude change can be targeted through a number of processes. Firstly, one needs to focus on raising awareness in terms of disability, human rights and development. In so doing it is hoped that the level of discrimination experienced by persons with disabilities and their families will be decreased. Awareness raising can be done on a number of levels to target a number of different communities. In the context of primary healthcare, therapists, in conjunction with CBRWs can run information workshops at local clinics and hospitals. This can be particularly effective if the presentations involve disabled persons or the caregivers of

disabled persons to provide a personal account on the experience of living with a disability. In addition, verbal information, posters and pamphlets can be introduced at community centers and churches. Bearing in mind the concept of *ubuntu* it is vitally important to include the community as a whole and to access the community by using culturally sensitive and appropriate channels of communication. This would include introducing new ideas and concepts via community leaders and engaging them as the first point of access to attitude change. Thus the ability to reconstruct and develop communities involves a recognition of, and intention to address the developmental needs of disabled people within a framework of inclusive development.

5.7 DEVELOPING PUBLIC POLICY

As a result of the increasing number of disabled persons, the field of disability has become important to researchers and policy-makers. Policy-makers need to be aware of the increasing number of disabled children in order to plan for their integration into mainstream society. According to the White Paper on an Integrated National Disability Strategy (1997), disability has historically been addressed in a piecemeal, fragmented way. According to policy makers, this is believed to be one of the key factors contributing to the marginalization of disabled people and the dire poverty of the circumstances in which the majority find themselves.

However, for policy to be effective and representative it is important that policy makers also take cognizance of the role that caregivers of disabled children have in forming such a process. It is important to realize that many mothers and grandmothers, even though they may be disadvantaged and marginalized in terms of resources, knowledge and information, are competent and effective caregivers. Yet, if this is to be realized, it is vital for us as therapists and healthcare providers to advocate the partnership between ourselves, policy makers and caregivers as equal partners in the delivery of services. Furthermore there is a need to support and redistribute resources equitably from institutions to primary healthcare centers, including both equipment and personnel, and in such a way make healthcare services accessible to all populations.

5.8 RESEARCH

In order to decide how best to deal with poverty and inequality in South Africa, we need to understand the exact size and dynamics of the problem. The White Paper on an Integrated National Disability Strategy (1997), has acknowledged the need for research in the area of disability and poverty, but has raised concerns regarding the nature of data gathering, such that it encompasses the biomedical aspects of disability as well as the social, economic and political aspects.

As is evident from this study, the use of participant observation and narrative interviews is a sensitive measure for researching disability and its effects in context. Furthermore, this study confirmed the need for further research to be done in the area of childhood disability such that findings can be used for proposing strategies for improved management of children with cerebral palsy. This is particularly relevant to rehabilitation professionals since we are in the ideal position to advocate for both patient and caregiver's needs.

5.9 CONCLUSION

Since April 1994, great strides have been made in the area of service provision to previously disadvantaged communities. However, this has yet in many areas, to access those who are truly marginalized. The acknowledgment of this and attempts to rectify the inequalities of the past is the first step towards achieving a caring nation, with recognized democratic values and a social justice system that is based on equality, non-racism, non-sexism and human dignity. But how are we going to attain this in a culture as diverse as South Africa? As a starting point we need to identify a means of obtaining such information. It has been said that ethnography reveals only part truths about *humans*, while the implementation of traditional quantitative research methodologies reveal part truths about *things* and thus loses sight of the highly subjective content of illness and healing as lived experiences (Scheper-Hughes, 1990). Thus, ethnographic principles allow us to derive personal meaning, which would not be possible using any other form of research. In addition to using ethnographic research methods, Stein et.al. (2007);

Brashers (1999); and Leydon et al. (2000) recommend eliciting narratives, specifically narratives of hope as a means of managing uncertainties as hope provides a mechanism of dealing with the present while accepting that the future cannot be controlled. Thus it can be said that qualitative research, including ethnographic principles, can be applied as a tool for better understanding disability within the South African context.

Secondly, these methods of collecting data, as well as their potential use within the clinical setting needs to be taught at both an undergraduate and postgraduate level and implemented within specific healthcare contexts.

Thirdly, the relevance of contextual information cannot be ignored and the potential for capitalizing on the notion of *ubuntu* in an attempt to change the attitudes of communities with regard to persons with disabilities needs to be a focus of the curriculum in South African training institutions in order to maximize on the efficacy of therapy.

In conclusion, I draw on the words of Louis Nzimande, DPSA National Chairperson (2001, p.vii-viii), who states *"…People with disabilities cannot achieve transformation alone – disability discrimination is about the attitudes of leaders and society as a whole. We therefore need the support of ALL leaders and decision-makers at ALL levels to consciously focus on the eradication of all forms of discrimination against people with disabilities and the promotion of a society for all"*.

CHAPTER 6
The road to a better future…



Image 7: The road leading to one of the participant's homes

Based on the discussions in chapters 4 and 5, it emerged that the experience of caring for a disabled child is extremely complex. It has physical, social, emotional, and financial implications, placing a great deal of strain on the caregivers. Furthermore, as has already been established, the majority of people with disabilities live in the most poverty-stricken and under-developed areas of South Africa (White Paper on an Integrated Disability Strategy, 1997) and poverty pervades all aspects of life as depicted in model 1 on page 70. This creates a vicious cycle, where poverty renders people vulnerable to disability and where disability reinforces and deepens poverty. Thus, the poor are marginalized and at a significant disadvantage in preventing the onset of disability and in ameliorating its effects (Alston, and Mngadi, 1992; McNeil, 1993; and Syme and Berkman, 1981). Research and intervention must therefore be aimed at promoting social and economic community development, particularly by empowering caregivers and promoting opportunities for people with disabilities in order to reduce the health, welfare and economic burden on South Africa.

The fact that only one participant in this study reported concern that her child was unable to speak and only a few participants reported health-related concerns is a point that requires further attention. This could be due to the fact that of the twenty-seven participants interviewed, all had access to rehabilitation services and therefore the responses obtained cannot be generalized for all caregivers caring for a child with cerebral palsy in Tonga, Mpumulanga. Of significance was the fact that the research mediator was aware of eight children with cerebral palsy whose homes were inaccessible by motor vehicle, and thus these caregivers' experiences may have been very different. Nonetheless, the fact that so few participants reported health-related concerns was alarming yet this concurred with the Nkomazi IDP Executive Summary (2003) where healthcare needs are ranked as the tenth most pressing need out of fifteen needs of the people residing in the Nkomazi municipality, as discussed in chapter 2. While this holds great implications for the role of the speech-language therapist working in rural areas, it is not a new theme, and concurs with the findings of Helander (1992), where it was reported that most commonly felt needs among those affected by disability in developing

countries are expressed as functional problems in daily life activities, education needs, needs for income generating activities, lack of family and social integration, concerns relating to participation and representation in community affairs and security needs. Furthermore, O'Toole (1991) points out that health needs come last in the needs of communities. In communities where poverty prevails, such as in the rural areas of South Africa, health needs are rated lowest against other pressing needs such as improved living standards, education and adequate food supply. This needs to be taken into account nationally, in the allocation of resources and budget, and in the development and implementation of policies. It is thus not plausible for us as healthcare providers to assume that we can be effective without addressing and advocating the rights of marginalized communities first, such as the provision of basic services.

The above finding places a burden on therapists working in the public sector, many of whom work in under-resourced areas without the support of a multidisciplinary team and as a result, the task of addressing all areas of disability (physical, social, emotional and financial) becomes the sole responsibility of the therapist. A study conducted by Kromberg, Crouch, Homer and Zwane (1998) revealed that healthcare professionals working in rural areas felt that they were unable to work effectively due to a heavy workload, unsuitable working space, lack of resources, little support and lack of supervision, and the experience of carrying too much responsibility. This needs to be urgently addressed at a national level, if therapists are expected to provide an accessible and equitable service to all (White Paper on an Integrated Disability Strategy, 1997). It cannot be expected that therapists will work efficiently and effectively if their work environment is not conducive to such output.

Not only are therapists burdened by heavy caseloads and few resources, but they are also faced with ethical challenges on a daily basis. The fact that South Africa is a multi-lingual and multi-cultural country with so many socio-economic gives rise to a special set of ethical concerns. Should therapists guard against imposing their own cultural and religious norms on their expectations of the client or patient? An ethical theory of relevance to this debate is that of cultural relativism which states that there are no

absolute, morally acceptable actions but that all actions can only be judged from the social context in which they occur. Cultural relativism, however, should not be confused with individual or ethical relativism in which each individual by determining what action in right for him, determines what is correct (Rosada, 1990). Cultural relativism rests on the basis that what is right depends on whether the society within which the act takes place regards it as being morally acceptable, and maintains that no one group can decide for another group what constitutes a moral behaviour. This needs to be addressed at an undergraduate level such that new graduates are equipped to work equitably in communities whose beliefs and practices are different from their own. This also implies that the discourse of healthcare needs to be revised so that it presents the notion of serving to empower the consumers of the healthcare service rather than judging, researching and presenting them to the public as hurt and in need of help. We as healthcare providers, clinicians and researchers need to review our methods and notions of 'help' in such a way that we move away from *'the gaze that judges'* to *'a gaze that looks back and sees'* (Abrums, 1995 in Abrums, 2000, p.93).

As revealed in the previous chapter, this study served to highlight the degree of marginalization among disabled people and their families in Tonga, Mpumulanga. By means of highlighting this plight, the study revealed a number of downfalls in the area of service provision in South Africa. Evidence of ignorance, misconceptions and negative attitudes towards those with disabilities emerged. This is consistent with the findings of the World Health Organisation (1995) where it was found that opinions, attitudes and beliefs about people with disabilities influences the way in which society interprets disability and interacts with disabled individuals. This is supported by the White Paper on an Integrated Disability Strategy (1997) which reports that society's negative attitudes towards disability has led to the marginalization of people with disabilities. This has contributed to a serious limitation in the capacity of provincial and local organisations to plan and implement disability-related programmes, particularly in rural areas. Thus, greater emphasis needs to be placed on the advocacy of research activities and the implementation thereof that will contribute to the development of public awareness through the adequate flow of appropriate kinds and levels of information and

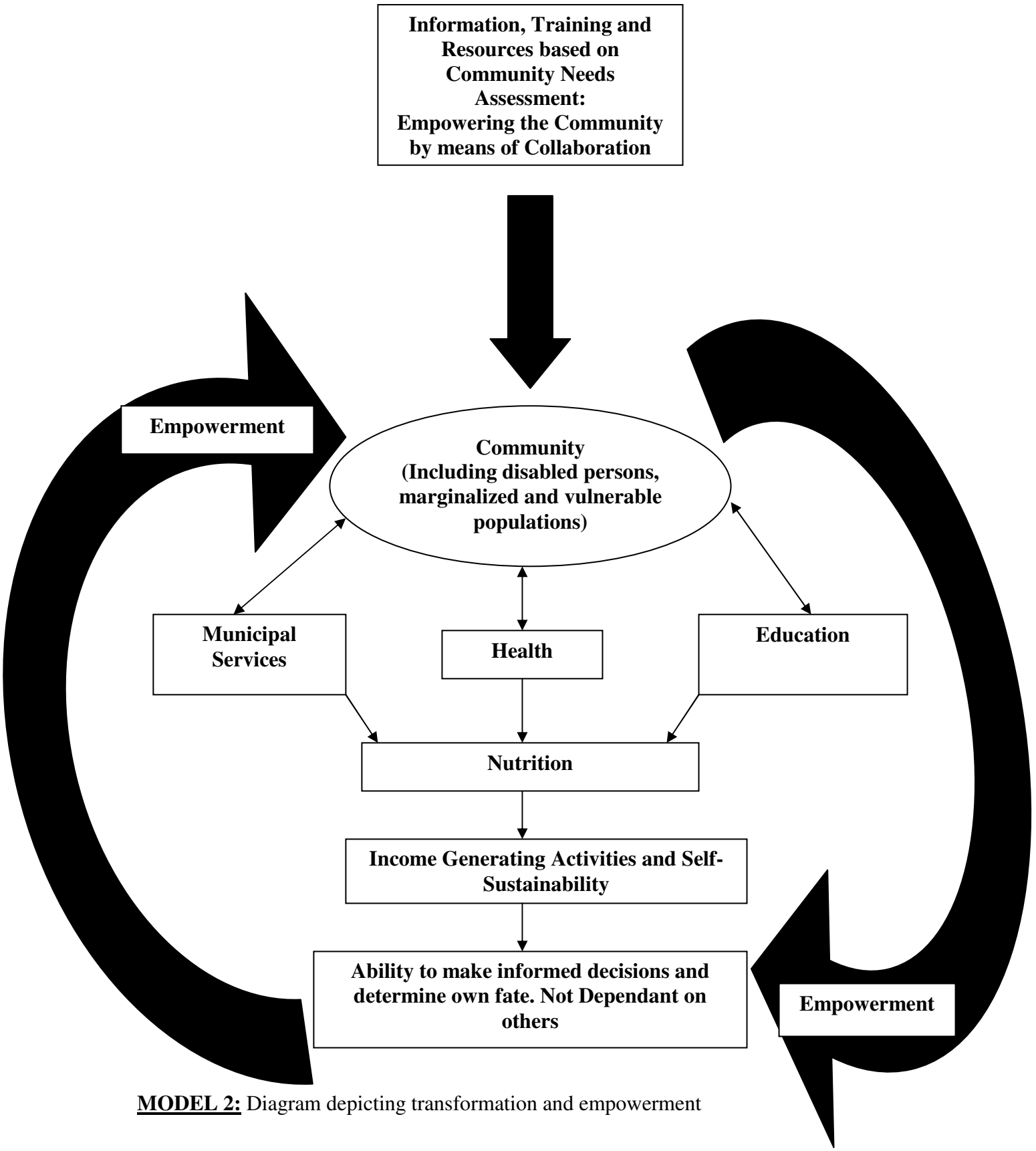
interventions so as to counter existing prejudice and stereotypes and to advance the rights of people with disabilities.

International experts have met on numerous occasions (WHO, 1982; and WHO, 2005) intent on making rehabilitation an essential form of healthcare which is practical, scientifically sound, accessible, affordable, acceptable and appropriate to individuals, their families and their communities. By focusing on therapy within the context of the community (as opposed to institution-based rehabilitation), the disabled person and their caregivers would be provided with education and rehabilitation which would focus on the individual's ability to function within the family unit and the community as a whole. This necessitates the recognition that it is important to bring about context-specific improvements amongst the entire population rather than to provide the highest standard of care for a privileged few (Mpofu, 1999). As mentioned previously, the White Paper on an Integrated Disability Strategy (1997) has identified women, children, the elderly, people with disabilities, people with intellectual impairments, people with Acquired Autoimmune Deficiency Syndrome (AIDS), and those living in rural areas as particularly vulnerable populations. While targeting these so-called 'vulnerable populations' is undeniably important, a vital research question to ask is *why* these groups are particularly vulnerable in the first place. Perry et al (1990) suggest that public health research and intervention programmes that target behavioural risk factors for disability without seeking to unravel and engage their psychosocial and environmental determinants would in all likelihood meet with limited success and do little to further the literature on disability. Identifying specific psychosocial and environmental determinants as targets for change, as well as gaining a comprehensive understanding about which factors are salient is crucial if health promotion interventions are to be effective and efficient.

Extrapolating from the above, if we are to develop a national coordinated approach to disability in South Africa, it is important to recognise that disability is a social construct and therefore needs to be mediated within a human rights and development framework, rather than being viewed as a health and welfare problem. Such an approach cannot be implemented without effective communication amongst disabled people, their families,

professionals, and with the knowledge of community resources. These factors are crucial for the amelioration of perceptions that cause stress amongst those affected by disability. In addition, changing the way in which people regard disability from a health and welfare issue to a primarily human rights and development issue has significant implications for the principles, objectives and goals of existing welfare services. It implies that welfare services need to be designed to facilitate independence in society rather than dependence on welfare services (White Paper on an Integrated Disability Strategy, 1997).

In reviewing the model presented on page 70 which depicts the pervasive nature of poverty it is clear to see that while poverty pervades all aspects of life, disability is central and reciprocal in nature to lack of access to healthcare, information and education; lack of safety and security; spread of disease; malnutrition; over-crowding and unsanitary living conditions; and unemployment. Thus what is needed is transformation such that marginalized communities including those living with disabilities and those caring for persons with disabilities are empowered to bring about change. The recurring comment throughout the interviews was ***"…but what can they do?"*** This implies that in order to bring about change a multi-sectoral approach must be implemented in collaboration with community members. Model 2 below provides a graphic representation of a model to bring about transformation and empowerment to this disempowered community.



MODEL 2: Diagram depicting transformation and empowerment

Based on the above, if transformation is to take place it must be acknowledged that this must occur at the level of the community. Based on the information obtained by means of narrative interviews and the element of disempowerment that emerged it is clear to see that the community would need assistance from the outside. However, this would need to be done based on a needs assessment of the community, particularly of the marginalized and vulnerable populations – in this case the caregivers of children with cerebral palsy. By assisting the caregivers to identify their needs and by providing or assisting the community in acquiring information, training and resources, would contribute to empowerment and community upliftment. This would rely on input from various sectors including social services, health, education and municipal services. However, independent living and self-sustainablity will not be possible if the provision of services and training is the end point, but should rather be seen as a means to an end. By assisting the community with the above it is envisaged that they will come to know their rights and be able to demand the provision of basic municipal services such as roads; electricity and water; access to appropriate and equitable healthcare; and education. In so doing the community would transform from a disempowered population ravaged by the effects of HIV, poverty and discrimination to an empowered society who is capable contributing, physically and emotionally to its well-being as a whole. At this point, the external source who provides information, training and resources to the community would gradually withdraw, but remain in contact with the community from a support point of view. Only with the provision of municipal services, healthcare and education will the community have access to and knowledge about appropriate nutrition. This implies that the community will be able to engage in income generating activities such as planting vegetable gardens and selling the crops, daycare centres, the production of arts and crafts, and the establishment of support groups. The success of this initiative would imply that the community as a whole, including disabled and marginalized populations would be able to make informed decisions and in such a way be able to determine their own fate.

While the above model does not apply implicitly to caregivers of children with cerebral palsy, it is applicable to any population or to the community as a whole. This is relevant as it is important to consider that no person or population exists in isolation, but rather

that all beliefs, actions and consequences are products of interactions with others. Significantly the application of this model does not rely predominantly on funding but rather on education and developing a culture of rights and responsibilities. Thus, both research into disability and intervention should reflect a shift away from traditional individualistic perspectives to social empowerment models that focus on the complex interaction between people, resources and the environment in an ideologically informed fashion (Fawcett, 1990). This approach implies that it is not possible to produce truly meaningful research or to bring about change without the partnership of the communities and people with disabilities. The use of ethnographic methods and narrative interviews in the study of the experience of disability has shown itself to be a useful research tool for understanding the nature and complexity of disability in context. Therefore, in order for research to be meaningful and effective, a process of participatory action research (Whyte, 1991) is recommended. By implementing participatory action research (Whyte, 1991), the most disadvantaged people are involved in the process of identifying their needs and establishing ways to empower themselves.

Of necessity, this community-based research must adopt a style that motivates local people or research findings will not be understood and therefore be meaningless to the community. In traditional research methodologies, results often emerge too late to be of value, and recommendations may not be appropriate. Participation by people affected by disability in decision making, planning and evaluation at all levels would provide a formidable impetus for addressing disability in a systematic and empowering fashion.

In conclusion, it is important to note that the above imperatives demand a holistic transformation of the disability service provision sector and it is unlikely to be realised in the absence of well-organised and collective national strategies. This will involve examining the chasm that exists between policy-making and policy-implementation, especially in the context of scarce national resources (Bhagwangee and Stewart, 1991). In particular, if the ideal of healthcare professionals is to work in the interests of people with disabilities and their families, it is vital that we as service providers redefine our roles beyond education and service provision, but extend this to include contributions toward

the empowerment of people with disabilities, and include such people in participatory research. Finally, research is meaningless unless it does justice to people with disabilities and they should be the ultimate judges of research and service excellence within a context of informed social transformation.

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Appendix 1 - Topic areas to be covered in interview with primary caregivers

1. Personal Experience of Cerebral Palsy

Tell me about this child?
Tell me about what the child can do?
Tell me about what this child likes?
Tell me about the things that are difficult for this child to do?
Tell me about what you would like this child to do?
What would make it easier for you when caring for this child?
How do the neighbours react to this child?

2. Role of Gender

What is your relationship to this child?
Who else helps you to care for this child?
What are your other responsibilities in the home?
How many other people live in the house? What are their responsibilities?
Tell me about the child's relationship with his/her father.
(If primary caregiver is not the biologic mother) Tell me about the child's mother. Does the child have contact with his/her mother?

3. Impact of Poverty

Where do you get money from to care for this child?
Does anybody else help you to support the child financially?
Tell me about the type of food that the family eats. Does the child eat the same food as the family?

4. Cultural Beliefs and Practices

Tell me about why you think the child is like this.
What do the neighbours think caused the child to be like this
What does the father think about the child's difficulties?
Have you taken the child to a traditional healer? What did the traditional healer tell you about the child?

5. Personal Experiences of Western Medicine

Tell me about the first time you took the child to the hospital or clinic because of the cerebral palsy.
Tell me what the doctors tell you about the child.
Tell me about any good experiences you've had at the hospital.
Tell me about any bad experiences you have had at the hospital.

Appendix 2 – Information letter for research mediator

Dear Lindiwe

As I have mentioned to you over the telephone I am doing a study to help speech therapists working in rural areas to better understand what it is like to care for a child with cerebral palsy. In addition, by carrying out this study I hope to gain a better idea of what the needs are of caregivers of children with cerebral palsy in rural areas. This will help speech therapists in being able to plan more appropriate therapy.

I will be collecting my information for the study next year over three months. I plan to visit Tonga to collect my information in March, April and May 2006 and each visit would last 3-4 days.

I would like to invite you to participate in this study for two reasons. Firstly you have an excellent understanding of disability and secondly I have worked with you before and I think that we have a good working relationship. I would obviously not expect you to do this for free and would pay you R100 per 8 hour day or R15 per hour.

Your role in the study would be the following:

- Identifying 3 children with cerebral palsy between the ages of 4 and 6 years who have a problem with communicating, feeding and other daily activities (such as dressing, bathing, going to the toilet)
- Introducing me to the female primary caregivers of these children (mother, sister, aunt, neighbour, etc) on my first visit to Tonga (in March 2006) and asking if they would be prepared to participate in the study.
- Going with me to the homes of the children with cerebral palsy (on my second visit in April 2006) and observing the daily routine of the caregiver and child
- Going with me again to the homes of the children with cerebral palsy on my third visit (in May 2006) and carrying out interviews with the caregivers (I will provide you with the questions that need to be asked).

Possible Risks

1. Although I will be consulting with your supervisor, Milani Wolmarans for permission for you to participate in the study, it is time consuming and will require your time for 12 days over three months (4 days per month). This will mean that you will be unable to do your usual work over these days.

Possible Benefits

1. You will be contributing to research in South Africa and ultimately improving the efficiency and effectiveness of speech-language therapy in rural areas.
2. You will be acquiring new interviewing skills which may in turn help you with interviewing and counseling new clients.

   If you agree to participate in this study I will discuss the terms of this contract with your employer in order to ensure that you do not lose any income while assisting me in this study.

Please consider the study and let me know if you would be prepared to assist me in carrying it out. You should not feel under any pressure to participate, however, if you do decide to participate I will ask you to sign a contract stating that you are committed to assisting me in carrying out the study over the full 3 months. In addition all information gained will be confidential and no participants' names or personal information will be mentioned in the study.

I think that this is an interesting study and that the results will be very valuable for speech therapists working in rural areas. If you have any questions or want to discuss the study you can contact me on my cell on 084 840 0046 or at work on (011) 488 4293. Alternatively you can send me a 'please call me' and I will call you back.

Yours faithfully

Joanne Barratt
Speech Therapist

Appendix 3 – Contract for research mediator

I _____ hereby agree to participate in the study concerned with caring for a child with cerebral palsy in a rural area.

I have read the information letter and understand the aims of the study and what will be required of me.

I understand that all information gathered during the study is confidential and no mention will be made of the participants' personal details.

I accept the remuneration offered to me in the information letter.

Signed _____ Witness _____

Date _____

Appendix 4 – Information letter for caregivers

Dear Caregiver

My name is Joanne Barratt and I am a speech therapist conducting a study to help us as speech therapists to understand what it is like to care for a child with cerebral palsy in a rural area. This will make it easier for us to see what your needs for your child with cerebral palsy are and so that we can provide children with cerebral palsy with better therapy.

I would like to invite you to participate in this study. The study will involve the following:

1. Allowing me, the researcher, and Lindiwe Thobela, the CBRW in the Tonga area to visit your home for a day so that we can watch your daily routine and obtain a better understanding of the difficulties involved in caring for a child with cerebral palsy in Tonga. This will take place in April 2006.
2. Allowing me, the researcher, and Lindiwe Thobela, the CBRW in the Tonga area to visit you in your home a second time (in May 2006) and talk to you about what it is like to care for a child with cerebral palsy in Tonga over the course of a morning or afternoon. This discussion will take place in Siswati, where Lindiwe will talk to you and I, The researcher will only watch the discussion taking place. Lindiwe will ask you questions about what it is like to care for you child with cerebral palsy, about your beliefs surrounding the causes of cerebral palsy, about your neighbours reactions to your child, and about who helps you to care for the child.This discussion will be tape recorded so that the researcher can listen to it again at a later stage and take notes. Once the information has been gained by listening to the tapes, the tapes will be destroyed.

Possible Risks

1. It is possible that the other members of your community may think that you are receiving special treatment since we will not be visiting all members of the

community and may treat you differently since you are receiving a visit from the hospital that they are not receiving.

Possible Benefits

1. You will be contributing to research in order to improve the services offered to caregivers and children with cerebral palsy in Tonga.
2. We will be addressing your individual concerns regarding the child with cerebral palsy and where possible, with your consent, we will refer you to the relevant authorities to address these needs.

You should not feel under any pressure to participate and if you decide not to participate, this will not change the treatment you receive at Tonga hospital or the service that Lindiwe delivers to the community. If you decide to participate but do not wish to answer some of the questions in the interview, we will respect that. In addition, if you decide that you would like to participate all information that you give us will remain confidential and neither your nor any of your family members' names or personal details will be mentioned in the research.

If you have any questions please do not hesitate to contact me on 084 840 0046 or to contact Lindiwe at Tonga Hospital on (013) 780 0222.

Yours faithfully

_____

Joanne Barratt
Speech Therapist

Appendix 5 – Informed consent form for caregivers

I, _____ hereby agree to participate in the study concerned with caring for a child with cerebral palsy in a rural area.

I have read/understand the study and understand what will be required of me.

I understand that participation is voluntary and should I wish to withdraw I may do so with no negative consequences.

I understand that all information gathered during the study is confidential and no mention will be made of the mine nor my family's personal details.

Signed _____ Witness _____

Date _____

Appendix 6 – Consent form for audio-taping

I, _____ hereby give consent for my conversation with Lindiwe Thobela regarding caring for my child with cerebral palsy to be taped. I understand that once the information needed from the tapes has been gathered, the tapes will be destroyed. In addition, I understand that all information on the tape is confidential and that at no point will any reference be made to my or my family's personal details.

Signed _____ Witness _____

Date _____

Appendix 7 – Information letter for rehabilitation department, Tonga Hospital

Attention: Mrs K. Cameron

Dear Sir/Madam

My name is Joanne Barratt. I am currently carrying out a study on the experiences of caregiver's of children diagnosed with cerebral palsy in Tonga in fulfillment of my Masters degree in speech pathology.

The study is relevant to the area of speech therapy since it will help speech-language therapists working in Tonga to develop a better professional understanding of socio-cultural processes in the context and ultimately to understand what it means to look after a child with Cerebral Palsy in a rural area. In addition, it will help to identify the needs of caregivers and persons with Cerebral Palsy living in Tonga and thus to better identify the role of the speech-language pathologist working in rural contexts. By implementing a system of ethnographic data collection it will be possible to assess the value of implementing techniques coined from other disciplines in terms of assessing and managing patients in need of speech-language therapy in rural areas.

The study will involve the following:

- The researcher will review the statistics in the rehabilitation department at Tonga Hospital in order to determine to what degree cerebral palsy constitutes the workload of the therapists.
- An interview with the therapists in order to determine the current nature of treatment offered to children with cerebral palsy residing in Tonga.
- Observation of treatment of a cerebral palsy child in order to verify the verbal report on the nature of treatment offered at the hospital.
- Observation of the child with cerebral palsy in his or her natural home environment in order to provide the researcher with a better understanding of what it means to have a child with cerebral palsy in Tonga.

- Interviewing the primary caregiver of the child with cerebral palsy in order obtain a better understanding of what it means to have a child with cerebral palsy in a rural area.

The study will be done over 3-4 months, with the researcher visiting the site of research for 3-4 days each month. The researcher will employ the services of the community based rehabilitation worker (CBRW) to mediate and translate during the data collection process.

You should not feel under any obligation to participate in this study. Should you decide to participate all information gained from your institution will be treated as highly confidential no individuals' names or personal details will be stated in the study or in the discussion thereof. In addition, should you agree to participate but with time choose to withdraw, you are welcome to do so without any negative consequences.

Should you have any queries regarding this study, please do not hesitate to contact me on 084 840 0046.

Yours faithfully

_____

Joanne Barratt
Speech Therapist

Appendix 8 – Information letter for Mpumulanga rehabilitation coordinator

Attention: Coordinator of Rehabilitation, Mpumulanga
Milani Wolmarans

Dear Madam

My name is Joanne Barratt. I am currently carrying out a study on the experiences of caregiver's of children diagnosed with cerebral palsy in Tonga in fulfillment of my Masters degree in speech pathology.

The study is relevant to the area of speech therapy since it will help speech-language therapists working in rural contexts to develop a better professional understanding of socio-cultural processes in the context of Tonga and ultimately to understand what it means to look after a child with cerebral palsy in a rural area. In addition, it will help to identify the needs of caregivers and persons with cerebral palsy living in Tonga and thus to better identify the role of the speech-language pathologist working in rural contexts. By implementing a system of ethnographic data collection it will be possible to assess the value of implementing techniques coined from other disciplines in terms of assessing and managing patients in need of speech-language therapy in rural areas.

I would like to ask permission to contact Ms Lindiwe Thobela, the community based rehabilitation worker in Tonga to act as the research mediator in the study. The study will be done over 3-4 months, with the researcher visiting the site of research for 3-4 days each month. Ms Thobela's role in the study would be the following:

- Identifying 3 children with cerebral palsy between the ages of 4 and 6 years who have impairments involving communication, feeding and other daily activities (such as dressing, bathing, going to the toilet)
- Introducing me to the female primary caregivers of these children (mother, sister, aunt, neighbour, etc) on my first visit to Tonga (in March 2006) and acquiring informed consent to participate in the study.
- Accompanying me to the homes of the children with cerebral palsy (on my second visit in April 2006) and observing the daily routine of the caregiver and child.

- Accompanying me a second time to the homes of the children with cerebral palsy on my third visit (in May 2006) and carrying out interviews with the caregivers (A list of guiding questions will be provided and training on carrying out the interview will be carried out during the first visit in march 2006).

While participating in this study in the capacity of research mediator will mean that Ms Thobela will not be able to carry out her usual work, she will be contributing to the development of speech-language therapy services in rural contexts and ultimately to improve the efficiency and effectiveness of these services. In addition she will receive training on using a narrative framework interview which may improve her interviewing skills. This interview technique strives to obtain an accurate and detailed explanation of the problem without the interviewer imposing their outlook on the interviewee. Due to the fact that Ms Thobela would be contributing significantly to the study, I would reimburse her for her time at a rate of R100 per 8-hour day or alternatively R15 per hour, which is in line with the University of the Witwatersrand guidelines for paying research assistants.

Please consider allowing Ms Thobela to participate in this study since not only will it strive to improve the quality of services in rural areas, but will also allow Ms Thobela to contribute to research in South Africa and also to acquire new skills in terms of interviewing.

Should you have any further queries, please do not hesitate to contact me at work on (011) 488 4293 or on my cell phone 084 840 0046.

Yours faithfully

Joanne Barratt
Speech Therapist

Appendix 9 – informed consent for Mpumulanga rehabilitation coordinator

I, _____ in the capacity of rehabilitation coordinator in Mpumulanga, agree to allow Ms Lindiwe Thobela participate in the study regarding the experiences of caregivers caring for children with cerebral palsy in Tonga as the research mediator.

I have read the information letter and understand the nature of the study.

Signed _____ Date _____

Witness _____

Appendix 10 – Information letter for Department of Special Educational Needs

Attention: Department of Special Educational Needs

Nkomazi Municipality

My name is Joanne Barratt. I am currently carrying out a study on the experiences of three caregiver's caring for children diagnosed with cerebral palsy in Tonga over the period April-May 2006 in fulfillment of my Masters degree in speech pathology.

The study is relevant to the area of speech therapy since it will help speech-language therapists working in rural contexts to develop a better professional understanding of socio-cultural processes in the context of Tonga and ultimately to understand what it means to look after a child with cerebral palsy in a rural area. In addition, it will help to identify the needs of caregivers and persons with cerebral palsy living in Tonga and thus to better identify the role of the speech-language pathologist working in rural contexts. By implementing a system of ethnographic data collection it will be possible to assess the value of implementing techniques coined from other disciplines in terms of assessing and managing patients in need of speech-language therapy in rural areas.

Part of my study involves an in-depth interview with the caregiver's of children with cerebral palsy in Tonga. The nature of the interview looks at personal experiences of caring for a child with cerebral palsy and probes the caregiver's concerns, as well as the nature of the caregiver's support systems, perceived stigma within the community, the role of religion, the role of gender within the community and personal experiences of western management of cerebral palsy at hospital level. Due to the nature of the interview it is possible that caregivers may raise the schooling for the child as a major concern.

I would like to ask permission to refer these participants to you should the caregivers raise education as an area of concern. Should you agree to consult with these participants should the need arise, I will contact you to discuss your process for referral.

Should you have any further queries, please do not hesitate to contact me at work on (011) 488 4293 or on my cell phone 084 840 0046.

Yours faithfully
Joanne Barratt
Speech Therapist

Appendix 11 – Informed consent for Department of Special Educational Needs

I, _____ as a member of the department of special educational needs agree to consult with the participants of the study who raise education as concern regarding their child.

I have read the information letter and understand the nature of the study.

Signed _____ Date _____

Witness _____

Appendix 12 – Information letter for Department of Social Work, Tonga Hospital

Attention: Social Work Department
Tonga Hospital

My name is Joanne Barratt. I am currently carrying out a study on the experiences of three caregiver's caring for children diagnosed with cerebral palsy in Tonga over the period April-May 2006 in fulfillment of my Masters degree in speech pathology.

The study is relevant to the area of speech therapy since it will help speech-language therapists working in rural contexts to develop a better professional understanding of socio-cultural processes in the context of Tonga and ultimately to understand what it means to look after a child with cerebral palsy in a rural area. In addition, it will help to identify the needs of caregivers and persons with cerebral palsy living in Tonga and thus to better identify the role of the speech-language pathologist working in rural contexts. By implementing a system of ethnographic data collection it will be possible to assess the value of implementing techniques coined from other disciplines in terms of assessing and managing patients in need of speech-language therapy in rural areas.

Part of my study involves an in-depth interview with the caregiver's of children with cerebral palsy in Tonga. The nature of the interview looks at personal experiences of caring for a child with cerebral palsy and probes the areas of support systems, perceived stigma within the community, the role of religion, the role of gender within the community and personal experiences of western management of cerebral palsy at hospital level. Due to the personal nature of the interview, it is possible that it may elicit large scale emotional responses by the caregivers. Alternatively, caregivers may raise questions regarding child support grants and/or disability grants.

I would like to ask permission to refer these participants to you should such a situation arise. Should you agree to consult with these participants should the need arise, I will contact you to discuss your process for referral.

Should you have any further queries, please do not hesitate to contact me at work on (011) 488 4293 or on my cell phone 084 840 0046.
Yours faithfully

Joanne Barratt
Speech Therapist

Appendix 13 – Informed consent for Social Work Department, Tonga Hospital

I, _____ in the capacity of social worker at Tonga Hospital agree to consult with any of the three participants in the study concerned with the experiences of caregivers caring for children with cerebral palsy in rural areas, should the interview elicit an emotional response or should the caregivers raise questions regarding social grants.

I have read the information letter and understand the nature of the study.

Signed: _____ Date: _____

Witness: _____

The following appendices contain the translated and transcribed interviews, as well as the field notes for all of the participants.

The information contained here is highly confidential. For this reason, and in order to maintain confidentiality, all names, legal status of the participants, place names, and geographical locations have been withheld. Transcripts and field notes are ordered randomly, and participants are referred to using random letter names. The order in which the transcripts appear does not relate to the order in which the participants were interviewed.

None of this information may be used, reprinted, quoted or reproduced without the written consent from the author.

Appendix 14 – Interview A

Where was the child born:

- he was born in Maputo
- his surname is XXX

What happened between you (mother) and the father:

- we broke up because of the child because I got the baby when I was 7 months pregnant
- He chased me away, he didn't want the baby because it was tiny he said I must go back home or kill the baby.
- My sister took me and him in when I got back home.
- I got a new man who we both stay with now
- He accepted my baby and loves him

What was your reaction when you realised that the child was disabled:

- it took me a while to understand, I just prayed and said he is my blessing from God
- it was very painful though.

What does the child do now:

- unlike other children his age he just started crawling now and he is 4years old
- he runs using his knees, but he plays with other children
- it is difficult for him because he cant do things that his friends do like he also wants to get up and run like every one else
- he tries standing up but cant so he resorts to his knees.

What do you do when he cries:

- I just carry him using my back until he keeps quiet (mother)
- I don't really give him anything I just tell him that I'm sorry

How do the neighbours treat him:

- they like him, he goes to them and they play with him but sometimes they just ignore him and not play with him
- the step-father's family do not like him at all

Do you stay with anyone:

- no the child does not even have any grand parents, they passed away so it is just me

What do you think can help the child?

- I think the walking ring or something similar since I can't afford one myself
- He does not even have a birth certificate so he does not get any money from the Government grant.

How many people live in your household:

- There are three children and I the father works far.
- The stepfather is the one who supports us and he is the only one
- The child's father is not helping in anyway
- The stepfather helps us a lot but other people influence him not to give us money
- The stepfather gives us R300.00 monthly if he can, but he tries to give me every month.

Are there other sources of income:

- yes I sell stuff like cooked fish but it does not give me much because sometimes people do not buy
- it is not easy supporting my two kids with the money I make, I feel that it is not enough.

What kind of food does he eat?

- He eats everything we eat in the house i.e. solids and liquids
- He really manages with everything that he is given, even though he could have a much better diet if I could afford it.

What do you think caused the child's disability:

- I think that maybe there was a problem when I was giving birth to him
- Traditionally speaking I would say it is what we call (umuti) polio.

What actions have you taken about this situation:

- I have been to traditional healers, they say it is polio and gave me medicine for it but it did not help
- after the traditional medication did not work I chose to stick to the western ways which seemed to be more effective

When you went to the hospital the first time, was it different from traditional ways :

- I got there and they took the child to gym which I thought as helpful
- They gave me reassurance that his situation would get better which really sounds more promising.
- I think the hospital is much better.

Is there any progress at the hospital?

- They said they will give us a walking ring to help him walk, but they have run out so far.
- the gym sessions are helping him a lot
- the people in hospital are very helpful and it is much simpler

Is there anything you do not like about the hospital system:

- no, so far everything I do not have any complains

What do your boyfriend's sisters or family say about your situation:

- My boyfriend has been good to me and the child even though he is not the real father he has been supporting us regardless of everything else
- I have experienced problems with his family who are against the relationship because they feel I am using him to support another man's child.
- It is very difficult to ignore such things, they went as far as telling him to kick us out of his house which is now our home. I am not moved though because I know that he loves us

Financial problems lead you to not being able to cater for your child's needs?

- yes I can not even afford to buy him the necessary equipment to help him cope with his situation
- also the fact that he can not get proper food

are there any other things that you would like to mention:

- it is difficult to see other children walk and yours can not.
- Another thing is that I always have to take him everywhere I go because no one would be willing to help look after him, they complain that he cant even say when he needs to go to the toilet, they say he is just an inconvenience
- I really would appreciate some help, those few that do care to help sometimes also say things about my son.
- It is very painful because I did not ask for a disabled child

How do you deal with all these emotions:

- it is very difficult, firstly dealing with the changes that I have had to go through to accommodate my baby
- most of the time I just let it pass, but I deal better with it when I go to the clinic and find other women who have children with the same problem it feels good to know that I am not alone.
- The difficulty of losing a person who claimed to love me because of the baby we had is just painful.

All we care about is the wellbeing of the child, would you say the child is well in this home:

- I would say that besides the financial problems he has all the love from me and the step-father.
- Although life has changed I feel that we are doing fine, we are well taken care off.

Appendix 15 - Participant A: Paraphrased Interview and Ethnography

Distance of home from tar road:	2km
Electricity:	no
Water:	no – collects water 3km away
Number of people living in house:	4
Sanitation:	long-drop on neighbour's property
Disability grant recipient:	no – child does not have birth certificate
Other financial support:	yes, mother's boyfriend
Belief in cause of disability:	problem while giving birth, umuti
Child's difficulties:	talking, standing, walking
Perception of child's needs:	walking ring, better nutrition
Support structure:	none

The interview was conducted with the mother of the CP child in XXX village on the afternoon of X May 2006. The weather was freezing cold, windy and raining. Lindiwe and I arrived at XXX clinic and phoned the mother to get directions to her home. Unfortunately the directions that she gave Lindiwe were not clear so she ran to the clinic to meet us and take us back to her home. The home was approximately 2km off the tar road. The sides of the road leading up to the home were lined with makeshift graves, covered with upturned basins – according to Lindiwe, a cultural belief that one should be buried with the product that was used to keep you clean and pure. The graves were not dug out, but rather corpses had been laid to rest and covered with mounds of sand. Minutes later we arrived at the house which was a single room which the mother shares with her 2 children and her boyfriend when he comes to visit.

On arrival we were greeted and taken into the single room home. The room was divided by a curtain separating the 'living area' from the 'bedroom'. A chair was put out for me to sit on and a space was made for Lindiwe's wheelchair. The CP child who was crawling around on all fours immediately began to play with Lindiwe's wheelchair. The mother turned over a bucket and covered it with a crocheted cloth as a table in front of me and sat down on her knees with the children even though there was a chair for her. The sound of kwaito music blaring from one of the neighbours' homes floated in the air and very quickly a group of inquisitive children gathered around the doorway to see what was going on and why a mulungu was visiting the house.

We sat down and Lindiwe explained why we were visiting and obtained consent from the mother. The mother sent the children over to a neighbour to play while the interview was conducted. A little girl who looked about 5 years old picked up the CP child and took him across to the neighbours. I went and sat in the car to record my field notes as it was raining and there was nowhere else for me to sit.

From the outside I realized that the house was still in the process of being built and there were 3 other rooms with half-built walls and no roofs. I found myself wondering if this house would ever be complete. Looking around there were no fences around any of the properties and no delineation of property. A sense of peace, freedom and naivety

permeated the environment. Looking around there was evidence of fertile land, with fruit trees and vegetables growing in the gardens. Neighbours lived in close proximity and I was able to watch children in the neighbour's garden chasing each other and a women with a baby on her back stirring a pot over an oven fire. All the yards were neatly swept and gardens appeared well tendered.

Inside the home I had noticed that there was a prepaid electricity point but no running water. When asked, the mother said that she had to walk about 2.5km to collect water and for this reason there was a huge drum inside the room filled with water. This posed a huge safety threat, not only having a deep tub of water in a room where young children were playing and climbing on the furniture, but also because the water was left uncovered to stagnate and attracted mosquitoes in this high malaria area.

There was no toilet on the property and mother said that she and her children use the neighbour's toilet.

The interview started with the mother informing Lindiwe that she and her children are not South Africans – they are illegal immigrants from Mozambique. When asked how they came to be in South Africa, the mother responded by saying ***"We broke up because of the child because I got the baby when I was 7 months pregnant. He chased me away. He said he didn't want the baby because it was so tiny. He said I must go home or I must kill the baby. I ran away with my two children and came here where my sister took us in".***

When asked what her main difficulties were in caring for the child, the mom responded ***"It is difficult to see other children walk and yours cannot. Another thing is that I always have to take him everywhere I go because no one is able to help look after him – they complain that he cannot even say when he wants to go to the toilet and that he is just an inconvenience. I really would appreciate some help, but those few that do care to help also say things about my son. It is very painful because I did not ask for a disabled child.***

From the observations of the child it appears that he is not a severe CP in terms of a medical diagnosis and he is able to navigate his way around by crawling and shows a distinct interest in the objects in his environment. The mom reported that he only began crawling at 4 years of age. She said he enjoys playing with other children although it is difficult for him because he wants to do things that other children do ***"and he wants to get up and run like everyone else"***. Sadly, while Lindiwe was conducting the interview I was observing all the children running around in the neighbours yard, while the CP child either watched the other children or chased then on his knees. This was substantiated in the interview where the mother reported (in a question as to how the neighbours treat him) ***"they like him. He goes to them and they play with him but sometimes they just ignore him and do not play with him at all".***

Listening to the mom's responses it appears that she knew the problem had been present since birth and said ***"I think that there was a problem while I was giving birth to him.***

Traditionally we call it umuthi". The mom reported that she had taken the child to traditional healers who confirmed that it was 'umuthi'. She said ***"They gave me medicine but it did not work. After the traditional medication did not work I chose to stick to western ways which seemed more effective".*** When asked what kind of treatment she was given at the hospital she said ***"I got there and they took the child to the gym which I thought was helpful. They gave me reassurance that his situation would get better which sounded promising. They also said they would give us a walking ring*** (standing frame???) ***but they have run out. The gym sessions are helping a lot and the people in the hospital are very helpful. It is much simpler".***

When asked how she responded once she realized that her child was disabled, she responded ***"It took me a while to understand. I just prayed and said he is my blessing from God. It was very painful though."***

Poverty was a major issue that came up in the interview and it spanned across a number of questions. It initially came up when the mom was asked what would make it easier for the child. She responded by saying ***"I think a walking ring or something similar but I can't afford one myself. The child does not have a South African birth certificate so he does not get the Government grant".*** She also reported that the father of the child does not help at all, but the stepfather, who works far away gives her R300 each month if he can. However, the stepfather's family tell him that they should not give her money or allow her to stay in his house as she is using his money to support another man's child. The mom reported that she tries to supplement their income by selling cooked fish but this does not bring in a lot of money. Twice during the interview she made reference to the fact that she wishes she could provide her children with a better diet. This was first mentioned when asked what types of food the child can eat. The mom responded by saying ***"He really manages with everything he is given even though he could have a much better diet if I could afford it"*** and secondly when asked about her financial problems she replied ***"yes, I cannot even afford to buy him the necessary equipment to cope with his situation. Also the fact that he cannot get proper food".***

From the above there is a strong sense of guilt coming through. This was compounded when the mom was asked what she does when the child cries and she responded ***"There is nothing I can do. I just keep telling him that I am sorry".*** When asked how she deals with these emotions, the mom replied ***"It is very difficult dealing with the changes I have had to go through to accommodate my baby. Most of the time I just let it pass but I deal better with it when I go to the clinic and find other women with children with the same problems. It feels good to know that I am not alone. The difficulty of losing a person who claimed to love me because of the baby we had is also painful".***

Ironically, looking around at the squalid surroundings and the lack of basic necessities, such as running water and toilets, the mom ended the interview by saying ***"I would say that besides my financial problems the child has all the love he needs from me and the stepfather. Although life has changed I feel that we are doing fine. We are well taken care of".***

Appendix 16 – Interview B

This interview was conducted with the child's mother and all questions were directed to the mother except where specified.

Tell me about the child. How was she born and what happened? Tell me everything about her birth.

- She was born in 2003 on the 27th January at 7am.
- The labour was long.
- We then stayed at the hospital for two weeks because I was sick at that time and she was in incubator because she was not crying.
- After six (6) months he got sick she was vomiting and I then took her to the clinic where they told me that she is disabled.
- They then gave me a referral letter to the hospital.

What is she doing to keep herself busy?

- She just tries to move her legs and also try to open his hands.
- Other than that, she is not doing anything because she can't hold things.

What is it that she likes to do?

- She likes playing with me and looking at other children.

What is it that the child can't do? What is it that is difficult for her to do?

- What is most difficult for her is sitting and holding things.

What do you think can make things easier for her to help her sit?

- If she can get a chair to sit or a sponge where she will sit on.

Do you have a wheelchair?

- No.

Did you asked it from the hospital?

- Yes I did and one white man told me that he will organise it for me when I come back for other appointments.

What are the neighbours saying, do they like the child?

- No., they just laugh at me saying that my child is disabled.

How is the relationship of the child with her grandmother (mums' mother)?

- It's fine.
- She loves the child so much and granny takes care of her most of the times.

Who is helping you to care of the child except granny?

- My sisters.

Who is supporting the child financially?

- It's my mother

How many are you here at your house?

- We are eight (8).

Who is supporting all of these people financially?

- It's my mother.

How is your relationship with the child's father?

- When the child was one (1) year old, he told me that he is no longer in love with me because I have a disabled child.
- I then reported this matter to both our families so that they will know what is happening.

Where is the child getting money?

- No where.
- I tried to apply for child support grant and I haven't got my reply yet.

Which food does she likes or dislike?

- She likes pumpkin, intestines, break and wheat bix.
- She doesn't like mielies alone without soup and most kinds of food.

Why did you apply for a child support grant because the child is disabled?

- They told me at the hospital that she won't get a disability grant until she is seven (7) years old.
- I also went to pension office and they gave me a child support grant form of which I have filling and sent back.
- I thought that the child dependent form is the same as the child disability grant.

What do you believe caused the child's disability?

- I don't know.
- But at the hospital they told me that she was affected and this is what I believe now.
- And my mother (granny) believes that it's because of all the misunderstandings between my family and the child's father's family.

What is the child's's father thinking about her disability?

- I really don't know.
- But what I have noticed is that, he doesn't play with the child and when he sees up he don't even greet or say anything to me or to her.
- Also he hasn't accepted that she is disabled.

What did the traditional healers say?

- We sent her to traditional healers and they said its evil spirit at home.

Tell me about the relationships of the two families (your family and the child's father's family).

- The child's father's mother doesn't want her.
- She is ashamed of her, she don't want even to go with her.
- She rather let her relatives to go with the child than her.

Before the child's birth, how was your relationship with the father?

- It was fine.
- We then broke-up after the birth of the child because of bad influence from his mother.

When you first go to the hospital, what did they do for the child?

- They gave me a sponge which they told me to put her on it no matter whether she cries or not, I must just leave her there.
- So that didn't sit well with me because she was crying very badly in such a way that I thought she might be affected because of this continues cry.
- They also showed me some exercises to do to help her.

What did the doctors tell you about the child?

- They told me that she got affected while I was giving birth.

What have you gain from all your hospital visits?

- I gained different ways of exercising her body parts and on how to feed her.

What is it that you dislike about the hospital?

- Filing process is not a problem as such for me.
- But what a have found to be a problem is the nurses listening skills.
- When I try to explain to them the child's condition they try to disagree with me thinking that I'm lying or something.

What about the doctors at the hospital, are you having problems with them too?

- No they are always understanding and sympathetic.
- There is one doctor I think he is from Cuba or anywhere in Africa.
- That doctor always gives me advises about what I should do and about life in general.

How long did it take you to accept the child's disability?

- It took 3 years to accept.
- And all this time I have been trying alternatives to help her get better.
- However, in all my hospital visits I have seen many people that are disabled like my child and that made me to accept and put things into perspective.

How long did it take the child's granny to accept her disability?

- It also took her a long time to accept.

What are your friends saying about the child's disability?

- Now I only have one true friend and all other friends of mine have left me.
- We are not friends with them anymore because they have been saying bad things about me and my child
- They've laughed at me because I have a disabled child of which I don't care.
- So I then decided that I won't be friends with them anymore and I also reminded them that they don't have any children and one day they will have a child and it might be disabled.
- So they shouldn't laugh at me because they don't know what future holds for them.

Since you have broke-up with the child's father. Do you have anyone that you now share your life with?

- There is one guy that I dated before the child's father.
- We lost contact and then I then I dated the child's father until the birth.
- Now that guy is back in my life and he treats the child as his own.

- He don't care that she is disabled, he loves him and he spent a lot of time with both of us.

Is this guy working?

- Yes.

What is it that you are both using with this guy to protect yourselves from diseases?

- We are using protection, condom protection.
- There are always there in his room and also tell him every now and then to go and test for HIV.
- This is because I know that I'm HIV negative.

What are your plans with the child's father number two (2)?

- He wants us to stay together as one happy family and I don't have any problem with that.

How is the child's relationship with her father number two (2) family?

- They love the child very much.
- This is not because she is distanced from them, they love her and they care for her.
- I visit the family alone they always ask me to go back and bring her along.

If the child is hungry, sleepy or thirsty, what is it that she does to show these needs?

- She cries all the time when she is hungry, but also I know that every morning at 8 am I have to feed her.
- And at around 11am she stops playing and come close to me, I then realise that she wants to sleep.
- However, I can't see if she wants water, I just use my imagination.
- Okay, what about an apple, does she eat an apple ((the interviewer asks))?
- No she don't like it ((says the mother)).
- Apples are healthy, always try to give her at least one apple per day ((says the interviewer)).

Is there anything that I have forgotten?

- I want to know about schooling opportunities because doctors at the hospital have been telling me to send her to school but I don't know where to take her.
- Ask the doctors to give you contact details of such schools because these schools are specially or private schools and there are very expensive ((says the interviewer)).

Why are you not working?

- I can't work because I have to take care of the child.
- And when I'm away for any reason, I get back and find the child refusing to eat because I'm not there.
- She only wants to eat when she sees me.

Does she have any other health problems except disability?

- Yes she is epileptic.

Does she hear and see well?

- Yes she can hear and see very well.

What does she do if she sees other children of her age?

- She become very happy and tries to call their names although she can't speak.

How many children do you have?

- One this one.

Can she hold things for a long time?

- Yes she can except in certain seasons where everything in her body become abnormal.

Do you find any difficulties in bathing or dressing her?

- Not when I'm bathing her.
- It's only when I'm dressing her, she becomes very stiff.
- I then leave her for a while and play with her because she tends to dress well when she is happy.

Where is she sleeping?

- She sleeps with me.

Is there anything that you would like to ask me?

- Yes, I want to know about how to apply for a grant.
- I'm not sure myself ((says the interviewer)).
- But you know what, I will give you my phone number so that you will call me ((says the interviewer)).

- I will go to the hospital and research about a disability grant for cerebral palsy children because these things (pension) changes now and then.
- What I knew was that cerebral palsy children can get grant in their first year not in their fourth year as they say.
- But I will check and then give me a call.

Appendix 17 - Participant B: Paraphrased Ethnography and Interview

Distance of home from tar road:	On tar road
Electricity:	yes
Water:	yes – jojo container on property
Number of people living in house:	8
Sanitation:	long-drop (+/- 5m from house)
Disability grant recipient:	no
Other financial support:	yes, gogo's pension
Belief in cause of disability:	unknown, mom was told child was affected at birth
Child's difficulties:	sitting and holding things
Perception of child's needs:	a chair
Support structure:	yes, gogo and other people living in house

The interview took place at the participant's home in XXX village on the morning of X May 2006. The weather was warm and sunny with a slight breeze blowing. We arrived at 8:30am and found the mother breastfeeding the child under a tree in the garden. Another lady was sweeping the verandah. From the outside the house appeared modern with large burglar-proofed windows, an ornate wooden door and a Kaizer chiefs doormat.

The house was fenced with creepers growing over the fences, so was quite private from the neighbours. Fragmented sounds of neighbours' conversations carried over the fence. The yard was neatly swept. A dog lazed under a tree and took no notice of us arriving at the house. To the left was a kraal area with an open fire roasting mielies. On the right-hand side was a long-drop toilet, a rondavel and a shed. An old truck was standing in the driveway and looked as though it at hadn't been driven in years. The garden was neat and well swept with well-maintained pot plants, trees and fruit trees and rows of vegetables.

After having to lift Lindiwe's wheelchair up the steps onto the verandah we were ushered into the house by the mother. Even from the entrance hall you could see that the house was well-equipped and excessively decorated! We were taken into the lounge where the interview was to take place. Grass mats lined the walls, a vase holding plastic flowers was on the coffee table, and plastic trinkets were adorning every surface. On the wall on my right-hand side was a poster of Adam and Even in the garden of Eden separated by a snake. On the opposite wall was a poster with an English verse from the Bible, while on the wall behind me on top of the TV cabinet was a large framed photograph of Nelson Mandela. The entire house seemed to be tiled and seemed to have most amenities. Water was stored in a large barrel outside while electricity was supplied inside the house.

Once again there was a significant lack of male presence. The mother of the child seemed very young, while the lady who appeared to be helping out with housework was also young and clinically appeared to be in the end stages of HIV. The woman's baby lay on the couch, groaning and lethargic.

Under a tree was a half-made wire car – the only symbol of some form of male presence.

This interview was interesting as the mom was quite forthcoming with information and gave detailed accounts. The mom recalls a long labour and then remaining in hospital for two weeks after giving birth as she was unwell, and the baby was premature and 'wasn't crying well'. However, it was only at 6 months when the child was sick and the mother took the child to the clinic that she was told that the child was disabled. Once again I was struck by the fact that the mother was so accepting of the disability, particularly when it was evident that she does not have a lot of support. The mom's recount of learning about the child's disability was ***"At 6 months she got sick. She was vomiting and I took her to the clinic where they told me she is disabled. They gave me a referral letter to the hospital".***

The mom reported good support, both financially and emotionally from her own mother as well as her sisters who live in the house with her. However, it appears that she has very little support from the community and her 'friends'. When asked how the neighbours react to the child, the mom reported ***"They just laugh at me saying my child is disabled".*** When asked about her relationship with her friends the mom replied ***"Now I only have one true friend and all other friends of mine have left me. We are not friends with them anymore because they have been saying bad things about me and (the child). They have laughed at me because I have a disabled child of which I don't care. So I then decided I won't be friends with them anymore and I also reminded them that they don't have children yet and one day they will have a child and it might be disabled so they shouldn't laugh at me because they don't know what the future holds for them.*** When asked about the mother's relationship with the child's father she said ***"When (the child) was 1 year old he told me he is no longer in love with me because I have a disabled child"*** and when queried about the father's thoughts on the disability the mother replied ***"I really don't know but what I have noticed that he doesn't play with (the child) and when he sees us he doesn't even greet us. Also he hasn't accepted that (the child) is disabled".***

The above relationship difficulties appear to in some way be attributed to the father's family's influence. The mother reported ***"(The child's) father's mother doesn't want (the child). She is ashamed of her".*** In addition the mother said that prior to the birth of the child the relationship between her and the father was fine, ***"We then broke up after the birth of (the child) because of bad influence from his mother".***

In addition to this emotional strain, the mother reported that she is unable to work because she needs to take care of the child. She reported ***"When I am away for any reason I get back and find (the child) refusing to eat because I am not there. She will only eat if I am there.***

When queried about the cause of disability the mother replied ***"I don't know. At the hospital they told me she was affected and that is what I believe now".*** However, upon further probing the mother reported ***"They told me that she was affected while I was giving birth"***. However, the mother did not seem to be able to link up the fact that the child was premature, did not cry at birth and is now disabled.

In general it seems that the mother has had good experiences at the hospital. The mother reported ***"I have gained different ways of exercising (the child's) body and they showed me how to feed her".*** The mother also has asked about a wheelchair and was told she will get one when she comes back for another appointment. However there does appear to be a degree of misunderstanding between the mother and the therapists, probably likely due to the language barrier. When asked what first happened when she went to the hospital, the mother replied ***"The gave me a sponge and told me to put (the child) on it no matter whether she cries or not I must just leave her there. So that didn't sit well with me because she was crying very badly in such a way that I thought she could become more affected because of this continuous cry".*** However, she also reported in relation to her acceptance of the disability, ***"It took me three years to accept. All this time I have been looking for alternative to help (the child) to get better. However, in all my hospital visits I have seen many people there that are disabled like (the child) and that made me to accept and put things into perspective".***

When asked what she dislikes about the hospital, the mother replied ***"What I have found to be a problem is the nurses listening skills. When I try to explain to them about the child's condition they try to disagree with me thinking that I am lying or something".*** Lindiwe then probed further to ascertain whether this was a general problem or specific to the nurses. The asked the mother whether she has the same problem with the doctors. The mother responded ***"No, they are always understanding and sympathetic. There is one doctor, I think he is from Cuba or anywhere is Africa. That doctor always gives me advice about what I should do and about life in general".***

The child is not receiving a disability grant. There still appears to be confusion regarding child support and disability grants. The mother said ***"I tried to apply for a disability grant but I haven't got my reply yet. They told me at the hospital that the child won't get a disability grant until she is 7 years old, so I went to the pension office and they gave me a child support grant form that I filled and sent back. I thought that the child dependent form is the same as the child disability grant.*** Lindiwe responded by saying *"I will go to the hospital and research about the grant for cerebral palsy children because the pension things change now and then. What I knew was that cerebral palsy children get the grant in the first year of life but I will check then you can call me".*

When asked how the mother is protecting herself from sexually transmitted diseases, she replied ***"We are using protection, condom protection and every now and then I tell him to go and test for HIV. This is because I know that I am HIV negative".*** It seems that this relationship is very supportive for the mother, and that the man's family are supportive of her and the child. She reported ***"They love (the child) very much. This is not because (the child) is distanced from them. They love her and care for her. When I visit the family alone they always tell me to go home and fetch (the child)".***

At the end of the interview the mother asked Lindiwe about schooling opportunities for the child. She said "***The doctors at the hospital have been telling me to send her to***

school but I don't know where to take her". Lindiwe informed the mother to ask the doctors at the hospital for details of these schools since they are private or expensive.

Appendix 18 - Interview C

Tell me about the child. How was he born and what happened? Tell me everything about his birth.

- he was born at nine months.
- He got stuck on his way out for about 8 hours until one doctor decided that they were going to pull him out.

What is he doing to keep himself busy?

- He just sits and plays all the time.

What is it that he likes to play with often?

- He likes playing with food.

What is it that he can't do? What is it that is difficult for him to do?

- He can't speak.
- He also struggles to eat meat, walk, sit and hold things.
- But he can roll by himself.

What do you think can help or make things easier for him?

- It's this wheelchair that he is currently using.

Does he play with other children?

- Yes, he plays with lot of children around this place.

Does the child have a relationship with his granny (father's mother)?

- No.

Is he getting a grant?

- Yes.

How many children do you have?

- Two.

Who is supporting both of your children?

- It's me.

Where are you working?

- I'm not working.

How is your relationship and the fathers' relationship with the child?

- It's not good because of the child maintenance.
- And I don't believe that he loves the child.

The problems that you are having with the child's father, when did they started?

- After the birth of the child.

How is the child's relationship with the whole father's family?

- They all love him except his father.

Where are you getting money to support the child?

- I use his grant which is about R820.

Who is helping you to support your children?

- No one except R300 maintenance money from the child's father.

Which food does the child likes or dislike?

- He likes porridge, apples, polony, yoghurt etc.
- He dislikes meat because it's difficult for him to chew.

Do you have a boyfriend currently?

- Yes I do.

What is your boyfriend saying about the child's disability?

- Nothing.

How is your relationship with this new boyfriend?

- It's fine although he has a wife that stays with him.

What precautions have you and your boyfriend taken to protect yourselves from diseases like HIV/AIDS that could affect your whole family?

- We haven't done anything.

Does that mean you have sexual intercourse without any protection?

- Yes.

Have you heard about HIV/AIDS and what it does to people?

- Yes I have but I haven't thought about the damages that it does to people.

So have you thought of telling your partner to start using condom so that you will both protect yourselves?

- No.

But are you going to ask him anytime soon?

- Yes I will tell him since I had time now to think about the damages that HIV/AIDS does to people.

What if he says 'no' he doesn't want to use condoms?

- I will persuade him to use them.

What do you believe caused the child's disability?

- I believe what all people believe.
- What is that ((the interviewer asked))?
- The disabilities are due to cross dressing of males and females within the house or young people dressing in older peoples' clothes.
- So all this cross dressing causes confusion within the family and lead to disability.

Do your neighbours believe in the same thing?

- Yes they do.

Have you taken the child to traditional healers?

- Yes we have.

What did the traditional healer said?

- They said it's this cross dressing thing.
- He then gave me some medicines.
- And I have been going there for three (3) years but there hasn't been any difference in his condition ever since.

What have you gain in your first visit to the hospital?

- When I got to the hospital they taught me body exercises that I can use at home with him.
- And when we first visited the hospital, the child couldn't control his neck muscles but he can very well.
- Also he can now play independently although he still struggles to sit without support.

What have the doctors said about the child?

- They didn't tell me anything about the child's disability.
- They just taught me body exercises that I do with him at home.

What is it that you dislike about the hospital?

- There's nothing.
- Perhaps it might the long hours that I wait to get a file so that I will go to the exercises.
- And usually I get there very late because of this filing system.
- At one time they lost my file and I had to open a new file.

Does your boyfriend support your children financial?

- Yes he does.

Does his wife know about you?

- No but she has heard rumours about me.

What would you like to ask me?

- I just want to know about support grant that people say its received by caregivers who take care of disabled children.
- Yes there is such a grant, it's just that I don't know whether children with cerebral palsy are eligible for that grant ((says the interviewer)).
- But let's ask on the 10th when you come for cerebral palsy group.

Is there anything else you want to ask?

- There is nothing else.
- It was just that.

Do you leave the child with neighbours?

- No, I always go with him wherever I go unless there is his brother.

How do you know if the child is hungry or thirsty?

- He communicate in signs that he's hungry or/and thirsty.
- But most often I have to guess what he might need.

What does he do if he wants to go to the bathroom?

- Nothing he just sits where he is.

Is there any of your neighbours who you trust that she can help you with the child?

- Yes I have one neighbour that we have a very close relationship.
- And that's the one that I believe can help me if I need help with him.

Has the child's granny (father's mom) came to visit him since he was born?

- Yes, she usually passes by from time to time just to greet us.

Does she help you with take care of him financial?

- Before getting her pension, she said she will help me out with money.
- But since then she hasn't helped me with anything.

What other problems you are facing especially with dressing the child?

- I don't have a problem with washing him except that when I'm dressing him one of his leg and arm becomes very stiff.
- And also he doesn't want to eat food from neighbours.

How is the child's relationship with your new boyfriend?

- My boyfriend loves all my children.
- He buys things for them every now and then.
- And everytime when he comes here he makes sure that he has at least sweets for the child or anything else.
- Also the child seemed to be okay when he's around my boyfriend.

What else would you like to ask from me?

- Nothing.
- Okay we are done ((says the interviewer)).

Appendix 19 - Participant C: Paraphrased Interview and Ethnography

Distance of home from tar road:	4km
Electricity:	no
Water:	water point on property
Number of people living in house:	3
Sanitation:	none
Disability grant recipient:	yes
Other financial support:	yes, father pays maintenance
Belief in cause of disability:	umuti
Child's difficulties:	talking, eating solids, sitting
Perception of child's needs:	the buggy that she is already using
Support structure:	boyfriend

The interview was conducted in the participant's home in village XXX on the morning of X May 2006. Lindiwe and I left from the hospital on this cool, cloudy morning and headed out towards village XXX. Once we had arrived in the village we called the mother of the CP child to get directions to her home. Seconds later we saw her running down the road in nothing but a towel to direct us to her 2-room home!!!! As we arrived she ran across the road to her neighbour to borrow a 'good chair' for me to sit in.

The home had two entrances, neither of which Lindiwe could access due to the steps leading up to the door. As Lindiwe and I made our way around the house to the back entrance the mom ran inside and got dressed. The interview was conducted behind the house, under the washline. I was given the 'good chair', which the mother covered with a piece of African print material. Once again Lindiwe explained why we were there and obtained informed consent from the mother. While Lindiwe conducted the interview I sat on the other side of the house and took field notes. From where I sat I could see Tonga Hospital in the distance.

The home consists of two rooms – 1 bedroom and 1 cooking area that the mother shares with the 4 year old CP child and her 8 year old son. There was a water point on the property, but no electricity. At the back of the property was a long-drop toilet which appeared to be shared with the neighbours. In front of the home was a well-tended garden with bricked off flowerbeds filled with succulent type plants. The home was spotlessly clean but very sparsely furnished and decorated. The CP child, who is a spastic quadriplegic with contractures was lying on a mat with a little plastic doll in the cooking area of the home. Her face lit up when I went to sit next to her and it was obvious that she is a very responsive child – she smiles, laughs and makes vegetative sounds in response to speech. In the corner of the room was an open fire with a cast iron pot on it. The shona buggy issued by the hospital was in the corner of the room.

Next door on the left-hand side of the house was a man holding a baby peering intently over the fence, watching the goings on with interest. On the next door neighbours' plot on the right-hand side was a gogo tending her vegetables. Across the road, a woman was sitting alone feeding a baby, and diagonally opposite on the other side of the road, 3

young children were playing in the sand. All of the yards were well swept and there was a sense of peace in the community. All that could be heard was a rooster crowing, the distant hum of a neighbour's radio, the sounds of children playing and the rise and fall of conversations. This perception of peace and safety was compounded by watching the neighbours' children roaming from house to house, something that rarely, if ever, happens in urban settlements. While Lindiwe was busy with the interview I was intermittently aware of the occasional inquisitive neighbour peering through a window or over a fence or around a wall to see what I was doing.

While sitting outside the house, I was warmly greeted by passersby. Almost all passersby were women carrying babies on their backs and buckets of water on their heads. Interestingly, all women greeted me in Siswati, while the few men that walked past greeted me in English. An old man on a bicycle, decorated with streamers and bits of plastic called me over to show me how he had decorated his bicycle.

While sitting there I was struck by a few thoughts and interesting questions:

- Where are all the men????? There were far more women present than men and from my observation, the women were doing all of the chores, such as caring for the children, and carrying shopping, firewood and water, while the men that passed me by just appeared to be ambling along.
- Do the men's perceptions of disability in urban African settings differ from those in rural settings?
- Does the white man's perception of disability differ from that of the black man?
- What is it that influences our perceptions on disability? Culture? Education? Money? Wealth? Knowledge? Exposure?

From the interview it appeared that the mother seemed to be coping relatively well with caring for her disabled child. She did not report any difficulties in caring for the child without significant probing. She reported that the main difficulties that the child is experiencing include inability to speak, walk, sit, and hold things in his hand, as well as inability to eat textured foods. She reported that she able to read the child's signs when she communicated hunger or thirst but most of the time she just guesses what the child needs.

Upon interviewing the mother with regard to the birth history, she reported a long labour with the child remaining stuck in the birth canal for 8 hours until ***"one doctor decided that he had to pull (the child) out".*** However, there was no evidence whether the mother linked this difficult birth to the disability since when the interviewer asked her what she believed caused the disability she reported ***"I believe what all people believe"*** and had to be probed further by the interviewer before she admitted that she believed that disabilities are caused by *'umuti'*. This appeared to indicate that she knew that this belief opposed that of western medicine and thus she was hesitant to admit to this belief. When this issue was pursued the mother reported that she had been taking the child to see traditional healers for the last 3 years but has still not noticed any improvement. This made me wonder why she continued to visit the healers, knowing they are costly, if she had not seen any improvement – fear of repercussions or familial pressure. This also made me

think that in most families the elders are consulted about what to do about illness and disability and the normal decision is to take the person to a traditional healer, but now that healthcare is more accessible and many people are noticing improvement in their child's condition after hospital visits, what will the role of the traditional healer be in 20 years from now?

When asked about the child's relationship with her father the mother reported ***"It is not good because of the child maintenance and I don't believe that he loves (her)".*** However, it was reported that the rest of the father's family are emotionally supportive of the child. There did not appear to be any significant reaction on the behalf of the neighbours with regard to the child's disability. However, the mother did report that she does not leave the child with the neighbours but will only leave the child with her brother, although there is one neighbour that she feels she could call on in case of emergency.

One of the main topics of discussion during the interview was the relationship between the mother and her boyfriend (who is married). Two issues arose out of this discussion: HIV and the type of support that the boyfriend is able to provide. When asked how her relationship with her boyfriend is, the mother replied ***"It is fine although he has a wife who stays with him",*** and when asked if the wife knows about this relationship, she replied ***"No she doesn't but she has heard rumours about me"***. This made me wonder whether this type of relationship is a cultural phenomenon or whether the mothers of disabled children are so isolated and discriminated against that they are prepared to accept any scraps of relationships or human contact that they can.

Once again HIV was a large and controversial phenomenon. The mother quite openly reported that she and her boyfriend were not using any form of protection during sexual intercourse. This raised questions about why this was so – fear of abandonment, power dynamics and the inability to confront men, lack of knowledge, myths about transmission, or pure irresponsibility. However when the interviewer asked the mother if she knows about HIV and its effects and who would care for her disabled child should she contract the disease, she replied ***"Yes I have but I haven't thought about the damages it does to people"***. This was quite an interesting response as it personified the disease.

In general it appeared that the mother had had a good experience of western medicine at the hospital. She reported that she had been taught exercises that improved the child's neck control and she had learned to roll. Her only complaint was the long queues and lack of organisation in obtaining a file which frequently made her late for the CP group.

The only subject that the mother brought up during the interview was the issue surrounding grants. The child is receiving a disability grant, but the mother was enquiring

whether she was also eligible for a care-in-aid grant. This is positive as it shows that information about rights is filtering through the communities. The interviewer did not know the answer to this question but said that they could find out when the child comes for her next appointment at the hospital, which is a good example of the good communication channels and the role of the CBR consultant in the community.

Appendix 20 – Interview D

1. **Please tell me about this child:**

   - Its just that I didn't know, I just realised when the child was born I only realised after that the child was disabled.

2. **what does the child do /behave now**:

   - he cant sit properly its only when someone is carrying him
   - he cant hold anything he just sits in his pram
   - holding things and sitting is a problem and is quite difficult for him
     He likes it when you play with him or dance for him he laughs

3. **what do you think can help him to sit or improve his situation:**

   - the exercises they make him do in hospital
   - the walking rings that they sometimes put him in to help him stand
   - the walking ring seems to work better than anything else
   - we can see the improvement after the hospital visits

4. **how do the neighbours react or behave around him:**

   - they love him they play with him
   - They learn a lot from the way that we treat him because even though he is disabled he is always clean.

5. **how is the relationship between the grandmother, mother and the child:**

   - it is a very good relationship mainly because he stays with his grandmother and when the mother comes back the gran always knows what to do and instructs the mother
   - he has even bonded with the grandmother as a result of this strong relationship

6. **Who supports this family/ who is the source of income:**

   - my father , grandfather of the child
   - even if my father's money delays he still supports him from when he was born.

7. **Do you or the child have a relationship with the father and what kind is it:**

- We do not have a relationship
- He denied the child when he was born and after he saw that he was disabled.

8. **how many of you are there in your**

- There are 23 of us, no there is no one else who supports this child financially.

9. **where do you get money to support the child:**

- I get money from my father
- I now get from the police station because I took him to the police so he could pay child support.
- I only get about R 400.00, so my father still ends up helping out.

10. **What does the child eat:**

- pap and milk , banana and milk as well as potatoes with soup
- he does not eat solids because he can not chew

11. **why do you think the child has this disability**:

- it is because the mother was not eating well for the whole nine months
- he even stayed in an incubator for two weeks after he was born
- People don't know they are just like us as to why the child is disabled, they just know that he has polio.

12. **what does the father say about all this**:

- he does not really care because he does not even come visit him
- it is easy for him to say he does not love the baby because he is disabled

12. **have you tried other alternatives i. e. witchdoctors** :

- yes we took the baby to a witch doctor but they tried and found it difficult
- Now we are hoping that the hospital will try harder.

13. **what do you think is more likely to work, hospital or African medicine:**

- I think the hospital because they checked out the structure of his bones
- They said his bones are not strong enough, I thought it was good for my baby and they would help, it looked promising

14. **what is your personal experience of western medicine** :

- they said the child falls under disabled people
- they also said he falls under C.P's
- I thought what I was given in hospital was good i.e. I got the walking ring
- My son was also taken to physiotherapy, where he exercises and learns to sit.
- I don't see the disadvantages of western medicine, all is well there.

Appendix 21 - Participant D: Paraphrased interview and ethnography

Distance of home from tar road:	500m
Electricity:	yes
Water:	yes – jojo reservoir on property, no running water
Number of people living in house:	23
Sanitation:	long-drop (+/- 15m from house)
Disability grant recipient:	no
Other financial support:	yes, father and grandfather
Belief in cause of disability:	unknown, polio, mother did not eat well while pregnant, because he was in an incubator for 2 weeks after birth
Child's difficulties:	sitting and holding things
Perception of child's needs:	exercises taught at the hospital, walking ring
Support structure:	yes, grandparents and community
Father involved:	no, only pays maintenance

The interview was conducted with the mother, gogo and nkulu of a child with cerebral palsy in XXX village on X May 2006. The weather was cold and windy and the clouds looked threatening. Lindiwe and I left from Tonga hospital and traveled to XXX village and stopped outside 'XXX Fish' shop and picked someone up who accompanied us to the participant's home.

On arrival we were clearly expected and the family were sitting outside waiting for us. We were greeted and shook hands with the nkulu and gogo while the mother who is only 16 years old and the CP child stood in the background. The grandfather kept remarking how pleased he was that we were there by saying '*Siyabonga, siyabonga'*. On arrival Lindiwe and I were ushered into the nkulu and gogo's bedroom – a thatched rondavel hut in the middle of the plot. A large 'main house' stood to the right-hand side of the rondavel and water reservoirs and two long-drop toilets were on the left-hand side on the border of the property. Chairs were set out in the grandparents' bedroom and a table with a tablecloth was set out in the middle of the chairs. Lindiwe explained why I was there and we obtained consent from the nkulu to conduct the interview. The nkulu stated that he would answer the questions in the interview as ***"the mother is too young and knows nothing of the child's problems and the grandmother only speaks Swahili. I look after the child and understand the problems therefore I will answer the questions."***

Before commencement of the interview, I was given a guided tour of the property by the gogo and nkulu. The land was a rather large plot owned by the grandfather and inhabited by him, his second wife (first wife has passed away) and 23 children and grandchildren. Special mention was made of places where the CP child baths, plays, is fed, etc. The garden was full of fruit trees, sugar cane and vegetables and chickens ambled around aimlessly pecking at the ground. Nkulu specifically took me and showed me the pet dog, who was extremely thin and chained to a tree.

Everybody took their shoes off before entering the house. Ironically in this rural almost forgotten part of South Africa, a horse-shoe (western symbol of good luck) adorned the front door. The house was large and had modern amenities. There was a prepaid electricity meter and a water point on the property. The CP child shares a bedroom with his mother and it is comfortably fitted out with a double bed. The Shona buggy issued by hospital stood in the corner of the room.

While Lindiwe conducted the interview I sat outside and observed what was going on. Many children were playing outside in the garden. 2 young women sat braiding each other's hair near to the main house, while 2 other young women were washing clothes near the water reservoir. An older woman was filling buckets of water then carrying them to the main house – one on her head and one in each hand. While sitting outside I was given a show by some of the younger children who were clearly entertained to have a 'mulungu' visiting and were showing off in front of me. Some older, school age children started singing each time they passed me.

The women appeared to have a submissive role and the grandfather was very clearly the head of the family. There were no other men around, apart from the nkulu and some school-age boys. All the school-age children greeted me in English.

From the interview it became apparent that the child is at present still completely dependent on others as he is unable to sit or to hold objects in his hands. The nkulu reported that he notices improvement after the grandmother has taken the child to the hospital and the exercises that she has been taught are helping him. The nkulu reported that the relationship between the child and the gogo is very strong and that the gogo looks after the child while the mother is at school. When the mother returns home from school the gogo instructs the mother on what to do with the child in terms of exercising and feeding him.

When asked how the neighbours react to the child the nkulu replied, ***"They love him and they play with him. They have learned a lot from the way that we treat him because even though he is disabled he is always clean".***

No one in the interview really understood the cause of the disability. The nkulu said he thought it was because the mother was not eating well while she was pregnant and because the child had to stay in an incubator for 2 weeks after he was born. Nkulu reported that people in the community are just like them and do not understand why the child is disabled, ***"they just say he has polio"***.

When asked about the relationship that the child has with his father the mother replied ***"we do not have any relationship since he denied the child after he was born when he saw the child was disabled. It is easy for him to say that he does not love the baby because he is disabled'.*** The father does however pay child support. It was reported that he did not want to pay child support but the mother reported him to the police so he now pays R400 per month.

The family reported that they took the child to a witchdoctor once they realized that he was not developing normally ***"but they tried and found it very difficulty. We are now hoping that the hospital will try harder".*** The nkulu said that at the hospital ***"they checked the baby's bones and said they were not strong enough. They gave us exercises to improve the strength. It looked promising".*** He added that they were informed that ***"the child falls under the disabled people. He is also a CP".*** The mother reported that she is happy with the hospital because her child received a chair and at physiotherapy he is given exercises and is learning how to sit alone.

Appendix 22 – Interview E and F

In this household two sisters had children with cerebral palsy. This interview was conducted with the child's aunt (older sister of the child's mother) and all questions were directed to the aunt except where specified.

Participant E

Tell me about the child's disability, how did he get disabled?

- I don't know anything about his disability.
- It's only his mother who knows something about this.

When did the child's mother notice that he is disabled?

- She noticed when he was one (1) year.

What is he doing to keep himself busy?

- He crawls and plays.
- He also tries to talk although he is unintelligible.

What is it that he likes to do?

- He likes playing and looking at children or me and get excited.

What is it that the child can't do? What is it that is difficult for him to do?

- He can't eat and walk independently.

Who is with the child staying often?

- He is staying with his granny (mother's mum).
- Okay, please call granny in (says the interviewer).

What do you think can make things easier for him?

- Anything that can help supports his spinal cord and makes it strong.

Then granny walked in. The following questions were then directed to granny

What are the neighbours saying, do they like the child (asking granny)?

- They like them like any other child (says granny).

How is your relationship with the child's mother (asking granny)?

- It fine, I haven't seen any problems.

Who is helping the mother to take care of him?

- Anyone who is here at home.

Who is supporting the child financially?

- His mother and father.

How many are you here at your house?

- We are sixteen (16).

Who is supporting all of these people financially?

- It's the child's grandfather.

How is the child's relationship with his father?

- Its fine, he loves the child very well.

How long did it take you to realise that the child is disabled?

- It took me four (4) months.

What did you do when you realised that he is disabled?

- It took me four (4) months.
- We then took him to doctors and traditional healers.

What did the child's father do when he find out that he was disabled?

- He didn't say anything.
- Except that he was happy to have a son.

Which food does he likes or dislike?

- He likes all kinds of food; there is no food that he doesn't like.

What do you believe caused the child's disability?

- I don't know.
- I think it what people have been saying about cross dressing.

What are the neighbours say about the child's disability?

- They also think it's the same cross dress story.

What did the traditional healers say?

- They also say its cross dressing.

When you first go to the hospital, what did they do to him (asking aunt)?

- We were all going together with both children and at that time both child E and child F couldn't walk.
- They taught us exercise that we can use at home to train him and (participant F) how to walk.

What have you gain from your hospital visit (asking aunt)?

- I gained different ways of exercising the child's body parts.
- And now he can crawl and speak although he is still unintelligible.

What is it that you dislike about the hospital (asking aunt) ?

- I don't know because in most cases he goes to hospital with his mother.

Is he getting a grant and how much (asking granny)?

- Yes, he is getting R800.

Participant F

Participant F is Participant E's cousin. And interview was done with all the people in the house especially granny, mother and aunt. However, most questions were directed to the mother except where specified.

How long did it take you to accept that both of your grandchildren are disabled (asking granny)?

- I haven't accepted it.

Tell me about the child's birth (asking mother).

- She was born at nine (9) months and she cried like any other child.
- And after a month I realised that she was disabled.

Granny how long did it take you to realise that the child is disabled?

- I realised at the same time as her mother.
- It was when she was a month old.

What is she doing to keep herself busy?

- She talks and plays a lot.
- She can sit although she can't maintain posture.
- She also likes playing with other children.

Do other children enjoy playing with her?

- Yes I believe they do.

What is it that she can't do? What is it that is difficult for her to do?

- It's walking and standing.

Do you have any other child either than this child?

- Yes we have one younger child.

Is she also disabled?

- No.

How old is child 1 and child 2?

- Child 1 is three (3) years and child 2 (participant F) is four (4) years.

What is it that she likes to do?

- She likes playing other children.

What do you think can make things easier for her?

- Maybe if she can get a walking ring so that she will have an opportunity to step down on her feet and allow her feet to touch the ground often so that she will learn how to walk.

How is the child feeding?

- She can feed herself.

How is the relationship of the child with her mother and you granny (asking granny)?

- Its okay because everywhere the child's mother is here for her I'm also there ((says granny)).
- And I take all of these children as my own.

Who is helping the child's mother to care of her (asking granny)?

- It's me and her aunt.

Who is supporting her financially?

- It's her grandfather and her father.

Are you working (asking father)?

- Yes.

Is she getting a disability grant?

- Yes she is getting R800.

How is your relationship with the child (asking father)?

- It's very good
- Sometimes she doesn't even want to stay with her mother but she wants to stay with me.

What do you believe caused the child's disability (asking granny)?

- It what people have been saying about cross dressing.

What did you do when you find out that the child was disabled (asking father)?

- I was very disappointed since it was my first born
- I expected that since she is my first born she is going to be everything I ever wanted from a child (first born).

How old were you when you conceived the child (asking mother)?

- I was eighteen (18) years old.

Do you usually talk about trust in your relationship?

- Yes we do talk about trust although the conversation ends-up sour ((says father)).

Is it easy for both of you to use protection?

- Yes it's easy ((says father)).

Do you see a need of using a condom since you are staying together?

- No ((says mother)).
- I don't ((says father)).

Does the child gets all she wants (asking father)?

- Yes she does.

Which food does the child likes or dislike?

- She likes all kinds of food that is eaten by any adult like pap (porridge), cakes, yoghurt, milk, soft meat like a wors, corn flakes etc.
- She dislikes maize meal and wheat bix.

How do you know that she had enough food?

- She tells me that she is full.
- She then asks for water or juice and then show me her tummy so that I can see that its big, therefore, she is full.

What does she do if she wants to go to the toilet?

- I have been trying to teach her without much success.
- So ended up putting her in nappies.
- But sometimes she tells me that she wants to go to the toilet, but its usually when she is happy.

Does she have any sight or hearing problems?

- No.

How is her cognition (mental ability)?

- She is okay ((says mother)).

What are you thinking about the child (asking father)?

- I'm just thinking how long it will take the child to start walking on her own ((says father)).

What did the traditional healers do to the child?

- They gave some herbs and liquid medicine.
- And when she was very young they showed me how to position her so that she will get used to sitting independently.

When you first go to the hospital, what did they do to the child (asking mother)?

- They examined her.
- They then told me to bring her to the hospital gym (physiotherapy).
- However, they got us from one the wards; we didn't just go there on our own.

Did she gain anything from the hospital gym?

- Yes because now she can play.

What have you gain from your hospital visit?

- Now she can use her hands to crawl, she can sit independently and can now play unlike before.

What is it that you dislike about the hospital?

- It's the filing system that takes very long to get and by the time you get to the gym it's already late.
- Getting a file takes more than two (2) hours.

What else do you think I have forgotten to ask about the child?

- I want to know why the gym doctors (physiotherapists) don't listen to things that we need ((says the mother)).
- Because one day I told them that she can sit independently and now I want something that will help strengthen her legs and feet muscle so that she will be able to walk.
- And they told me that, what I'm asking is something they will see later.

What else?

- There's nothing else I think we have covered everything ((says the father)).

Do neighbours like the child?

- Yes they do ((says the mother)).
- She even goes and visits some of the neighbours children and plays with them.

When you are going somewhere, do you leave her with any of your neighbours?

- No I don't because granny is always here, so I usually leave the child with her.
- And even when granny is not here I have never thought of leaving her with neighbours.
- I rather go with her if there's no one here at home.
- Neighbours take the child if I'm here at home otherwise I don't want them to take her because she needs constant care.

How are you feeling about the child's disability (asking the mother)?

- At first I felt terrible, I lost weight and I used to spend time alone thinking about the child's disability ((says the mother)).
- But after two (2) years I accepted the situation as it is and I regain weight again.
- Also to see other disabled children at the hospital helped very much because I was able to see and compare her condition.
- And what I have realised is that my child is less disabled than any other children I have seen at the hospital.

Is there anything you would like to add (asking the mother)?

- Ja, at the clinic the nurses don't know how to talk to people.
- And the child has asthma but she sometimes doesn't get the help that she needs at the required time because of the nurses attitude.
- I sometimes go to the hospital at 9am and I only got help at around 6pm.

Is there anything that you would like to ask me (asking father)?

- No.

Appendix 23 - Participant E and F: Paraphrased Ethnography and Interview

Distance of home from tar road: 1km

Electricity:	yes
Water:	yes (running water in house)
Number of people living in house:	16
Sanitation:	long-drop (+/- 5m from house)
Disability grant recipient:	yes
Other financial support:	yes, father and grandfather
Belief in cause of disability:	umuti
Child's difficulties:	eating and walking independently
Perception of child's needs:	something to support the spinal cord
Support structure:	yes, both parents, family and neighbours

The interview took place in village XXX, approximately 1km off the main tar road. This was an interesting set-up as the home consisted of 16 family members, of which two sisters each had a child with cerebral palsy. The children are 5 and 6 years old respectively. The first interview was conducted with the one child's aunt and gogo as her mother works at XXX and is only home on weekends. The second interview was conducted with the child's mother and father. However, both children are cared for by all family members.

On arrival we found a large modern home with all amenities, except for a flush toilet. The house is situated on a large piece of land which is immaculately kept. Lindiwe explained to me that this was the gogo and nkulu's home and that their children and grandchildren are living with them. The grandmother was sitting outside on the floor skinning squashes and various other people were milling about. There were plenty of people around and Lindiwe was greeted warmly. All of the adults greeted me in English and I immediately got the impression that this family was well educated. Another impression that struck me immediately was that all of the family members appeared supportive. They were interested in the study and keen to participate.

Once again we were faced with the problem that the only access into the house was via a number of steep steps so it was decided to conduct the interview outside next to the mielie patch. Various men carried out chairs and a small table. By this stage I was starting to become accustomed to this rather formal procedure. Unfortunately just as we were starting the interview it began to rain. A number of the men said that this was not a problem and they promptly picked Lindiwe up in her wheelchair and carried her up the 6 steep steps! Walking through the home it was evident that the family was relatively wealthy compared to the rest of the community and that the house was well furnished. We were taken through a first lounge and on to a second more formal lounge where the interview took place. In the lounge were home-made chairs which had obviously been constructed by someone to accommodate the needs of the two little girls with cerebral palsy. In the corner of the lounge was a hospital-issue standing frame.

Strangely enough, in this far-off settlement, which still appears to be taking in the effects of the apartheid government 10 years post transformation, with poor access to services and poor provision of basic needs, the sounds of radio Jacaranda drifted through the house!

The first part of the interview was conducted with the aunt and gogo of the child whose mother works at XXX. Interestingly, when Lindiwe asked the aunt (mother of the other CP child) about her sister's child's disability she responded by saying ***"I don't know anything about his disability. It is only his mother who knows about this".***

Throughout the interview it became increasingly apparent that there was a strong sense of both emotional and financial support within the family. When queried who helps to take care of the child while the mother is at work the gogo responded ***"Anyone who is here at home".*** A similar response was obtained when the gogo was asked about the first time they attended the hospital, she replied ***"We were all going together with (child 1) and (child 2) because at time both couldn't walk".*** A similar response was obtained when asked how the neighbours respond to the disabled child the gogo replied ***"They like him like any other child"***. In addition it was reported that the father is very involved with the child and that he loved him very much. When asked how the father responded when he found out that the child was disabled, the gogo reported ***"He didn't say anything. He was just happy to have a son"***. However, when the gogo was asked ho long it took her to accept that two of her children were disabled, she responded by saying ***"I still haven't accepted it".***

Once again, as was the case in most of the other interviews, there did not seem to be any firm understanding on the cause of the disability. When asked what she thought had caused the disability, the gogo replied ***"I don't know. I think its what people have been saying about cross-dressing*** (umuti)***"***. It was reported that once the family first noticed that the child was not developing age-appropriately ***"We took him to doctors and to traditional healers"***, which was interesting that the western model and the traditional model of medicine were approached simultaneously.

Generally the gogo seemed happy with the treatment they had received at the hospital ***"…because I gained different ways of exercising (the child's) body and now (the child) can crawl and speak although he is still unintelligible".*** The gogo said she could not comment on anything that she did not like at the hospital since the child's mother normally accompanied him to the hospital. This is an interesting facet of the culture, since even though the child spends most of his time with a caregiver, the mother usually takes time off work to accompany the child to the hospital.

Appendix 24 – Interview G

This interview was conducted with the child's mother except where it's specified.

Tell me about the child. How was he born and what happened? Tell me everything about his birth.

- I gave birth to him at home at exactly nine (9) months and, then I took him to the clinic for check-up of which he turned to have no abnormalities.
- He started sitting at six (6) months and then at eight (8) months he walked using a walking stick.
- At one (1) year three (3) months he stopped walking and sitting on his own.
- I then took him to the clinic for examinations and they told me to go to the hospital where they would help him to sit again.

What is he doing to keep him busy?

- ((answer unintelligible because of background noise))

What is it that he likes to do?

- Laughing especially when he sees his granny.

What is it that he can't do? What is it that is difficult for him to do?

- He can't wake up independently.

What do you think we can help or make things easier for him?

- If he can find a nice chair that is strong enough to assist him in sitting.

Does he have a hospital wheelchair?

- Yes he has one but it's broken.
- I asked the hospital to fix it for me and they said they will fix it, I don't know when.

What are the neighbours saying, do they like the child?

- If it was according to them I would have taken him and give him away or throw him in the dustbin.
- They don't think he will ever be a normal person at all.
- Even his father's family doesn't like him.

How is the child's relationship with you and his granny?

- Granny loves him very much, she even take care of him.
- But she is not really his granny but it's my granny.
- However, we are staying very well with her because she loves him like her own child.

Who is staying with the child?

- Granny.

Who else is helping your granny to take care of the child?

- No one.

Who is supporting the child financially?

- It's granny with her pension.

How many people living in this house?

- We are fourteen (14).

Who is supporting all of these people financially?

- It's granny.

Who is helping granny to support this family?

- No one.

Is the child getting a disability grant?

- Yes.

How much is he getting?

- R180
- This is not the grant I'm asking about ((says the interviewer)).
- Oh, I haven't registered for that grant ((says the mother)).
- Why not ((says the interviewer))?
- I don't have the right information on how to apply for the grant ((says the mother)).
- Okay, I want to go and apply for it ((say the interviewer)).
- First you will go to the pension office and collect a form that you will take with you to room 3 at the hospital.
- And that is where they will help you through all processes.

Tell me about your relationship with the child's father?

- We first started the relationship in 1999 and we stayed together for a very long time until the birth of our first daughter child.
- We continue staying together until the birth of the child.
- We then decided that I will go and stay with him at his house where I stayed for a year.
- I then decided to go back home after because the father's mother was saying that the child is not his son's boy.
- The child then started getting sick while I was at home.

Why did you come back home?

- It's because the child's fathers' mother was busy influencing the father, saying that the child is not his son.
- One day we had a fight and the father told me that he knows that the child is not his son.
- He also told me that they have never had a disabled person in their family.

Which food does the child like or dislike?

- He likes all other food except intestines and meat.

What do you believe caused the child's disability?

- I believed that, it's because of cross dressing of males and females within the house or young people dressing in older peoples' clothes.
- So they say all this cross dressing causes confusion within the family and leads to disability.
- But now I have confirmed that it's not that it another thing that I don't know.

What are the neighbours say about his disability?

- They believe the same thing.

What is the father thinking about the child's disability?

- He has just distanced himself from the child and when he comes to visit he just plays with the other child (daughter).

What did the traditional healers say?

- I went to two traditional healers who all promised to heal the child.
- But since then I haven't seen any improvements, so I have decided to stop go to any traditional healer.

On your first visit to the hospital, what did they do?

- The doctor examined him and then he sent me to rehabilitation unit.
- At the rehabilitation unit they taught me how to exercise the child's body.

What have you gain from your hospital visits?

- They taught me how to assist the child so that his body will move and roll.
- They also taught me lot of things like how to assist the child to lift up his head etc.

What is it that you dislike about the hospital?

- Nothing except that I wait for a long time waiting for the file.
- And it always seem like I'm a late comer at the rehabilitation ward because of this long waiting period.

How do you know that the child is thirsty, hungry or wants to sleep?

- If he wants to sleep he just cries.
- And if he wants food he just uses his hand and point in his mouth.
- But when he's thirsty, he just acts as if he is very happy when you pass him and raise his hands.
- Then you will know that he's thirsty and he wants water.

Are there any other family members that are staying here with you and the child, like your auntie etc?

- Ja, I have my auntie and her children staying here at home.

How is their relationship with the child?

- I can say its fine, but there is one child (auntie's child) that likes him very much and which the child gets along with very well.

Are you still in love with the child's father?

- No.
- He can't face his problems and be a man.

So do you have a boyfriend now that you are no longer in a relationship?

- No.

If you happen to find a boyfriend, what do you think you will use to protect yourself from diseases like HIV/AIDS?

- If I get a boyfriend I will always use a condom because I don't want to have another child.
- Also I do regular HIV tests to make sure that I haven't contracted any disease.
- But you know that condoms are used by males ((says the interviewer)).
- Yes I know ((says the mother)).

What if that man doesn't want to use a condom?

- I don't know what I will say or do.
- Or I will just tell him that things are not working out so lets break-up.

What kind of a person you are looking for in a relationship?

- I want someone with children but not in a relationship with anyone else.

Can you leave the child with any of the neighbours?

- No, because I haven't seen any neighbour that likes the child around here.

What are your friends saying about the child's disability?

- I don't have friends.

If you receive the child's disability grant, what will you do about it?

- I will buy him clothes and other things that he needs like blankets.

With that R180 that you are getting from government. What do you do with it?

- I buy him clothes.

Granny how did you feel about the things that the father's family has done to your grand-daughter (asking granny)?

- I didn't feel right about it, but I told myself that the child is the gift that God has given us, so we need to cherish him ((says granny)).
- And when he got sick I knew it was my duty to take him to all the medical professionals for help using my pension funds.
- I even sent him to traditional healers.
- Before he became disabled, he was sitting, crawling, standing up and beginning to walk.

How old is the child (asking the mother)?

- He’s four (4) years old ((says the mother)).

What will you do if the father get back to you and ask you back in his life (asking the mother)?

- I won’t accept him back because if he wanted me to be his wife, he should have not said all the things he has said about the child.
- So I won’t have any relationship with him anymore.

Where is the father working?

- I don’t know at the moment.
- He left his previous job and he said it’s because of me.
- So now I don’t know where he is working.
- Okay, it’s important to tell the person that you will meet in future to use condoms whenever you have sexual intercourse so that you will protect yourself and the people that you love like your children ((says the interviewer)).

Appendix 25 - Participant G : Paraphrased Ethnography and Interview

Distance of home from tar road:	5km
Electricity:	no
Water:	no
Number of people living in house:	14
Sanitation:	long-drop 100m from house
Disability grant recipient:	yes – child support grant
Other financial support:	gogo's pension
Belief in cause of disability:	unknown
Child's difficulties:	lifting up his head
Perception of child's needs:	a chair to assist him in sitting
Support structure:	gogo

The interview took place at the home of the participant in village XXX on a hot and windy afternoon on the afternoon of X May 2006. From the time we called for directions we were regarded with suspicion. Lindiwe was interrogated, even though the mother knew her from the hospital and was asked who she was, what she wanted, and why she wanted to visit, even though this meeting had been pre-arranged when the study was discussed at Tonga hospital in March 2006 and the mother had given verbal informed consent. Under my instruction, Lindiwe reminded the mother about the study and told her that she was free to withdraw if she wanted to and we would not come to her house. However, the mother agreed that it was fine for us to come and visit and gave Lindiwe the directions.

Upon arrival we were met by the mother and the gogo (carrying another baby on her back) and were regarded with suspicion. Both the mother and the gogo kept a safe distance from the car!!!

The interview was conducted outside behind the house as Lindiwe could not access the house due to a low brick wall barring access. The was one small free-standing room in the middle of the plot which Lindiwe would have been able to enter but according to Lindiwe, the mother and gogo were superstitious and said we could not go into that room.

While Lindiwe conducted the interview I went and sat in the car as I realized that neither the mother nor the gogo were completely comfortable with our presence. As I sat in the car, trying as unobstructively as possible to make field notes, the gogo stood vigil a few meters away.

From my observations, the house was a small 2-room shack approximately 100m from the closest neighbour and about 5km from the tar road, with the last km leading up to the house providing almost impossible access by car. The was no running water or electricity, and the only form of sanitation was a falling-down long-drop toilet about 100m from the house. The property was fairly large and fenced. The yard immediately surrounding the house was neatly swept, yet the rest of the property was just a mass of

scrub. A couple of trees within the property provided nice shade and some respite from the hot sun.

Sitting in the car, not much appeared to be going on in the surroundings. Once the gogo decided I was not going to cause any harm sitting in my car she moved away and began to till the soil with the baby on her back. Dry mielies rustled in the wind. Empty plastic barrels for collecting water lay scattered in the yard. A pile of firewood lay neatly stacked in the middle of the yard, and a bricked off area on the outskirts of the yard contained a mound of sand, which I eerily wondered if it was a grave.

Electricity lines lined the dirt track leading up to the few houses in this apparently god-forsaken part of the country, symbolizing hope for a better brighter future. I found myself hoping that this expectation has not faded into the some distant memory as it has been 11 years since the people of South Africa were promised a new life with running water, electricity, houses and jobs.

Once again, there was a distinct absence of men.

Once Lindiwe had finished the interview with both the mother and the gogo I gave them gifts of clothes and toys for the children to say thank you for allowing us into their home. By now they were far more relaxed with us and asked us if we would like to see the child with cerebral palsy who was asleep inside the house as he was sick. This meant that they were going to take us into the house, which I was quite surprised at since only hours before they had been very suspicious of us. Inside the house were two rooms. The first had a single bed and an old gas oven/stove. The adjoining room had two single beds and a makeshift bed on the floor where the child with CP was lying. He looked really ill, malnourished and quite possibly suffering from HIV (as the mother, gogo and other baby all clinically looked as though they had AIDS). Looking down at the CP child I counted 5 flies eating away at the sores on his head. Turning to leave, ironically, I noticed a piece of African print cloth, covering a box that was used as a table. On the piece of material was the South African Coat of Arms and below it was printed:

“Mpumulanga Department of Health and Social Services”
“Training Grannies on HIV/AIDS and caring for affected or infected children”

As I left this tragic home I noticed a cast iron pot on a bed of coals cooking the family’s meager offerings for their next meal.

From the interview it became apparent that the child had been born at home. There appeared to be no complications and the child started developing normally. At 1 year 3 months the child started to regress. The mother took the child to the clinic where she was referred to the rehab department at the hospital.

Apart from the obvious poverty that the family was subject to, and the isolation from the neigbours, it was immediately apparent that the mother has no support structure other than her grandmother who helps her to take care of the child, and that she has been

completely shunned by the community for having a disabled child. When asked how the neighbours react to the child the mother responded by saying ***"If it was according to them I would have taken (the child) and give him away or throw him in the dustbin. They don't think he will ever be a normal person at all. Even the father's family don't like (the child)".*** When probed further about the mother's relationship with the father she reported ***"We first started our relationship in 1999 and we stayed together for a long time until the birth of our first daughter child. We continued staying together until the birth of (the child). I then went to live with him at his family's house. While I was living there (the child) got sick. I then decided to leave and come back home because the father's mother was saying that (the child) is not her son's boy".*** When probed further about the reason that the mother left she reported ***"It was because the father's mother was influencing the father, saying that (the child) is not his child. One day we had a fight and the father told me that he knows (the child) is not his son because they have never had a disabled person in their family".*** When asked whether she still has feelings for the father, she responded ***"No. He can't face his problems and be a man".*** However, it also became apparent that the mother has been subjected to blackmail on the part of the father. She reported ***"I don't know if he is working at the moment. He left his previous job and said it was because of me".***

In addition to the above, the mother reported that she has no friends and is unable to leave the child with any of the neighbours since ***"I have not seen any of the neighbours who like (the child)".*** However, the gogo appeared very supportive, and as head of the household took it upon herself to help the mother and the child. She reported ***"I did not feel right*** *(about the way the father and his family treated the child)* ***but I told myself that (the child) is a gift that God has given us and we must cherish him. When he got sick I knew it was my duty to take him to all the medical professionals for help using my pension funds. I even took him to traditional healers".*** At this point the gogo allowed her self to dwell on what the child had been like before he became ill, and wistfully reported ***"Before (the child) got disabled he was sitting, crawling, standing up and starting to walk".***

When asked about the beliefs surrounding disability, the mother said that the community believes that disability is caused by *umuti,* and on a personal level she said ***" I used to believe that it is because of cross-dressing of males and females within the house or young people dressing in older people's clothes, so they say this causes confusion in the family and leads to disability. Now I have confirmed that its not that, its something else that I don't understand"***. The mother reported that she had taken the child to two traditional healers. ***"They promised to heal (the child) but since then I haven't seen any improvements so I decided to stop going to any traditional healers".***

The mother reported that the first time she went to the hospital the doctor examined the child then sent him to the rehabilitation unit where they taught the mother how to exercise the child's body, and taught her to assist (the child) in learning to roll and to lift up his head. Once again the negative experiences related to going to the hospital related to the filing system. In addition the mother reported ***"It always seems like I am the late comer to the rehabilitation unit because of this long waiting period".***

When questioned about HIV and protection from sexually transmitted diseases the mother reported that she does not have a boyfriend but if she meets someone she will always use a condom because she doesn't want any more children and will also go for regular HIV tests. However, when asked what she would do if the man does not want to use a condom, the mother replied ***"I don't know what I will say or do".***

When Lindiwe discussed grants with the mother she said that the child is receiving a child support grant and said that ***"I don't have the right information on how to apply for a disability grant"***. Lindiwe explained exactly where she should go and what she should do in order to apply for a disability grant. The mother said that should she obtain the grant she will buy things that the child needs ***"…like blankets and clothes".***

Appendix 26 – Interview H

Tell me about the child. How was he born and what happened? Tell me everything about his birth.

- He was born exactly at nine (9) months.
- However, he was not crying for one (1) week and thereafter he started crying like any other child.

How old is he?

- He is one (1) year old.

What is he doing to keep himself busy?

- He is just trying to crawl, although he can't sit or walk.

What is it that he likes to do or that makes him laugh?

- He likes looking at other children playing.

What is it that he can't do? What is it that is difficult for him to do?

- He can't sit and his neck looks weak.

What do you think we can offer to help or make things easier for him? If we can.

- I think that a walker will help his neck.

What about the hospital wheelchair, can't you use it?

- Yes, I can also use that.

Have you asked the wheelchair at the hospital?

- No I haven't.

What are the neighbours saying, do they like him?

- I don't know they look as if they like him.
- And they sometime give us advises to consult traditional healers who will help him.

What are friends saying about the child's disability?

- My friends are no longer coming to see me.
- They used to come and spend time with me, but since I gave birth to the child there are no longer coming.
-

Tell me about the child's relationship with his grandmother and you (his mum).

- His granny takes care of him when I'm not around or when I'm busy with other things within the house.

Who else is helping you with the care for the child except his granny?

- No one.

Who is supporting the family financially?

- His granny.

Where is granny working?

- She is a pensioner.

How many people living in this house?

- We are five (5).

Who else is helping granny to support this family?

- No one.
- The father left the house looking for a job and since then he hasn't returned.

Tell me about the child's relationship with his father while he was still here.

- He loved the child so much.
- He used to spend a lot of time with the child, playing with him or visiting his friends with the child.

What did this family say (fathers' family) when the child was born?

- They were all happy.
- And the child's granny felt honoured to have a grandson.

Was he disabled when he was born?

- No he was not.
- He started being disabled at age four (4) months.

Granny what do you believe caused the child's disability?

- I don't know.
- I have been thinking about different things that might have caused this disability.
- I even thought it might be witchcraft, but anyway I have realised that it's none of the things I'm thinking.
- The child is just disabled and we all have to accept that.

How long did it take you to accept his disability? (asking granny)

- It took me at least one (1) month to accept ((says granny)).
- I even told the child's mother to accept his disability.
- It took me one (1) month after the child's disability to accept ((say mum)).

Who is supporting the child financially except granny (asking mum)?

- I loan money from people and then pay back using my other child support grant which is R180 per month.

How much do you usually loan and what do you do with it?

- I usually loan R50 just to take him to the clinic or hospital.

What did your mother say about the child's disability (asking mum)?

- She is very hurt because she still wants grandchildren and the child's condition just turns her down.

Does your mother take care of the child when she's here (asking mum)?

- Yes, she does.

How is the child's relationship with other members of the family?

- They all love him.

Which food does the child like or dislike?

- he likes beans, soup, soft porridge and weetbix.
- He dislikes meat and water.

Is the child getting a disability grant?

- No.

Have you applied?

- Yes we have and we are still waiting for the results.

What are you planning to do with the child's disability grant?

- I'll buy him food, clothes, a bed and toys.

What has the father done with regards to the child's disability?

- He didn't do anything.
- He told us to accept the child as he is and as the gift from God.

What did the traditional healers say?

- They said its witchcraft and evil spirit.
- They then gave us herbs to chase evil spirit away.
- But we haven't seen any improvements in the child's condition.

When you first visited the hospital, what did you do there? (asking mum)

- When I first visited the hospital did medical examination.
- Then they showed me exercises that I should do with him.

What have you gain from all your hospital visits?

- Nothing except that they show me exercises.
- They don't give me any medication to assist the child with his condition.

What is it that you dislike about the hospital?

- Nothing except getting a file which takes very long.

If he is hungry or thirsty, what is it that he does to reflect these needs?

- When I have a bowl or a cup, he just looks me straight in my eyes and start crying.
- I then realise that he is thirsty or hungry depending on what I have in my hands.

Which problems do you usually encounter with the child?

- It's the fact that he can't sit and walk.
- Also his neck that is weak.

Is there anyone in both families (mum family and dad family) who is disabled or who was disabled?

- Not that I know of.

What does the child do if he wants to sleep?

- He just cries.

How many children do you have?

- I have two (2).

How well do you trust the child's father and does he trust you?

- The father trusts me.
- And as for me I don't trust him because I know that he sleeps around too much and I don't care about that.
- He tries to hide it but I do know that he does it.

What are you using with the father to protect yourselves from diseases?

- We are using condoms.
- But there was a month where the father told me that he is tired of using condoms he think we should stop using them.
- I left him at that time and I went and stayed home for sometime until he apologised.

Do you trust that when the father is away, he is using condoms?

- No, I know that he is not using condoms.

What are you going to do if you now decide that you want another baby with this child's father?

- We will go to the clinic and do HIV tests at least twice.

Have you told the father about this and what did he said?

- Yes I have told him.
- But he hasn't said anything and that's the way he usually does things.

- He prefer to keep quit when I say something, but he end up doing it.

Have I forgotten anything?

- No.
- Except that I would like doctors to help me to get the child a wheel chair.

Do you know how to get it?

- Yes I know.

Have you asked the wheelchair from the doctors?

- No, I have asked about something that I can use to keep the child's neck stable not about the wheelchair.

Does he have any other sicknesses except disability?

- Yes he usually has stomach ache.

Have you taken him to the clinic for this condition?

- Yes.

What did they say?

- They gave me medication.

What will you do if one day you decide that you want to have a child and the father doesn't want to go for HIV testing, instead he chase you away or decide to take another woman?

- I will ask his parents to speak to him and get sense into his head.
- And if he wants t take another woman, I would say anything as long as he is going to support all of us financial and satisfy all other needs as women.

Have I left anything that you would like to ask?

- No.

Appendix 27 - Participant H: Paraphrased Ethnography and Interview

Distance of home from tar road:	45km
Electricity:	no
Water:	yes, water point on property
Number of people living in house:	5
Sanitation:	long-drop behind house
Disability grant recipient:	no
Other financial support:	gogo's pension
Belief in cause of disability:	unknown
Child's difficulties:	holding head up, sitting
Perception of child's needs:	something to hold up the neck
Support structure:	gogo

The interview took place on the morning of X May 2006 at the home of the participant in village XXX. Village XXX lies in a valley between the mountains of Swaziland and Mozambique, and it took approximately an hour and a half to get there by car from Tonga. We left from the hospital and drove towards the XXX border post into Swaziland. At village A we turned off the tar road onto a gravel road and traveled for about 45km before we reached village XXX. While traveling on this stretch of road we did not pass a single vehicle! Taxi's don't go to the village, which means that people needing to go from village XXX into town or to the hospital need to walk the 45km to the tar road or need to hitch a lift with one of the apparently few vehicles that travel too and from the larger villages. There is no clinic in village XXX and the nearest clinic is 50km away.

Once we got to village XXX we stopped outside the village school and phoned the home-based care worker with whom Lindiwe had arranged to meet to take us to the home of the child with CP. The home-based care worker met us and accompanied us to the house. We were met and greeted by the mother, gogo and a 4-year-old little girl with a beautiful smile wearing a green satin dress. On arrival, the gogo clasped her hands and exclaimed 'siyabonga siyabonga', meaning 'thank you, thank you'. Once again the absence of men was noticed.

The house was once again inaccessible for Lindiwe in her wheelchair, so the interview was conducted outside. The mother laid out a grass mat while the little girl brought out 2 red stools. Both the mother and the gogo knelt on the mat at my knees with their hands clasped and their eyes lowered. Once Lindiwe had introduced me and explained that she would be conducting the interview, I went and sat on the steps to the house a few meters away from Lindiwe, with the little girl. While sitting there I noticed that while Lindiwe conducted the interview the mother sat on the chair while the gogo remained on the grass mat.

The plot was large with a fence and gate separating it from its neighbours. The main house was large and built from brick with a corrugated iron roof. In addition, there were 2 smaller thatch rondavels and a mud shelter without a roof. The yard was immaculately cleared and swept with small bricked-off flower beds surrounding the main house. From

the border of the cleared area extending as far as the eye can see were an abundance of mielie plants, banana trees and paw-paw trees. Behind the house was an extensive vegetable patch.

Looking around the house it was evident that there was no electricity or running water. I later found out that water was collected from a central point in the village. There was also no toilet on the property, so a grass shelter with a deep hole had been created for the disposal of sewerage.

It was extremely quiet sitting outside the house. Ever now and the sound of the wind in the trees could be heard and at one stage the sound of passing conversation carried on the wind but other than that there was absolute silence.

I sat next too the little girl taking my field notes while she sat eating pomelo's that she kept picking off the tree. At one point she got up and went inside the main house. As far as I could see, inside the house, the floor was polished cement. A piece of material was hung across the room as a curtain. The room was bare except for a table with tea, sugar and a jar containing spices. Posters of soccer players adorned the walls.

Once the interview was over I asked if I could take a photograph of the child with cerebral palsy. I was told that he was asleep in the kitchen. I was taken to one of the rondavels, which was the kitchen and found the child asleep on a grass mat, covered with a towel, next to an open fire with a cast iron pot on it. Gogo was sitting on the floor preparing mielies. A cat lay on the corner of the grass mat where the child lay.

Just before leaving I gave the mom a packet of clothes and some toys for the children to say thank you for letting us visit her in her home. She seemed taken aback, took the packet from me and started walking away. Suddenly she turned around and almost as an after-though, lowered her eyes and said 'Dankie' using the white Afrikaans term for 'thank you' instead of 'siyabonga' meaning 'thank you' in Siswati.

Approximately 2 hours later while I was recording field notes at the next participant's house I heard the sound of footsteps and singing. I looked and saw the mother walking down the road carrying a large packet of mielies that she had harvested in her own garden to give to me and Lindiwe to say thank you for visiting her.

During the interview the mother reported that the child was born at 9 months post conception at home. The child did not cry after birth, and only cried for the first time one week after birth. The mother first noticed that the child was not developing appropriately at 4 months.

Generally, it appeared that the immediate support structure in the home was good. The grandmother was reported to care for the child when the mother is not at home or when she is busy doing the chores. In addition, the grandmother supports the child financially. When asked if the neighbours like the child, the mother responded by saying she thinks that they do, and that sometimes they give her advice about what to do with the child.

The mother also reported that the child had a good relationship with his father and his father used to take him along when he went to visit friends. However, the father had since gone off in search of work and had not had contact with the family. When asked how the father's parents responded to the child, the mother responded ***"They were all happy, and (the child's) granny felt honoured to have a grandson".*** However, when asked what the mother's friends say about the disability, she responded by saying ***"My friends are no longer coming to see me. They used to come and spend time with me but since I gave birth to (the child) they are no longer coming".***

When asked what the mother and the gogo think caused the child's disability, both replied that they do not know. The gogo added ***"I have been thinking about different things that might have caused the disability. I even thought it might be witchcraft but anyway I have realized that its none of the things I have been thinking. The child is just disabled and we all need to accept that".*** In addition, when asked about the father's response to the diagnosis of disability, the mother reported ***"He didn't say or do anything. He just told us to accept (the child) as he is and as a gift from God".***

Although the family appeared to be quite accepting of the disability, they had taken the child to traditional healers. The mother reported the following ***"They said its witchcraft and evil spirit. They then gave us herbs to chase the evil spirits away, but we haven't seen any improvement in the child's condition".***

There was no information as to how the mother came to use western medicine. However, there did seem to be a discrepancy in her expectations of the hospital and the treatment she received. The mother reported ***"When I first visited the hospital they did a medical examination. Then they showed me exercises that I should do with (the child).*** When asked what the mother has gained from the hospital, she responded ***"Nothing except they showed me exercises. They don't give me any medication to assist (the child) with his condition".*** Once again the mother's main complaint regarding the hospital was the filing system.

Trust between the mother and the father appeared to be a significant issue that was raised during the interview. When asked about issues of trust, the mother responded ***"(the child's) father trusts me. As for me I don't trust him because I know that he sleeps around too much and I don't care for that. He tries to hide it but I know that he does it."*** The mother reported that she and the father use condoms as a means of protection, but at one stage the father said he wanted to stop using condoms. At this time the mother reported that she left the father until he apologized. However, she said that she knows that the father is not using condoms while he is away from home. I was surprised in this far-off village that the mother was so well-informed regarding HIV testing. When asked what she would do should she decide to have another baby, the mother responded ***"We will go to the clinic and do HIV test at least twice".*** When asked how the mother would respond if the father left her because of the demands she was making on safe sex, she said ***"…and if he wants to take another woman I wont say anything as long as he is going to support all of us financially and satisfy all our needs as women".***

Appendix 28 – Interview I

This interview was conducted with the child's' mother and all questions were directed to the mother.

Tell me about the child. How was she born and what happened? Tell me everything about her birth.

- She was born at exactly nine (9) months.
- However, it was a very long labour.
- I then stayed with her in the hospital for a week.
- She was feeding in nasogastric tube at that time or that week.

What is she doing to keep herself busy?

- She can't do anything even if she likes because her hands are not working.
- She even likes to call us in the house but she can't as she can't speak.

What is it that she likes to do?

- She likes laughing and smiling.
- She usually plays own her on making noises.

What is it that she can't do? What is it that is difficult for her to do?

- I think what is difficult for her is here in the chest.
- If she could speak she would have been able to tell me what's wrong or what is bothering her.
- So the fact that she can't speak and walk is a big problem.
- However, she can sit because I've trained her to sit but these days it look as if she can't sit anymore.

What do you think can make things easier for her?

- I don't know.

What are the neighbours saying, do they like her?

- They don't like her and I don't know why.

Can she go to the toilet on her own?

- She can't.

How is the relationship of the child with her grandmother (mums' mother)?

- It's fine.
- She loves her so much although she is not staying with us.

Who is helping you to care of the child?

- It's her father.

Who is supporting the child financial?

- She is supporting herself with the government disability grant.
- But also her father assists in supporting her.

How many are you here at your house?

- We are eleven (11).

Who is supporting all of these people financial?

- Her father.

What is her money doing?

- It supports her with her needs especially medical treatment and other needs that are specific to her.

How is her relationship with her father?

- He loves the child like any other child.

Which food does she likes or dislike?

- She likes everything meat, rice, beans, eggs, cabbage, macaroni, soup, porridge, milk, tea, bread and sometimes fish.
- She dislikes intestines (cow, goat and sheep intestines).
- But because she can't eat on her own, I feed her.

What do you believe caused her disability?

- I don't know.
- I just think she is my gift from God and God is tempting me to see if I would rise above this challenge.

What did the traditional healers say?

- They said its evil spirit at home.
- But they have failed because we haven't seen any improvements.

When you first go to the hospital, what did they do for her?

- When I first visited the hospital it was because I want disability grant for her because her father had lost his work.
- The doctor there just did some body exercises with her and that was all.
- But I never went back to that hospital again.

Why?

- I just didn't want to go back.
- There is nothing that made me not to.

What is it that you dislike about the hospital?

- There's nothing except that when I need to go to the hospital it a mission because I have to find a car to take the child to hospital.
- And also she doesn't like too many people, when there are too many people she just cries non-stop.

What did the doctors said at the hospital?

- They just told me that she is disabled.

What have you gain from all your hospital visits?

- They helped me very much with her birth.
- I could have died with the child that day because the labour took the whole day.

How long did it take you to accept her disability?

- It took me the whole year to accept.
- In that year I cried all the time.

How long did it take her father to accept her disability?

- It took him the whole year to accept as well.

How long did it take the granny to accept her disability?

- It also took her a long time to accept.

What did the fathers' family said about her disability?

- Her father doesn't have any family.
- He only has relatives of which they haven't said anything about the child's disability.

Is the child staying in a comfortable place and room?

- She doesn't have a room but, she sleeps well and comfortable with me and her father.

Does she get all the clothes she need?

- Yes, we are trying to give her almost everything that she might need.

How is the child's health in general?

- She is fine in general.
- And she usually enjoys staying in the sun outside.

Is she safe in this house in such a way that they is nothing that would happen to her?

- Yes, she is very safe here because I'm always with her everywhere I go.

Is there anything that you and the father use to protect yourselves from contracting diseases?

- For me, I'm very safe and I don't sleep around.
- And the father is too old to be cheating and, I don't think he sleeps around.

Is there any other disease that the child has except disability?

- No, she hardly gets sick at all.
- But if there's anything wrong with her. I always know that there's something wrong with her.

What do you do in the child's birthday? Do you do anything for her at all?

- Yes I always buy her a birthday cake.
- And what I have noticed about the child is that, she likes nice and sweet food.

Do you have friends? And if you have them, do they spend time with you and the child?

- Ja, I have friends and they usually ask me about the child all the time I'm with them.
- And usually when I'm with them, it's at the time when my older children are back from school and there are able to stay with her for that short period while I'm with one of my friends.
- But in general they all love her.

Do you find any difficulties in bathing or dressing the child?

- Not at all.
- What I have noticed is that when we dress her body is usually stiff and she cries all the time.
- However, we don't let her crying scare us we continue dressing her and making her fresh with perfumes etc.

If the child is hungry or thirsty, what is it that she does to show these needs?

- She usually calls for what she wants in her own distorted way that gets the message across.

So in general the child doesn't give you any problem?

- Yes, she doesn't.
- And if I have a problem with the child, I usually call my mother to assist me or advise me.
- Okay, I think we have exhausted our hour that we have been given ((says the interviewer)).
- So this is the end of our interview because you have told me everything I wanted to ask ((says the interviewer)).

Appendix 29 - Participant I: Paraphrased Ethnography and Interview

Distance of home from tar road:	10km
Electricity:	yes
Water:	yes, water point outside house
Number of people living in house:	11
Sanitation:	long-drop behind house
Disability grant recipient:	yes
Other financial support:	father is employed
Belief in cause of disability:	unknown
Child's difficulties:	speaking and walking
Perception of child's needs:	don't know
Support structure:	gogo, father, siblings, mother's friends

The interview took place on the afternoon of X May 2006 at the participant's home in village XXX. The participant lived approximately 10km off the tar road in a large house which had electricity and a water point on the property. It was quite difficult to find the house and Lindiwe and I spent about half an hour driving round in circles before we stopped and asked a woman who was outside hanging up her washing if she knew where the family lived. She then got into the car with us and directed us to the house.

On arrival we found a few primary school children outside in the yard and the mother sitting on the floor preparing mielies to be crushed into maize meal. We were greeted warmly and then everyone disappeared inside for about fifteen minutes, leaving me and Lindiwe outside in the yard! I was just starting to wonder what was going on or whether we weren't welcome when they opened the door and it became apparent that they had washed the floor of the room where the interview was to take place and the mother was busy washing the child with cerebral palsy. Chairs were arranged in a circle for the interview, with a coffee table in the middle. The CP child was carried outside and put on a plastic chair under the supervision of her younger siblings. Once I had introduced myself I left Lindiwe with the mother to conduct the interview and I went to sit outside with the children.

From the outside, the plot of land was fairly large and the yard was immaculately swept. The plot was fenced and clothing hung to dry on the fence, but it was quite easy to see what was going on in the various neighbours homes. As per usual I attracted a lot of attention and many of the neighbour's children came into the yard or stood and watched me over the fence, calling 'Mulungu, mulungu'. Once their interest in me died down a bit daily life continued. For ages I watched two little boys in the yard next door chasing chickens, trying to get them to jump over the fence. Sounds of conversations, roosters crowing and people going about their daily activities floated on the air while the sounds of "Micheal Learns to Rock" drifted through the open windows of the home.

Once again the absence of men was noted.

For the duration of the interview I sat with some of the children of the house – the 14year old child with cerebral palsy, an 11 year old girl with a baby on her back, and 2 boys aged approximately 4 and 5 years. The child with cerebral palsy is 14 years old. She has spastic quadriplegia and from my observation is only mildly responsive to those in her environment. Her legs are scissored and contracted at the ankle, knee and hip. Her arms are contracted up against her body. She is unable to hold anything in her hands and is unable to hold her head up for any period of time. In addition, she did not appear to be able to focus her eyes on anything. While Lindiwe and the mother were engaged in the interview, the child was left in the care of her 11 year old sister, who for the duration of the time kept a hand on the child shoulder and made sure that her arms were comfortable. From time to time the CP child's body was gripped by cramps. When she was tired, the 11 year old sister took the baby off her back, handed it to a younger sibling and picked the child up, mindful of her head, to take her inside to sleep.

From the interview it became apparent that the child was born at 9 months, but it was a difficult labour and the child did not cry at birth. She had to remain in hospital for a week after birth and was fed via a nasogastric tube. However, when the mother was asked what she believes caused the disability, she replied ***"I don't know. I just think (the child) is my gift from God and God is tempting me to see if I can rise above this challenge.*** The mother reported that they have taken the child to traditional healers who said that the disability was caused by evil spirits at home ***"…but they have failed because we haven't seen any improvements".***

For the first time it seemed as though the mother's main concern was the fact that the child is unable to speak. The mother reported ***"I think what is difficult for (the child) is here in the chest. If she could speak she would be able to tell me what is wrong or what is bothering her. So the fact that she can't speak is a big problem".*** However, the mother did say ***"(The child) usually calls out for what she wants in her own distorted way and that usually gets the message across".***

In general it seemed that the child was well cared for and that the mother had an extended support network. The mom reported ***"I have friends. They usually ask me about (the child) whenever I am with them. And usually when I am with them its at a time when my older children are home from school and they are able to stay with her for that short period while I am with my friends. But in general they all love her."*** However, when asked how the neighbours react to the child she responded ***"They don't like her and I don't know why."***

The child receives a disability grant which her mother uses to pay expenses related to medical treatment and other needs that are specific to the child. In addition, the child's father is employed so he assists in supporting the child.

This child was different from the rest in that she does not attend the hospital regularly. When asked about the first time the mother took her to the hospital, she replied ***"When I first visited the hospital it was because I wanted a disability grant for (the child) because her father had lost his work. The doctor there just did some body exercises***

with (the child) and that was all. I never went back to the hospital again. There is nothing that made me not to". When asked if there was something specific that she dislikes about the hospital, the mother reported ***"There is nothing except that when I need to go to the hospital it is a mission because I need to find a car to take (the child) to the hospital. And also (the child) don't like too many people, when there are too many people she just cries non-stop".***

When asked what she has gained from the hospital, she said ***"They helped me very much with (the child's) birth. I could've died then because the labour took the whole day".***

Despite all the support, it appears that it took a long time for the family to accept the disability. She reported ***"It took me a whole year to accept. During that time I was just crying all the time."*** In addition she said that it took the father and the gogo a long time to accept the disability.

When asked if the mother has any difficulties in caring for the child the mom reported ***"Not at all. What I have noticed is that when we dress (the child) her body is usually stiff and she cries all the time. But we don't let her crying scare us. We continue dressing her and making her fresh with perfumes. If I have any problem with (the child) I usually call my mother to assist or advise me".***

Appendix 30 – Interview J

This interview was conducted with the child's father, mother and stepmother. Most of the questions were directed to the child's father and mother except where it's indicated.

Tell me about the child How was he born and what happened? Tell me everything about his birth (asking the mother).

- He was born normal at nine (9) months without any disability.
- I first realised that he was disabled when he was five (5) years.

What is he is doing to keep him busy (asking the mother)?

- He just sit and crawling if he wants to go somewhere.

When did he start sitting and crawling (asking the mother)?

- He started when he was five (5) years.

What is it that he likes to do (asking the mother) ?

- He likes looking at other children playing as he can't play with them.

What is it that he can't do? What is it that is difficult for him to do (asking the mother)?

- He can't walk independently.

What do you think we can offer to help or make things easier for the child? If we can (asking the father).

- A wheelchair can help him to walk himself to where he wants to go.

Because you often go to the hospital, have you asked the wheelchair (asking the father)?

- I never asked.
- I thought he will recovery without it ((says both mum and father)).

Does he usually go to the hospital (asking the mother)?

- Myself I haven't taken him yet.

Does he usually go to the hospital (asking father)?

- Yes he does.

What do they do with him at the hospital?

- They teach him body exercises (says father).

What are the neighbours saying, do they like him (asking both mother and the father)?

- Yes they do like him and, they believe like us that he will walk one day.

Does he have all his grannies (asking both mother and the father) ?

- No, his fathers' mum has passed away.
- But his mothers' mum is still alive and she is working.

How is his relationship with his granny (asking both mother and the father)?

- It's okay.
- She loves him.

Who is staying with the child?

- It's his father ((says stepmother)).

When did you start staying with the child (asking the father)?

- I started last year when he was five (5) years.

Who is helping you to take care of him here at home?

- His stepmother.

How many people are living in this house?

- We are eight (8).

Who is supporting all of these people financially?

- It's me ((says father)).

Where are you working?

- I'm unemployed.

So how do you support all of these people?

- I'm a farmer, so I use what I have in the farm to support this family.

How is the child's relationship with his father (asking the mother)?

- It's okay.
- They love each other.

Who else is helping you to support this family financial (asking the father)?

- No one.

Which food does he like or dislike?

- He likes meat, all diary products and all sweet things.
- He doesn't like vegetables.

Is he getting a disability grant?

- He was getting a grant but now he is not getting.
- However, we are working on renewing the grant contract.

In the middle of the interview, child's stepmother walked in and some questions were directed to her.

How is your relationship with the child (asking the stepmother)?

- It's okay.
- I'm usually the one that is with him most of the time.

How many children do you have (asking the stepmother)?

- I have six (6) children.

So how do you take care of the child?

- All my children are at school during the day.
- So I use that time while there are at school to take care of him.

What do you believe caused the child's disability?

- At first I believed that, it's because of cross dressing of males and females within the house or young people dressing on older peoples' clothes (says the father).
- So they say all this cross dressing causes confusion within the family and lead to disability.
- But now I have confirmed that it's not that it another thing that I don't know (says the father).

What are the neighbours saying about his disability (asking the father)?

- Nothing.

What difficulties have you come across with the child (asking the father)?

- Taking care of the child if his stepmother is not around.

What did the traditional healers say (asking the father)?

- They said there is a misunderstanding between the elders of child's mum's family and the fathers' family.
-

When you first go to the hospital, what did you do there (asking the father)?

- When I first visited the hospital they did a complete medical examination that included mental/cognitive abilities examination.

What have you gain from all your hospital visits (asking the father)?

- Nothing.

What is it that you dislike about the hospital (asking the father)?

- Most of the time when I go to the hospital they just ask me about the child's condition and don't give me any medications.
- I often stay there between two to three hours waiting for a file and nurses sending me everywhere.

How did the child got to stay with you (asking the father)?

- He was abandoned by his mother at age four (4) because he was sick and she left him with me.
- What is painful about this is that, his mother loved him when he was not sick and when she was busy using his disability grant for her personal use.

Why did you leave him at such a time?

- I left him with his father because I didn't know what to do with him because he was very sick and no one was able to help him.
- So I came to his father for help.
- However, at that time he was not disabled, he became disabled while he was with his father.

Did you think about the child while he was here and you were not with him (asking the mother)?

- Yes.

Do you think it was right what you did to abandon your child like that?

- No, I always thought about him.
- My father said I should leave him here until he gets better.

What is your mother saying about this situation (asking the mother)?

- She feels pain about this situation.

So, why she is not asking you to bring the child back?

- I don't know why.

Stepmother please tell me about your relationship with the child's mother:

- The child's mothers' granny and my granny are born in the same family.
- So basically we are sisters.

So how was the child conceived then?

- My sister used to come here to see the child's father and everyone at home used to come here even when I was not around (says the stepmother).
- So I didn't have any problem with that.
- Then I found out that my sister (child's mother) was then pregnant with the child and he was my boyfriend's son.

How long did it take all three (3) of you to accept the child's disability?

- It took me long time (says the mother).
- I accepted immediately when the child's mother abandoned and left him here (says the father).
- And I don't think the mother has accepted that he is disabled because she don't even show care and love for him at all (says the father).
- She doesn't want him to touch her and when he cries she just leaves him there without caring (says the father).

Do you trust each other the three (3) of you?

- We used to trust each other myself and the child's mother (says the father).
- I don't have any problem with either of them. I do trust them (says the stepmother).

Do you all use anything to protect yourselves from diseases like HIV/AIDS?

- No (says the father).

Why not?

- I don't like using condoms (says the father).
- You know, this is important for your health and for the child's sake because if you die, he will be stranded (says the interviewer).
- So you need to start using protection and also taking necessary precautions to protect yourselves and the child from diseases like HIV/AIDS.

What about you mother are you taking any precautions to protect yourself from these diseases?

- No.

Do you know that it's important to take precautions?

- Yes.

So have you advised your current boyfriend to use condoms for both of your sakes?

- Yes.

So what did he said?

- He said he don't like it.

Have I said or done anything that all of you didn't like?

- No, I'm just glad that you gave us vision and light about the child's disability and you also told me where I'm going wrong. I thank you for that (says the mother).
- I don't think you have said nor done anything wrong. But even if you did, I wouldn't be angry because you are helping us (says the stepmother).
- For me, I thank you for advising the child's mother. I hope she will change because she has been advised a lot and pretend as if she hears what people are saying while she don't.

Have you ever advised your family that it wrong what there are asking the child's mother to do?

- Yes, I have but they didn't listen (says the stepmother).
- Even my father told the child's granny and grandfather about the wrongs of what there are doing, but still they haven't listen to anyone (says the stepmother).

Does the child's mothers' family like him (asking the father)?

- No they don't love him at all.
- What they've done to him shows very well that they don't love him.
- Cause even his mother doesn't show that she loves and care for him.
- When she's around him she doesn't show that happiness and enthusiasm of being around her child.
- Yes I agree, when the child's's granny is here, she usually say bad things about the child (says the stepmother).
- She even said, she wishes this situation will be over. I don't know what she meant about the situation being over or maybe she wishes the child to die? I don't know (says the stepmother).

How is your relationship with the child's mother since she's back (asking the father)?

- The relationship is not good.
- We can't even resolve things like adults.
- She is always upset without any reason.
- She doesn't even communicate whats wrong, she just become angry without any reason.

How is your relationship with the child's father (asking the mother)?

- It's okay I don't see any problem as the father says.

Have you advised the father to use protection to protect yourselves (asking the stepmother)?

- No I haven't.

Okay, what do you think needs to be done to avoid diseases (asking all three)?

- I think we need to start using condoms (says the stepmother).
- I don't know what I will do, I will see (says the father).
- I will start using condoms (says the mother).
- Okay then (says the interviewer).

Appendix 31 - Participant J: Paraphrased Ethnography and Interview

Distance of home from tar road: 50km

Electricity:	yes, electricity meter
Water:	no
Number of people living in house:	8
Sanitation:	long-drop 100m from house
Disability grant recipient:	no – grant has been stopped
Other financial support:	none. Land sustenance
Belief in cause of disability:	unknown
Child's difficulties:	walking
Perception of child's needs:	wheelchair
Support structure:	father and stepmother

We were accompanied to the home of the J participant by the mother of participant X. The home was not far from participant X's home but was completely isolated from the neighbours and there was no other sign of life for as far as the eye could see in all directions. I had been briefed by Lindiwe that this case was different from the others as the child's mother had abandoned him and he was now in the care of his father and his father's second wife. However, Lindiwe had contacted the mother and asked her to join us for the interview.

The house was inaccessible by car so we parked along the dirt road and pushed Lindiwe's wheelchair up the path leading to the house. The path was steep and rocky and Lindiwe was terrified that a snake would slither out from the dense scrub on either side of the path! At the top of the driveway was the 'main house' – yellow brick with a corrugated iron roof. The yard was cleared and swept. A dog and a number of cats lazed in the sun and chickens wondered around aimlessly. 2 small rondavels marked the border of the property behind the house. Plastic drums for collecting water lay scattered round and a metal lay in a pile of ashes from heating up water earlier in the morning. Surrounding the house was a fence which was strung with washing out to dry. Beans and mielies grew wild on the plot.

We were taken around to the back entrance of the main house where Lindiwe was able to enter with her wheelchair. The child with CP was placed on all fours kneeling over the step into the house in the sun. The room that we were taken into was the kitchen. It was fairly modern. Counters lined the kitchen and a 'snowy' tv was in the corner showing an episode of *'Lovelife'*. The chairs were pulled out for me and Lindiwe, while the stepmother immediately took her place on the grass mat in the corner and held the CP child on her knee.

Once again, once we had introduced ourselves I went to sit outside while Lindiwe conducted the interview. There was in fact very little to observe and a deafening silence permeated the environment. I was surprised to see that the house had an electricity generator. There was no running water, and a longdrop was visible about 200m from the house.

Interestingly, there were more men than women walking up and down the road. At about 1pm children started drifting home from school. I once again attracted much attention and a large crowd gathered around my car. The Stepmother started cooking lunch for the family while Lindiwe continued with her interview.

A while later a bakkie that had passed me a couple of times, with 3 men in the front seat, slowed down then came to a stop a few meters from where I sat. Naturally I though 'Oh-oh here comes trouble'. They greeted me in Siswati and I responded in Siswati. They then continued in English, saying that it was a pleasure to see a white person in their community and that I must enjoy my stay and they thanked me for helping the people in their community. I was overwhelmed by their gratitude.

Some time later a woman with a baby on her back stopped and began speaking to me in Siswati. I didn't really understand her but she seemed to be asking me in a non-interrogational way, what I was doing there. I couldn't understand what she was saying so she ended off by saying 'OK, sis, siyabonga." Once again I was taken aback by her gratitude, especially since I hadn't done anything for her.

I made my way back up to the house and sat under a tree. A little girl, probably no more than three years old, followed me and sat on a pipe extending from the house. She was wearing a vest and had a dishcloth wrapped around her waist as a skirt. The little girl's aunt, who is her primary caregiver, came outside and asked me if I didn't want to take her home with me so she could go into the city in search of work.

The interview itself took over 3 hours to complete and many issues were raised. The mother reported that the child was born at 9 months and she did not realize that the child was disabled. She only realized when the child was 5 years old as this is when he first starting sitting unsupported and crawling. This showed a distinct lack of insight into the child's development. In addition, lack of insight was displayed when Lindiwe asked the mother what she thought would make life easier and she replied ***"…a wheelchair".*** When asked why this had not been requested at the hospital, both mother and father replied ***"I thought he will recover without it".*** When asked how the neighbours respond to the child, the father replied ***"They like (the child) and like us they believe that he will walk one day".***

After much discussion it became apparent that the mother had been living away from the father and taking care of the child since birth after which she abandoned him with the father. The father reported ***"(The child) was abandoned by his mother at age 4 because he was sick and she left him with me. What is painful about this is that (the child's) mother loved him when he was not sick and when she was using the child's disability grant for her own use".*** During the interview it became apparent that the child had been a disability grant recipient but that the disability grant had been stopped. The father reported that he is unemployed and provides for his family by growing the food that they eat on his plot.

When Lindiwe asked the mother to recount why she had abandoned the child, the responded ***"I left (the child) with his father because I didn't know what to do with him because he was very sick and no one was able to help him so I came to his father for help…I always thought about him. My father said I should leave him here until he gets better".***

When asked about the family's belief in the cause of disability the father replied ***" I used to believe that it is because of cross-dressing of males and females within the house or young people dressing in older people's clothes, so they say this causes confusion in the family and leads to disability. Now I have confirmed that its not that, its something else that I don't understand"***. The father reported that the traditional healers response to the cause of disability was ***"They said there is a misunderstanding between the elders of the mother's and father's family".***

The issue of acceptance was interesting. The mother reported that it took her a long time to accept while the father said that he accepted the disability immediately when his mother abandoned him. However, he added ***"I don't think (the child's) mother has accepted that he is disabled because she doesn't show care or love for (the child) at all. She doesn't want (the child) to touch her and when he cries she just leaves him there without caring".*** When asked what the mother's family thinks of the child, the father responded ***"They don't love him at all. What they have doen to (the child) shows very well that they don't love him. Even his mother shows that she doesn't love or care for him. When she is around (the child) she doesn't show that happiness or enthusiasm of being around her child".*** The step-mother added ***"Yes, I agree. When (the child's) granny is here she usually says bad things about the child. She even said she wishes this situation would be over. I don't know what she meant about the situation being over of maybe she wishes (the child) to die. I don't know".***

Lindiwe went on to ask what the relationship is now like between the mother and the father. The father replied ***"The relationship is not good. We can't event resolve things like adults. She is always upset without reason. She doesn't even communicate what is wrong. She just becomes angry and upset without reason".*** However, the mother said ***"I don't see any problem*** (with the relationship) ***as the father says".***

The father reported that he is the one who takes the child to the hospital. The mother said ***myself, I haven't taken him yet"*** showing how she has distanced herself from the child. When asked what the father has gained from his visits to the hospital he replied ***"Nothing. Most of the time when I go to the hospital they just ask me about (the child's) condition and don't give me any medications. I often stay there for 2 to 3 hours waiting for a file and the nurses sending me everywhere."***

Another interesting issue was HIV and the use of protection during sexual intercourse. All 3 of the interviewees reported that they do not use protection. The father reported ***"I don't like using condoms".*** The mother reported that she had asked her boyfriend to use condoms but ***"…he said he don't like it".*** Lindiwe went on to stress the importance of using protection to prevent contracting HIV so that the child will not be stranded. Both

women agreed that it would be important to start using condoms, however, the father reported ***"I don't know what I will do. I will see."***

At the end of this controversial interview, Lindiwe asked if any of the interviewees thought that she had said anything wrong or offended them in any way. The mother responded ***"No. I am just glad that you gave us vision and light about (the child's) disability and you told me where I am going wrong. I thank you for that."*** The step-mother replied ***"I don't think you have done nor said anything wrong, but even if you did I wouldn't be angry because you are helping us".*** The father responded by saying ***"For me, I thank you for advising (the child's) mother. I hope she will change because she has been advised a lot and she pretends she hears what people are saying even if she don't."***

Appendix 32 – Interview K

This interview was conducted with granny of the child and responses were all hers.

Tell me about the child. How was she born and what happened? Tell me everything about her birth.

- I don't have that kind of information, it is her mother who has it.

What is she doing to keep herself busy?

- She doesn't do anything; she is like any other child with normal gestures like laughing etc.

What is it that she likes to do?

- She likes smiling and laughing to everyone especially her grandfather, father and other children.

What is it that she can't do? What is it that is difficult for her to do?

- She can't sit, walk, or hold her body and eat independently.
- She can't even speak.

What do you think we can offer to help or make things easier for her? If we can.

- I don't see anything that can help her and I haven't thought of anything.

What about the hospital wheelchair, can't you use it?

- Yes, the wheelchair is very useful.
- It helps her to sit properly and also relieve her from sleeping all the time.
- It also helps me not to carry her all the time.

What are the neighbours saying, do they like the child?

- I don't know because there is no one that comes near her and play with her.
- Also they just don't say anything about her or to her.
- There is only one woman that usually comes and prays for her recovery.

How is your relationship granny with the child?

- It's okay.
- I love her.

How did the child come to stay with you?

- She was brought back by her mother and the mother's family when she was only 1 year old.
- They said they are bringing the child so that her mother will continue with school because she can't continue schooling if the child around.
- They also told me that they don't want the child back in their house, I should keep her forever.
- I then reported the whole issue to the chief and the social workers so that she will get a disability grant.

Who is helping you to take care of the child here at home?

- No one.

Who else do you think can stay with the child except you?

- No one, but they do love her.
- When I'm sick, the child's aunt takes care of her

How many are you here at your house?

- We are seventeen (17).

Who is supporting all of these people financially?

- It's my older son.

Where is he working?

- He's a taxi owner.

Where is he staying?

- Here in this house with us.

Who else is helping your older son to support this family financially?

- It's me.

Who is supporting the child financially?

- My older son.
- But also she is supported by her disability grant.

Which food does she like or dislike?

- She likes everything except that she finds it hard to eat meat.
- So I make food very soft and other hard food so that she will be able to eat them easily.
- I use plastic cup and a spoon when she drinks water and other things.

How do you see that the child is hungry or thirsty?

- She doesn't do anything to request or show that she is hungry or thirsty.
- I just use my imagination that she needs food now or needs water.
- However, if I give her food and she is full, she doesn't eat it and also if I give her water and she is not thirsty, she doesn't drink them.

Granny what do you believe caused the child's disability?

- Because she was born disabled, I believe she got her disability in her mothers' womb.

What are the neighbours say about her disability?

- Nothing.

What has the father done for the child based on her condition?

- Her father hasn't done or said anything about her disability.

What did the traditional healers say?

- They said its evil spirit at home and so they gave us herbs and other liquids to drink.
- But we haven't seen any improvements.
- The only improvement we seen was that she stopped having fits.

When you first went to the hospital, what did you do there?

- When I first visited the hospital they helped her to strengthen her bones and also showed me body exercises.
- But also I haven't seen any improvements.

What have you gained from all your hospital visits?

- They gave me a wheelchair which is helping me so much.

What is it that you dislike about the hospital?

- To get a file takes a long-time and, sometimes they give people that came before us files while we have been waiting and not receiving our own files.

How are the doctors in the hospital?

- There are very sympathetic and understanding.
- They always help with everything I need especially tablets.

What about the nurses?

- There keep us waiting in a line.
- But they end up giving me tablets.
- Likewise, other nurses are not friendly.

Why do you think child's mother's family dislike her?

- They said they don't like a disabled child.

Does the child's mother have another child?

- I heard that she has one other child.
- But I don't know exactly because I don't go where they stay because they dislike me, the child and my family.

Who do you think will take care of the child if you pass away?

- I don't know at this moment but it something I think about everyday.
- I always pray that God will bring solution this problem because there is no one I trust to take a good care of the child like I do.
- But maybe her aunt would help but I don't know.

Is there anyone in your family that was disabled?

- No, there is no one.

How long did it take you granny to accept the child's disability?

- It took me nine (9) years to accept her disability.
- From time-to-time I become upset when I see other children walking and going things for their grannies and mine can't do anything for me.

Have I left anything that you would like to ask?

- No, there is nothing that I would like to ask or that I think you've left.

Appendix 33 - Participant K: Paraphrased Ethnography and Interview

Distance of home from tar road:	15km
Electricity:	yes, electricity meter
Water:	yes, tap on property
Number of people living in house:	17
Sanitation:	long-drop
Disability grant recipient:	yes
Other financial support:	uncle is a taxi driver
Belief in cause of disability:	became disabled in the womb
Child's difficulties:	holding her head up, sitting, walking, eating, speaking
Perception of child's needs:	unknown
Support structure:	aunt

After a very stressful drive we eventually arrived at the home of participant K. The home was in village XXX and approximately 15km off the tar road, and barely accessible by car. Once again this participant was different from the rest in that the child had been abandoned by her mother and was now in the care of her paternal grandmother.

On arrival we were greeted in SiSwati by 2 women who shook our hands. Once again the absence of men was noticed. The buggy issued by the hospital was in the garden while the child with cerebral palsy was inside.

The one gogo went inside to fetch the child with cerebral palsy while the gogo laid out a grass mat with a folded up blanket for the child to rest her head on. The gogo told us that it was time for the child to eat and asked us if it would be alright if she fed the child while we interviewed her. The gogo went inside and fetched tea and bread. She proceeded to break the bread into pieces and placed them in the tea to soak as this is the only consistency of food that the child is able to swallow. The gogo then positioned the child between her legs, covered her with a blanket and fed her while Lindiwe conducted the interview.

The child is 12 years old. She is severely contracted at all joints and drools badly. At regular intervals she let out a high pitched moan, but according to the gogo she is unable to vocalize in any other way. The child is responsive, and will look at you and maintain eye contact with you when called. The first thing that I noticed about the child was that she was beautifully dressed in a checked dress. During the feeding and throughout the interview, the gogo made a concerted effort to ensure that the dress was hanging nicely and that the child was covered, thus ensuring her dignity.

The house was fairly large and modern. It consisted of the main house, where, peering through the open front door I could see a polished cement floor and a wooden lounge suite. There was an outbuilding on the right-hand side of the house where a lady was cleaning the patio and music was blaring from within. On the left-hand side of the main

house was another outbuilding which appeared to house another family. The house had an electricity meter but no running water and sanitation was in the form of a long-drop toilet about 50m from the house.

The yard was well swept and had neat flower beds and trees. The entire front bed was a vegetable garden, with lots of junk lying in amongst the vegetables, like plastic bottles, tins, and plastic bags. Lindiwe conducted the interview under a tree whose branches had been used, along with other branches and some old sacks to create a makeshift shelter. Under the shelter was a row of seats removed from a combi and propped up with rocks to provide seating for visitors.

Based on my observation, although the house was in quite close proximity to the neighbours, it was fairly private, with the house and outbuildings on each side of the property and large trees and creepers growing in front of the house. I noticed occasional passersby in the street but no one stopped in at the house.

At around 11am students started to drift home along the streets. Lindiwe informed me that at break-time most of the children go home. Many of the girls walking home from school were carrying babies on their back. This raises so many questions, like:

- What type of education do these schools offer and what is the quality of this education
- With all these students milling the streets, it made me think that each of these people need to be schooled, clothed, fed and get jobs one day. This has scary implications for our economy.

During the lunch break a girl of about 12 years came home holding the hand of a little boy who looked about 3 years old. They wandered into the house then came back into the yard and began to play. It seemed she had no intentions of going back to school.

The gogo reported that the mother and the mother's family had brought the child to her when she was 1 year old. ***"They said they were bringing (the child) so that her mother can continue with school because she can't continue with schooling because she cant continue with schooling if the child is around. They also told me they don't want (the child) back in their house and that I should keep her forever. They said they don't want a disabled child. I then reported the whole issue to the chief and also to the social workers so (the child) could get a disability grant".***

The gogo reported that since the child was disabled since birth she believed that the disability was caused by something in the womb. However, they had taken the child to traditional healers. ***"They said it is evil spirit at home so they gave her herbs and other liquids to drink but we haven't seen any improvements".***

When asked about her experiences at the hospital, the gogo replied ***"When I first visited the hospital they helped her to strengthen her bones and also showed me body exercises but also I haven't seen any improvements."*** Once again getting files seemed to be the gogo's main complaint, while the attitudes of the nurses also seemed to be a

problem. The doctors/therapists were reported to be ***"…very sympathetic and understanding. They always help with everything I need especially tablets."***

Acceptance also appeared to be an issue. Although the gogo reported that she has accepted the situation, it appeared that she has not yet fully accepted it. She reported ***"it took me 9 years to accept her disability. From time to time I still become upset when I see other children walking around and doing things for their gogo's and mine cant do anything for me".*** From the interview it was apparent that the father is involved with his child.

Although the family seemed accepting of the child's condition, the gogo's main concern appeared to be who would care for the child should she be unable to do so. She reported ***"It is something I think about everyday. I always pray that God will bring a solution to this problem because there is no one I trust to take good care of (the child) the way I do. Maybe (the child's aunt would help, but I don't know".*** While there was no overt report of the community not accepting the child, the gogo reported ***"there is no one that comes near her or plays with her. Also they don't say anything about her or to her. There is only one woman from the church that usually comes and prays for her recovery".***

Appendix 34 – Interview L

This interview was conducted with the child's parents (mother and father) and all questions were directed to both of them except where specified.

Who is often staying with the child (asking the mother)?

- It's me (says the mother).

How old were you when you conceive the child (asking the mother)?

- I was eighteen (18) years old.

And now how old are you (asking the mother)?

- Twenty one (21).

How old is the child?

- She is two (2) years going to three (3).

Tell me about the child. How was she born and what happened? Tell me everything about her birth.

- She was born at exactly nine (9) months.
- She then fall and began crying.

What is the child doing to keep herself busy?

- She plays a lot but sometimes she just doesn't want to sit on her own.
- She just wants my attention

What is it that she likes to do?

- She likes looking at children playing in front of her.

What is it that she can't do? What is it that is difficult for the child to do?

- She can't sit.
- She is always asleep.
- She also can't talk but she can vocalise.

What is it that she can do?

- She can grabs things and plays with them.

What do you think can make things easier for her?

- A wheelchair will make things better.

What are the neighbours saying, do they like the child?

- They love her so much in such a way that I can leave her with them.
- But there are those people who don't love her.

How is the relationship of the child with her grandmother (mums' mother)?

- Granny loves her so much but the child don't like her granny.

Who is helping you to care of the child?

- It's her father.

Who is supporting this home financially?

- It's my cousin (says the mother).

Who is supporting the child financially?

- She is supporting herself with the government support grant of R190.
- But also her father try to support her

How many are you here at your house?

- We are seven (7).

How is your relationship with the child (asking the father)?

- It's troublesome.

Have you registered or applied for disability grant (asking the mother)?

- Yes I have gone to the doctors and I have filled all the forms.
- I'm now just waiting for the reply.

Which food does she likes or dislike?

- She likes porridge, banana, bread and other kinds of soft/puree food.

- She dislikes yoghurt.

How many children do you have (asking the mother)?

- She is the only one.

What made you to stay together even after the child's disability?

- We stayed together because we love each other and also we both love the child very much (says the father).
- I believe that God made us strong through everything in such a way that even after the child's disability he kept us together (says the mother).

How long did it take you to accept her disability?

- I first realised that she was disabled when she was six (6) months (says the mother).
- And it took me years to accept her disability.
- It also took me years (says the father).

What do you believe caused her disability?

- People say it's the cross dressing or disturbance at home (umuti).

What are the neighbours believes about the child's disability?

- They are saying the same story.

Are you having difficulties with the child (asking the father)?

- I just wish she can learn to sit so that she will be fed better etc.

What did the traditional healers say?

- We went to many different traditional healers.
- They all said its evil spirit at home.
- And they can't manage it.

When you first go to the hospital, what did they do for her?

- They told me to go to the physiotherapy doctors.
- They then taught her exercises.

What did the doctors said at the hospital?

- They just told me that she has bone problems.

What have you gain from all your hospital visits?

- They helped with their exercises because now she can turn herself over and she can grab things etc.
- She is even trying to sit on her own.

What is it that you dislike about the hospital?

- I always ask for a wheelchair and no one is helping.
- And the files are the problem.
- I spend more time trying to get a file.

Do you both trust each other?

- Yes we do (says the mother).
- Yes (says the father).

What are you both using to protect yourselves from disease like HIV?

- The mother is using contraceptives and also we use condoms to protect ourselves (says the father).

What is your family saying about the child (asking the mother)?

- There are confused because there is no one in my family that is disabled or who was disabled before.

Is there any one who is disable in your family (asking the father)?

- Yes it's my cousin.
- He is even using walking sticks to walk.

Do you have any questions so far?

- No (says the mother).
- Nothing (says the father).

Are you working (asking the mother)?

- No (says the mother).

Why not?

- The child needs lot of care and attention of my own.

Do you find any difficulties in bathing or dressing her?

- Not at all.
- I have no problem bathing her or dressing her

If the child is hungry or thirsty, what is it that she does to show these needs?

- She vocalise when she wants food especially when she sees a bowl and also vocalise when she sees a glass showing that she wants water.
- And if she wants to got to the toilet she just tap down using her feet.
- If she wants to sleep she just cries.

Does she have any hearing or visual problems?

- No (says the father).

So have you told your family that you have a disable child (asking the father)?

- Yes I have told them and my father (child's grandfather) loves her.
- But my stepmother don't like her and I think it's because she don't like me either (says the father).

Is there anything that I'm forgetting?

- No (says the father).

Then child's granny (child's mum mother) entered.

What is wrong with this child (participant's cousin)?

- She is also disabled (says granny).

If participant was not staying here would have stayed with her?

- Yes.

How many children do you have?

- Seven (7).

Appendix 35 - Participant L: Paraphrased Ethnography and Interview

Distance of home from tar road:	1.5km
Electricity:	yes
Water:	yes (running water in house)
Number of people living in house:	7
Sanitation:	long-drop (+/- 5m from house)
Disability grant recipient:	child support grant
Other financial support:	mother's cousin
Belief in cause of disability:	umuti
Child's difficulties:	sitting and talking
Perception of child's needs:	a buggy
Support structure:	yes, both parents, family and neighbours

The interview took place at noon on X May 2006. The interview was conducted with the mother, father and grandmother of the child with cerebral palsy. Lindiwe and I were welcomed to the home by the mother, the child and various other children who were very inquisitive about being visited by a mulungu at home! The mother and the grandmother helped us out of the car and the mom insisted on carrying my basket for me. We were welcomed into the home and taken into the lounge. Before entering the house we all took off our shoes.

The participant lives in the house with her mother, father, grandmother and aunt, as well as numerous young children. The home is situated in XXX village, approximately 1.5km off the main road and near to the shops. The house was well-equipped with all amenities. The house had an electricity meter and a water point on the property. The long drop toilet was about 10m from the house. Inside the house, the father was sitting on the couch watching TV, while the aunt was outside washing dishes in a basin and the gogo was minding the children.

While Lindiwe conducted the interview with the mother, father and gogo, I sat outside with the gogo, aunt and all the children, observing what was going on. Once again I was amazed how spotlessly clean and well swept the yard was. The house is fenced and there did not appear to be much interaction amongst the neighbours. Similar activities appeared to be going on in all the yards.

Once the aunt had finished washing the dishes she began cleaning the long drop, and once that was done she began removing stones from the yard by picking them up with a shovel. The aunt and the gogo were very welcoming towards me. The gogo went inside and fetched a packet of biscuits which she kept encouraging me to eat. In addition, both the aunt and the gogo kept trying to initiate conversation with me but eventually, due to the language barrier they gave up. At one point I managed to understand that the gogo was asking me 'if I had come to check the child for the exercises'. I perceived this to mean one of two things:

- Firstly, the parents are doing the exercises they have been taught at the hospital at home

- Secondly, gogo was consulted prior to taking the child to the hospital

Although the gogo was minding all of the children she had one child, about 2 years old who sat on her knee the whole time I was there. She explained to me that the child was ill. I was later informed by Lindiwe that it transpired in the interview that the child was the gogo's child and that both of them are HIV positive and that this is putting huge strain on the family.

Looking around at the children, all of them appeared to be sick. I was quite entertained watching the children playing and observing the way in which they were able to entertain themselves for ages with so little. Initially a little boy was hitting a stick against the fence, accompanied by a little girl. The little girl then wandered off and came back with a roll of toilet paper which she unraveled so that she could use the empty toilet roll as a microphone. This kept them busy for most of the duration of the interview. Eventually they got bored, and brave enough to approach me, because as in all of the previous households, the children were most interested in what a mulungu was doing at their home. At this point the children began copying all of my actions and words, and the older ones who appeared to attend a crèche and had some exposure to English gave me the speech about 'myself' that they had learned at crèche!

From the responses obtained in the interview it appeared that the child with cerebral palsy comes from a supportive background. She is cared for by her mother, father and grandmother and can be left in the care of the neighbours. The father reported that he had told his parents that the child is disabled but ***"they still love her"***. The household is supported by the mother's cousin, while the child receives a child support grant and is awaiting approval of her disability grant forms.

Once again, although the mother was able to describe that the child 'fell' shortly after birth, she did not seem to link this fall with the disability. Once again, the disability was believed to be caused by 'umuti' and it was reported that the neighbours hold the same belief. The parents reported that they have taken the child to traditional healers and were told that the disability is a result of evil at home and ***"they cannot manage it"***. This must surely have been a devastating revelation to the parents and it would not be surprising if it had caused problems relating to trust within the family. The fact that the traditional healers said that they cannot manage the disability is problematic if there was no further referral given.

When asked what the child is unable to do, the parents reported that she can't sit, is always sleeping and although she can vocalize she is unable to speak. The mother reported that she thought a wheelchair would make life easier for the child, while the father reported that he wishes the child could learn to sit so that it would be easier to feed her.

When queried about the parents' relationship after learning about the child's disability, the father reported ***"We stayed together because we love each other and we both love (the child) very much"*** while the mother reported ***"I believe that God made us strong***

through everything in such a way that even after (the child's) disability He kept us together". However, with more probing it became apparent that both parents were struggling with accepting the disability. This appeared to be because the child was developing differently from other children and also because they did not know the cause of the disability.

At the hospital the patient was referred to the physiotherapy department where she was given exercises to improve her muscle strength. Both parents reported that they have noted improvement from the hospital visits as the child is now able to roll, hold objects in her hands and is trying to sit independently. However, she faced the same problem with long queues and extended waiting times when opening her hospital file. She also reported ***"I always ask for a wheelchair and no-one is helping"***.

This family appeared to be educated in terms of HIV/AIDS. Both parents reported that they trust each other but still use condoms as a measure of protection. This is interesting in light of the fact that all the children were ill-looking and that during the interview it transpired that the grandmother and her child were both suffering from HIV.

Appendix 36 – Interview M

Tell me about the child . How was she born and what happened? Tell me everything about her birth.

- The child was born one month earlier, so she had a breathing problem.
- I then had to stay at the hospital for one week because she was not even crying at that time.
- She only cried after two weeks.

What is she doing to keep herself busy?

- She is using her body to play all the time.

What is it that she likes to do?

- She often likes children because she sometimes cries if she sees another child and sometimes she doesn't.

What is it that she can't do? What is it that is difficult for her to do?

- She can't hold things firmly and she can't eat cakes without juice.

What do you think we can offer to help or make things easier for her? If we can.

- I'm not sure, but I once used a tyre to help her sit and she couldn't as her bones are too floppy.
- So I'm using the same tyre to allow her to rest or sleep in it.

What about the hospital wheelchair, can't you use it?

- Ja, I often use it.
- It's just that I don't have a space in my house to put it.
- Also the wheelchair is no longer in good condition.

What are the neighbours saying, do they like her?

- Yes, they like her.
- But I don't know if I can leave her alone with them.

How is the relationship of the child with her grandmother?

- Her granny loves her so much.
- She also takes care of her when I'm not around.

Who else do you think can stay with the child except her granny?

- It's my sister.

Who is supporting the child financially?

- It's the government.
- She is getting a grant of R820.

How many are you here at your house?

- We are thirteen (13).

Who is supporting all of these people financially?

- There are supported by the child's father.

Where is the father working?

- In Witbank.

What is he doing there?

- He's working.

How is the child's relationship with her father?

- He loves her so much.

How is the child's relationship with other members of the family?

- They also love her.

Who's also helping the child's father to support the family?

- It's me.

Which food does the child like or dislike?

- She likes beans, macaroni, soup, porridge, milk, tea, bread and sometimes fish.
- She also likes sweet and nice dairy products.
- She dislikes polony.

Granny what do you believe caused the child to be disabled? (asking granny)

- I don't know.
- Anyway I heard elders saying that if the child is disabled, it's because of cross dressing of males and females within the house or young people dressing on older peoples' clothes.
- So they say all this cross dressing causes confusion within the family and lead to disability.

What has the father done for the child based on her condition? (asking granny)

- He took her to traditional healers and none of them were able to help her.
- So he decided that we should leave the child as she is causes he sick and tired of all the run around.

What did the traditional healers say? (asking granny)

- They said its evil spirit and so they gave us herbs and other liquids to drink.
- But we haven't seen any improvements.

When you first go to the hospital, what did you do there? (asking mum)

- When I first visited the hospital it was because of the child's tongue that seemed stuck inside her mouth.
- The doctor I found there told me that he don't see anything wrong with her tongue.
- He then sent me to doctors who deal with bones formation and structure.

What have you gain from all your hospital visits?

- The exercises that they have shown me at the hospital have helped me a lot because before she couldn't move her body and she couldn't roll herself but now she can.

What did you buy with that first money?

- I bought her clothes.

What is it that you dislike about the hospital?

- To get a file takes a long-time and sometimes I stay more than one hour to get a file.

How long did it take you and mum to accept the child's disability? (asking granny)

- It took me at least a year to accept.
- It took me two years to accept (say mum).

Where is your home? (asking mum)

- It's at XXX.

Is there anyone else at your home except you?

- Yes.

Does your family love the child?

- They all love her as they love me.

How many children do you have except this child?

- I have one other one, so there are two.

What does the child's grandfather say about the child? (asking granny)

- He also believes that we should stop sending her to traditional healers.

Have you all accepted the child's disability?

- Yes we all have. We believe God knows what his doing. (says granny).

What do you do with the child's money?

- I buy her clothes, blankets and food.

Who do you think will take care of the child if you and her father pass away?

- It's her granny.

Who do you think will take care of the child if granny, yourself and her father pass away? (asking granny)

- I think anyone will stay with her.
- But anyway that person will show herself if the time comes.

Do you trust yourself and the father that you won't contract any diseases that will jeopardise the child's health and wellbeing?

- I trust myself that I wont' contract anything that will affect the child's wellbeing.

- But I don't know about the child's father cause he is not with me all the time, he is working far from here.
- Anyway I trust that he's not doing anything that could affect her.

Do you use any protect with the father?

- No, we haven't thought about it.

If you could ask the father to use a condom, do you think he will use it? If he doesn't what will you do?

- I don't know if he will use it.
- And if I ask him and he don't want to use it, I don't know what I will do.

What else would you like to ask from me?

- Nothing.
- I'm just happy that we got information about the child's health and how we can help her (says granny).

When you gave birth to the child did your family accept her or not? (asking mum about her not the family in-law)

- I soon as knew that I was pregnant, my family in-law took me to their home.
- I then gave birth at their home.
- So my family didn't have much to say.

Have you ever thought that the child maybe not one of your own family? (asking granny)

- No, I have no doubt that she is my granddaughter.
- And no one in my family has ever said that.

Is there anyone in your family that was disabled? (asking granny)

- I heard that there was one person who passed away before I grew up.

Have I left anything that you would like to ask?

- I want to know what else can I use that is comfortable enough to ensure that the child sits well in this wheelchair?
- Go to the group at hospital, they will then advice you of what you can use. (says the interviewer).

If the child is hungry or thirsty, what is it that she does to request something?

- She just becomes irritated and cries.
- But she does that when she sees someone else having or eating food.

What does she do if she wants water?

- I won't lie, the child don't like water.
- If I try to give her water, she spites them out.
- Okay, try to ensure that she drinks water, because water is important in an ones body.

Appendix 37 Participant M – Paraphrased Ethnography and Interview

Distance of home from tar road:	8km
Electricity:	yes, electricity meter
Water:	yes, tap on property
Number of people living in house:	13
Sanitation:	long-drop
Disability grant recipient:	yes
Other financial support:	father
Belief in cause of disability:	umuti
Child's difficulties:	holding things and eating solid food
Perception of child's needs:	unknown, something to support her in sitting
Support structure:	extended family and neighbours

The interview took place in village XXX. We arrived at participant number M's home only to find that the another participant, number X was the next door neighbour. These two participants live approximately 8km off the main road, and their homes are barely accessible by car. We phoned for directions, and the mother came to meet us at a nearby primary school.

Upon arrival we were clearly expected! Plastic chairs had been set out in a circle and the mother, gogo, aunt and two men were sitting there. The child was in her buggy that had been issued by the hospital. A little boy who was about 5 years old was chasing chickens, while a toddler of about 18months was wandering around playing with a ping pong ball.

Soon after we arrived the men got up and left, leaving the property and walking down the street. They did not bid farewell or say where they were going. After explaining the purpose of our visit Lindiwe took the mother aside to the edge of the property so that she could conduct the interview. The gogo took responsibility for the CP child and sat with her on a grass mat under the trees talking softly. From time to time she also spoke to and scolded the other children.

I sat under a tree, observing what was going on and taking down field notes. Two of the men that had walked down the road came back. The one man lay down on the grass and lit a cigarette, while the other man came and sat next to me. He introduced himself and told me that he had completed matric last year and was unable to find a job. We sat and chatted for a while. The aunt had gone back to cleaning the house and a young man came out of the house, filled a bucket with water and took it to the wash area at the back of the plot. The house had a water point on the property and an electricity meter in the house.

The main house was modern and made out of brick and African jive music was drifting through the open windows. There was also a second smaller house on the property and a mud shack at the side of the house. The yard consisted of grass, swept ground and trees.

I noticed the close proximity of the neighbours and the fact that one could easily see what was going on in the neighbours gardens. I observed women doing washing, hanging

washing up to dry, tending vegetable gardens and filling buckets of water. Once again the absence of male contributions to the daily chores was noticed.

One of my thoughts as I sat there was "I wonder how open these women will be able to be" given that there were three men sitting around trying to listen in on the interview. At one point the aunt stopped cleaning and sat a meter or two from where the interview was being conducted and seemed to be listening to what was being said in the interview.

The toddler wandered over to where the interview was being conducted and started disrupting the proceedings. The man who had been sitting next to me went over and picked the toddler up and brought her back to where we were sitting to play.

At one point the gogo got tired on holding the child with cerebral palsy. The aunt went inside and fetched a walking ring which she put the child into. In this way the child was able to navigate her way around the yard and sit with fairly good trunk control.

At around lunch time the mother went inside and brought out a plate of soft porridge and gravy. The gogo held the child with cerebral palsy on her knee and fed her by rubbing the porridge into her mouth then waiting for a few minutes for it to slide down her throat.

Later on in the afternoon I went and sat down on the patio near to where Lindiwe was conducting the interview. The mother stood up immediately and brought me a chair, saying *"Take a seat"*.

Just after the children started arriving home from school the gogo called for one of the young boys. She spoke to him in Siswati and then placed some money into his hand. He ran off down the road. About half an hour later I saw the same child sunning back down the road in the direction of the house, carrying a 1litre bottle of Fanta Grape. He handed it to the gogo who came over and handed it to me. Lindiwe translated for her that she was giving this to me as a token of thanks to the white doctor who had come to visit them in their home and to thank me for all I had done to help the child.

The sense of support came through strongly in the interview. The mother reported ***"As soon as I knew I was pregnant my family-in-law took me into their home. I then gave birth at their home. (The child) was born one month early, so she had a breathing problem. I then took her to the hospital and had to stay for 1 week because at that time she was not even crying. She only cried after two weeks".***

In general it seemed that all of the family and the neighbours were fond of the child. However, the mother said she was not sure if she would be able to leave the child with any of the neighbours.

When asked about the cause of disability, the gogo said she believed it was umuti. She reported ***"Anyway, I heard elders saying that if a child is disabled. It's because of cross dressing of males and females within the house or young people dressing in older people's clothes. So they say all this cross dressing causes confusion within the family***

and can lead to disability. The father took the child to traditional healers who said that the disability was the result of evil spirits and gave her herbs and liquids to drink but no improvement was noted. The mother reported ***"The father took her traditional healers and none of them were able to help her so he decided that we should leave (the child) as she is because he is sick and tired of all the run around".*** The grandfather agreed that they should stop taking the child to traditional healers.

The mother reported that the first time she visited the hospital was because she thought there was a problem with the child's tongue. The doctor found nothing wrong but referred her to the rehabilitation department. The mother said that she had noticed improvement at the hospital ***"…because before (the child) couldn't move her body and she couldn't roll herself but now she can".*** Once again the mother's main complaint was that it takes a long time to get a file at the hospital.

Both mother and gogo reported that they found it difficult to accept the child's disability. The gogo added ***"we believe God knows what he is doing".***

The mother reported that she needs something to help support the child's body in sitting. She reported that she is currently using a tire to seat the child in. She has received a buggy from the hospital but there is no space in the house to keep the buggy so it has become damaged as a result of exposure to the elements.

Once again the issue of HIV and the prevention of contractable diseases was discussed. The mother reported ***"I trust that I won't contract anything that will affect (the child's) well-being. But I don't know about (the child's) father because he is not with me all the time – he is working far from here. Anyway, I trust he is not doing anything that could affect (the child).*** When Lindiwe asked if the mother thought that the father would agree to using condoms she replied ***"I don't know if he will use it, and if I ask him and he doesn't want to use it I don't know what I will do".***

Appendix 38 – Interview N

This interview was conducted with the child's cousin and responses were all his except where it's indicated.

Tell me about the child. How was he born and what happened? Tell me everything about his birth.

- I don't know much about him.
- When I first met him he was already disabled.

What makes him happy?

- He becomes happy when he sees his father or me.
- He doesn't like children.

What is it that he can't do? What is it that is difficult for him to do?

- He can't sit, walk, or hold his body and eat independently.
- He can't even speak or hear you when you are speaking.

What do you think we can offer to help or make things easier for him? (asking the neighbour)

- I think this wheelchair that he was given at the hospital is of great use to him.
- So I really think this wheelchair has made things easy for him.

What are the neighbours saying, do they like the child?

- They usually feel sorry for him, but anyway they love him like they love any other children.

How is the relationship of the child and his granny (if available)?

- He has no relationship with his granny and I don't know why she dislikes him.

Who is helping the mum to take care of the child here at home?

- It's me.
- But if I'm not around, there is no one.

Who is supporting this home financially?

- It's the father.

How many are you in this house?

- We are five (5).

Who else is helping the father to support this family financial?

- No one.

How is the relationship of the child, his father and his mother?

- It's okay.
- But the child loves his father more than his mother.

Which food does the child likes or dislike?

- He likes eating everything that is mashed.
- He even eats meat.
- he also like drinking water, tea etc.

How do you see that he is hungry or thirsty?

- When he is hungry take a dish/bowl and start crying.
- And when he's thirsty, he takes a cup and start crying.

What do you believe caused the child's disability? (asking both the cousin and neighbour)

- I don't know (says cousin).
- Since I was a child I was told that disability is because of the parents not respecting a mourning period and sleep together before the mourning period is over (says neighbour).
- They then say that causes disability on the born child which was conceived during that period of mourning (says neighbour).

What are the neighbours say about his disability?

- Nothing.

What is the father thinking about the child disability?

- Nothing, he just loves his son.
- The father once said to me; if we can find anything at all that can help the child to able to do things independently, he will be grateful (says neighbour).
- He further said; he wishes his son can be able to do things that any other person or any other child can do (says neighbour).

What did the traditional healers say when you took the child to them?

- We have never taken him to any traditional healer.
- And I've never seen anyone at home taking him to traditional healers.

What do you think the child gained from hospital visits?

- His mum said; he is getting better and he is recovering because at the hospital they have been teaching him exercises that make his body strong.
- So all his limbs have been strengthened due to these exercises.

What did the doctor tell the child's mum?

- He told her that the child is disabled and because of his bones.
- He then advised her to make the child do all the exercises that they have taught them at the hospital.

What is it that the mum dislikes about the hospital?

- She hasn't said anything about the things that she doesn't like about the hospital.
- She only told us about the things that she likes about the hospital like; the exercises that they have learnt with the child.

Have you heard about HIV/AIDS?

- No.

Do you have a girlfriend/girl lover?

- No, I don't.

If you happen to have one, do you know that you have to protect yourselves from diseases?

- Yes.

Tell me how you would protect yourselves.

- We will go to the hospital and get medication and injection.
- Okay, you need to get a condom and use it to protect yourself and your girlfriend from HIV and other killer diseases (says interviewer).
- This is important to protect yourself and your partner so that you will be able to preserve your life for the child's sake (says interviewer).

Have I said anything that I shouldn't have said to the cousin (asking neighbour)?

- No.
- I think you have helped (the cousin) to gain lot of information that he didn't know.
- It's also important to tell people about these diseases because as a person you give them a chance to fight against these killer diseases while there are not infected yet.
- Even the child's parent need to know that they need to protect themselves so that they won't get these diseases and thus also preserve their life for the good of their children.

Have the child's parent told you how he became disable (asking neighbour)?

- Yes, they told me that he was born disabled.

Do you know how many children does the child's parents have (neighbour)?

- I know only two (2) children.

Do you think the child's parent have accepted his disability (asking neighbour)?

- I spoke to the mum about that and she told me that; say she has accepted that he is disabled and there is nothing that she can do about it.
- She further says that; she would like to have another child independent of the fact that her last born is disabled.

Do the child's parents go with him to church or any other public place (asking neighbour)?

- Yes, they go to church with him and also they let him play with other children at church or around this area.

What do they do at church for him?

- They pray for him always when there are in the church.

Do you think you will ever get tired of taking care of the child?

- No.

What will you do if your wife dislikes him?

- I encourage her to take care of and, if she doesn't like to do that, I will then do it myself.

- And I don't think we will be happy as husband and wife.

How old is the child?

- I don't know.
- But I think she is seven (7) years old.

Have I left anything that you would like to ask?

- No, there is nothing that I would like to ask (says the cousin).
- I would like to ask, what can we do to avoid the child from leaning forward when he is sitting (says neighbour)?
- The wheelchair will help him. Just make sure that you teach him to bring his head up every time he is leaning forward. He will then do it automatically by himself every time he feels his body leaning forward (says interviewer).
- Okay, thank you (says neighbour).

What do you think can be done to make the child's granny to stop disliking the child?

- I don't know.
- I think she needs counselling that will help her and then stop disliking children because she doesn't only dislike disabled children but she dislikes every child.

Does the child's granny have any other children (asking cousin)?

- I don't know, I've never seen or heard about them.

Do other family members in your family like the child?

- Yes they do.

Where is the child's mother mum (Granny from the mothers' side)?

- She is at Mozambique.

Appendix 39 - Participant N: Paraphrased Ethnography and Interview

Distance of home from tar road:	45km
Electricity:	no
Water:	no
Number of people living in house:	5
Sanitation:	none
Disability grant recipient:	no
Other financial support:	father is employed
Belief in cause of disability:	sexual intercourse during period of mourning
Child's difficulties:	sitting, holding head up, speaking, eating, hearing
Perception of child's needs:	unknown
Support structure:	male cousin and neighbour

After a long day in village XXX, Lindiwe and I headed off towards village YYY to do our third interview for the day. On the way, as soon as we were back within cell phone reception, Lindiwe phoned the contact person that the mother had given her. The contact person was a neighbour who directed us towards the village. Once in the village we stopped at a school and called the neighbour again to come and meet us and accompany us to the home. As it turned out, this neighbour actually lived about 4km from the home, yet he was still the closest nieghbour!!!! We drove as far as we could get, but had to stop about 300m from the house as it was not accessible by car. We off-loaded Lindiwe's wheelchair and between the neighbour and I, pushed Lindiwe through the waist-high grass to get to the house! About halfway there I nearly stood on a snake that slithered through the grass right in front of me!!

Unfortunately on arrival we found that the mother of the child and the CP child were out for the day and only the CP child's cousin was home. Due to the fact that we had come all this way we decided that with the informed consent of the cousin and the neighbour, we would interview them on their understanding and experience of cerebral palsy is.

Lindiwe introduced us and explained the purpose of our visit. Once she had obtained informed consent she continued with the interview while I sat a few meters away and took field notes. The home consisted of 2 mud rondavels, completely isolated from any other form of life. The house was situated approximately 3km off the main gravel road and about 40km off the tar road, near to the border into Swaziland and on the other side of the mountain from village XXX. The house had no electricity or running water, and no sanitation, with the exception of a grass-shielded barrier around a pit toilet. The yard was well swept. There was no sign of any fruit or vegetables that had been grown, however, there were some mielies growing on the border of the property. There were also two wooden structures about a meter off the floor, holding chickens – obviously trying to keep them out of reach of the snakes!

The area had a very deserted feeling about it and we were regarded with a small degree of suspicion by the cousin.

The interview yielded some very interesting information. Basically it appeared that the child was accepted despite his disability. The cousin reported that he did not know what had caused the disability, but as long as he had known the child, had had been disabled. However, the neighbour reported ***"Since I was a child I was told that disability is because of the parents not respecting a morning period and sleep together before the mourning period is over. They then say this causes disability on the born child that was conceived during a period of mourning".***

Generally it seemed that the child with cerebral palsy is well liked however, the cousin reported ***"He has no relationship with his granny and I don't know why she dislikes (the child)".*** When asked what they thought could be done to stop the gogo from disliking the child, the cousin replied ***"I think she needs counseling to help her and then stop disliking the child".***

When asked who helps the mother to care for the child, the cousin responded ***"It's me but if I am not around there is no one".*** When asked if he tires of taking care of the child, the cousin said that he does not. In response to being asked if he got married and his wife does not like the child, the cousin responded ***"I will encourage her to take care of (the child) and if she doesn't want to do it, I will do it myself, and I don't think we will be happy as a husband and wife".***

In response to the being questioned regarding the father's relationship with the child, the cousin said ***"He says nothing, he just loves his son. He once said if we can find anything at all that can help (the child) to do things independently he will be grateful. He also wishes his son will be able to do things that any other child can do".*** The neighbour reported the following ***"I spoke to (the child's) mother and she told me that she has accepted (the child's) disability and there is nothing she can do about it. She further said she would like to have another child despite the fact that her last born id disabled."*** The cousin reported that the parents take the child to church and they pray for him there.

When asked how the neighbours react to the child, the cousin responded ***"They usually feel sorry for him but anyway they love him like any other child".***

Interestingly, this family who were one of the most rural that we visited had never taken the child to a traditional healer.

When asked what the mother thinks of the hospital, the cousin replied ***"(The child's) mother said that (the child) is getting better and he is recovering because at the hospital they have been teaching (the child) exercises that make his body strong so all of his limbs have been strengthened due to these exercises".*** When asked what the doctors had told the mother, the cousin replied ***"He told her that (the child) is disabled because of his bones. He then advised her to make (the child) do all the exercises they taught him at the hospital".*** When asked what the mother dislikes about the hospital, the cousin replied ***"she only told us about the things she likes".***

Interestingly, the cousin reported that he did not know what AIDS was. When asked what type of protection he would use with a girlfriend he reported ***"We will go to the hospital and get medication and injection".*** Lindiwe told him about HIV and explained why it would be important to use a condom. At the end of this discussion she asked the neighbour if she had said anything that she shouldn't have. The neighbour responded ***"No. I think you have helped (the cousin) to gain a lot of information that he didn't know. It's also important to tell people about these diseases because as a person you give them a chance to fight against these killer diseases while they are not yet infected. Even (the child's) parents need to know that they need to protect themselves so they wo'nt get these diseases and thus also preserve their lives for the good of their children."***

At the end of the interview, Lindiwe asked if there was anything else that either the cousin or the neighbour wanted to ask. The neighbour asked how they could stop the child from leaning forward when he sits. The interviewer replied ***"The wheelchair will help him. Just make sure that you teach him to bring his head up every time he is leaning forward. He will learn to do it automatically by himself every time he feels his body leaning forward".***

Appendix 40 – Interview O

Tell me about the child. How was he born and what happened? Tell me everything about his birth.

- He was born a very healthy boy at the right birth time with normal milestones like any other child.
- He then became sick of persistent cough around seven (7) months.

What is he doing to keep himself busy?

- He has a lot of interests but I noticed that he liked playing a lot with everyone and everywhere.

What is it that he likes to play with often?

- He likes playing with cans and stones.
- He uses then pretending as if his selling something.

Does he play with other children/

- Yes, he plays with lot of children around this place.

What is it that he can't do? What is it that is difficult for him to do?

- He can't dress himself on the upper half of his body.
- But he can dress himself anywhere else except on top.
- I think it's because of his disabled hand.

What do you think we can offer to help or make things easier for him? If we can.

- I'm not sure, but I spoke to another woman around here and she told me about this shoe that can help him to walk easily.
- I think that shoe will help strengthening his leg and foot and also make it easier for him to walk.

Because you often go to the hospital, have you ever told them about what you are telling me now?

- I told them, it was three of us who wanted these shoes.
- They told us to write our names in the waiting list in 2004 because these shoes were not available at that time.
- So we have been waiting without any reply from anyone.

When last did you go to the hospital?

- I last went when there were these black sisters with that one that is light in complexion.
- They are still there even today (says the interviewer)

When last did you go to the group?

- I didn't go for the whole of this month.
- But in January, February and March I did go, so it only this month.

What are the neighbours saying, do they like the child?

- Yes, they like him.
- It's only those that don't like him like Councillor DDD's wife. She doesn't like children that are not hers in her house.

What actual does this wife do to show that she don't like him?

- She doesn't like him to enter her home or touch anything that belongs to her.

What do you think caused this wife to dislike him?

- I think she just hurt him because his disabled.
- However, I might be wrong because I don't know how this wife feels but that's what I think in my own mind.

You said you live alone? Where are the child's grandparents?

- His grandparents in his fathers' side passed away. But my parents, his grandparents are still alive.

Who's helping you with the child?

- It's my family and my neighbour.

Who is supporting your family?

- It's the child's father.

How many are you at home?

- We are three and four with other child who is now staying at Johannesburg.

How is your relationship and the fathers' relationship with the child?

- He loves both of us in the same way because if I leave the child cries but also if his father leaves he also cry.

Who is helping you financially to support the child?

- Its his father.
- But also he is getting a grant of R820 which makes things much better.

Does he use his money to buy food at home?

- No he don't, it's his father who buys food

What do you do with his money?

- I buy food that he likes and also buy him clothes.

When did he start getting a grant?

- In August 2005.

What did you buy with that first money?

- I bought him clothes.

What do you to celebrate his birthday

- Last year we were at church on his birthday.
- I bought him a cake and people at church gave him gifts.

Which food does he like or dislike?

- He dislike spinach and many other vegetables and, tea without milk.
- He likes meat like fish, beef, mutton, juice etc.

Does he get all of the things he likes?

- Yes, he does.

Does he speak?

- Yes, because I can hear him speaking.

How do you know if he's hungry?

- He communicate in signs that he's hungry or/and thirsty.

What caused the child's disability?

- I don't know exactly what caused his disability.
- But he started by getting sick and he was in and out of the doctors.
- One day his leg and hand didn't want to move anymore thus couldn't walk and that's where everything started.

Did you take him to traditional healers for his disability?

- Yes, I took him to only one traditional healer.

What did he said?

- He gave me some medicines.
- I also took him to XXX church and that's where he became better through prayers.
- He then started crawling and walking before going to physiotherapy training at the hospital.

When you first go to the hospital, what did you do there?

- I first heard about the hospital visit from one of my neighbours. Who told me that the hospital has asked people to tell everyone with a disabled child to come to hospital.
- When I arrive at the clinic I found you.

What did I told you to do?

- You told me to go to clinic VVV of which I did.
- When I get there they told me that I'm late others are already in the meeting.
- I found one nurse at clinic VVV who also told me to go to another room because I'm late.
- In that room I found another person who taught me how to seat the child and then she gave another date of coming back.

Since you have been going to the hospital for such a long time. What have you gain from all you visits?

- I have gained a lot of knowledge, because all this time I have been sitting with my child telling myself that I love him without teaching him anything that will help him.

- They taught me to teach the child many things like how to wash and dress himself independently and other things that will help him to be more independent.

What is it that you don't like about the hospital?

- It's only the filing system and the long waiting hours.

Does you feel that other family members from your side and the fathers' side accept the child?

- Yes they do.

Is there anyone that you feel s/he can stay with the child if you are away?

- I don't because when I leave I leave with him always.

Is there anyone who have confirmed family disability history from both of your families?

- There is no one who has said anything and I don't know when I not around but to me there is no one.

Who do you think will take care of the child your and his father pass away?

- My mother will take care of him.

How many children do you have?

- He is the only one.

Do you want another child or you don't?

- No, I still want another child even though this child is disabled but I still want another child.

How is the child mentally?

- He is fine mentally because when you ask him something, he do it or if he don't want to he just refuse.
- After refusing he then run away because I threaten to hit him.

What does he do if he wants to go to the bathroom?

- He just tells me that he wants to go to the bathroom.

- And when he is there, he can undress and also dress himself with minor assistance from me.

Are you happy about the child's condition at present?

- Yes.

When did he started walking?

- He started walking in 2005 when he was nearly 5 years old.

How long did it take you to accept his disability?

- It took me about two (2) to three (3) years to accept.

How long did it take the his father to accept the disability?

- His father didn't have any problem with him being disabled.

What did you do when you first see him walking?

- I cried and prayed to God to help me and help the child to be strong so that we will be able to walk.

At the church do they always pray for him?

- No, they pray for him once in every two weeks.

What steps have you and the father taken to protect yourselves from diseases like HIV/AIDS that could affect your whole family?

- We haven't done anything because the father always says he is clean so he don't need to protect himself cause he don't have HIV/AIDS.
- He further said he won't get it from anyone because he sleeps with me only.

Does the father have any other relationships except the one that he has with you?

- I don't know of any other relationships and I haven't heard that he has one.

If maybe you ask the father to use something like condom to protect both of you from HIV/AIDS and he refused. What will you do or say?

- I don't know.
- I haven't thought about it.
- But maybe we will talk about it and see what he says.
- But if its time, I will force him to wear protection.

What else do you need for the child except the shoe?

- It's only the shoe.
- Anyway, I want to take him for further check-up to evaluate why he is still drooling.

How do you feed the child?

- He feeds himself.
- He likes eating porridge rather than rice because the rice often comes out of his mouth.
- He also struggles to eat apples but he eats banana and other fruits.

What else would you like to ask from me?

- Nothing.

Appendix 41 Participant O – Paraphrased Ethnography and Interview

Distance of home from tar road: 8km

Electricity:	yes, electricity meter
Water:	yes, tap on property
Number of people living in house:	3
Sanitation:	long-drop
Disability grant recipient:	yes
Other financial support:	father
Belief in cause of disability:	unknown, illness
Child's difficulties:	dressing upper half of body, eating rice
Perception of child's needs:	orthotic shoe
Support structure:	mother's family and neighbour

During the interview with participant X, it became apparent that the next door neighbour also had a child who has cerebral palsy. The mother of participant X said to Lindiwe that she thinks that the neighbour would like to tell us her story, so one of the aunties went next door to call the mother and the child.

The interview was therefore conducted at the home of participant X.

The mother explained that the child was born without complications and developed age-appropriately. At 7 months he became sick. The mother reported ***"He was in and out of doctors. One day his leg and hand didn't want to work anymore and he was unable to walk".*** The mother said she took the child to a traditional healer who gave her some herbal medicine. However, the mother believes that the child was healed through prayer at the church. ***"I also took him to XXX Church and that's where he became better through our prayers". He started crawling and walking again before I took him to physiotherapy training at the hospital".*** In addition the mother added that at church they pray for him every two weeks. When asked how she reacted when the child started walking again, the mother responded ***"I cried and I prayed to God to help me and to help (the child) to be strong so that he will be able to walk again".***

However, the mother reported that she has gained a lot from her hospital visits. She reported ***"I have gained a lot of knowledge because all this time I have been sitting with my child telling him that I love him without teaching him anything that will help him. They taught me to teach (the child) so many things like how to wash and dress himself independently and other things that will help (the child) to be more independent.*** Once again the main complaint about the hospital was the long waiting periods to open a file.

When asked what she thinks would make life easier for the child the mother responded ***"I don't know but I spoke to another woman around here and she told me about this shoe that can help (the child) to walk easily".*** Lindiwe then asked, if since the mother visits the hospital frequently she has not asked one of the therapists about such a shoe. The mother replied ***"I told them. It was 3 of us who wanted those shoes. They told us to write our names on the waiting list in 2004 because these shoes were not available at***

the time. So we have been waiting without any reply from anyone. In addition, the mother said that next time she goes to the hospital she will ask if anything can be done about the way the child drools.

Interestingly, this was how the mother explained how she first came to use the hospital ***"I first heard about the hospital from one of my neighbours who told me that the hospital had asked people to tell anyone with a disabled child to come to the hospital. When I arrived there I found you. You told me to go to the clinic at clinic VVV which I did. I found a nurse who told me to go to another room. In that room I found another person who taught me how to sit (the child) and then she gave me another date to come back".***

Cognitively the child appears normal. The mother reported that he understands well and is able to follow instructions. He enjoys playing with other children in an age appropriate way. The mother reported ***"He can't dress himself on the upper part of his body but he can dress himself anywhere else. I think it is because of his disabled hand".***

The mother reported that it took her 2-3 years to accept the child's disability. Interestingly she reported ***"(The child's) father did not have any problem with him being disabled".*** The mother reported that she has support and help in caring for the child from her family and her neighbour.

When asked how the mother and father protect themselves from HIV the mother reported ***"We haven't done anything because (the child's) father always says he is clean so he doesn't need to protect himself because he doesn't have HIV. He further said he wont get it from anyone because he only sleeps with me."*** Lindiwe went on to ask the mother whether she has thought about asking the father to use a condom. She replied ***"I don't know. I haven't thought about it. But maybe we will talk about it and see what he says. But if it is time I will force him to wear a condom".***