UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

DEVELOPMENT OF A MODEL FOR THE REHABILITATION OF CHILDREN WITH DISABILITIES IN THE GREATER GIYANI MUNICIPALITY IN LIMPOPO PROVINCE, SOUTH AFRICA

By

DESMOND MATHYE

(26389101)

Submitted in fulfilment of the requirements for the degree

PHILOSOPHIAE DOCTOR (PHYSIOTHERAPY)

in the

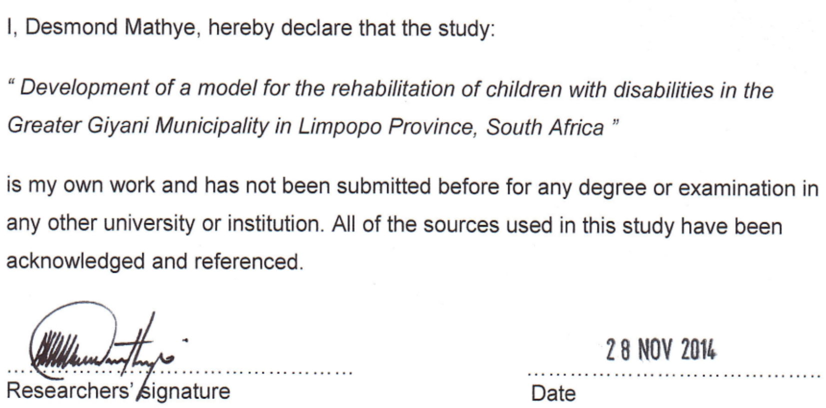
Faculty of Health Sciences

University of Pretoria

April 2015

Supervisor: Dr CA EKSTEEN

DECLARATION



I, Desmond Mathye, hereby declare that the study:

" Development of a model for the rehabilitation of children with disabilities in the Greater Giyani Municipality in Limpopo Province, South Africa "

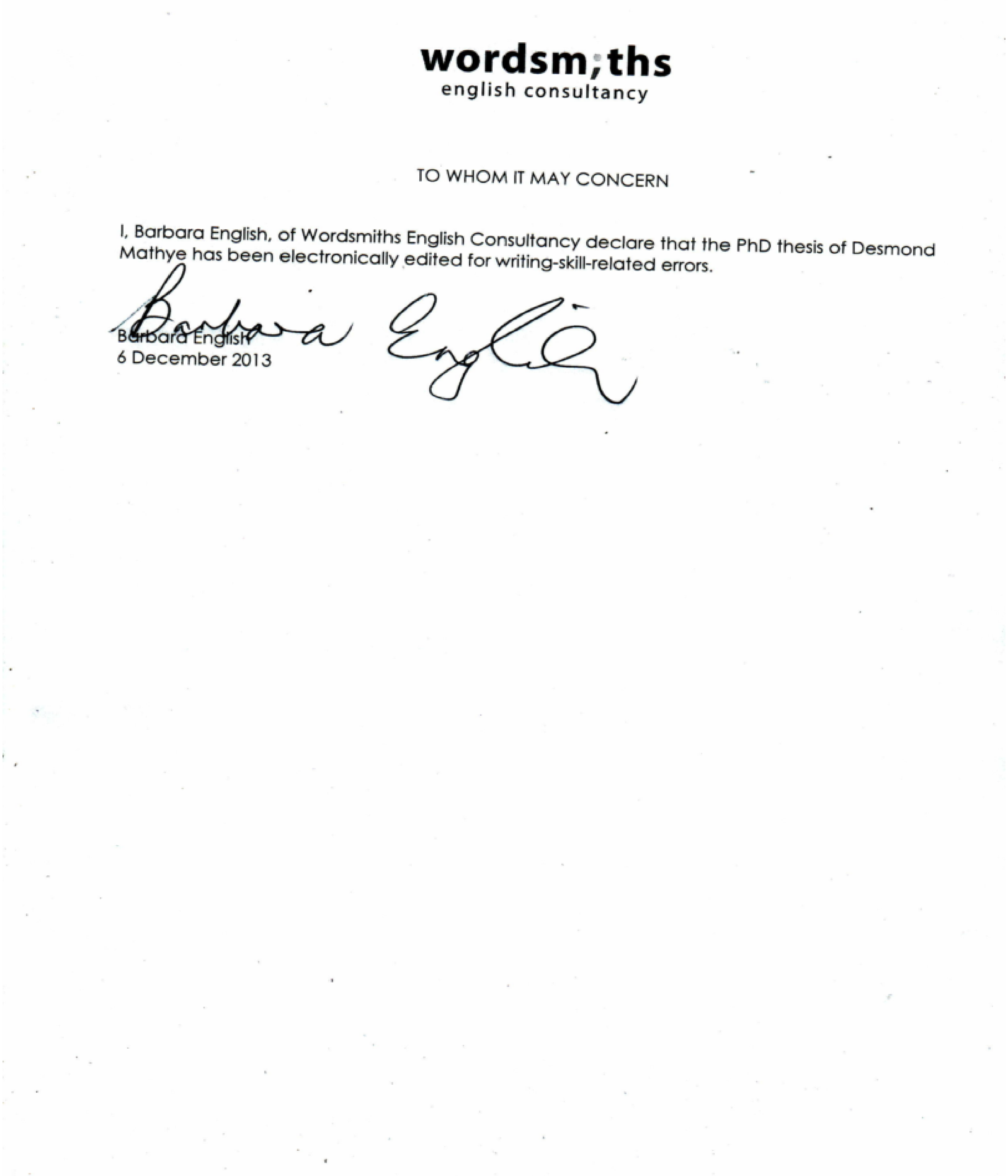
is my own work and has not been submitted before for any degree or examination in any other university or institution. All of the sources used in this study have been acknowledged and referenced.

Researchers' signature

28 NOV 2014

Date

DECLARATION BY THE LANGUAGE EDITOR



wordsm;ths
english consultancy

TO WHOM IT MAY CONCERN

I, Barbara English, of Wordsmiths English Consultancy declare that the PhD thesis of Desmond Mathye has been electronically edited for writing-skill-related errors.

Barbara English

Barbara English
6 December 2013

ACKNOWLEDGEMENTS

My greatest appreciation goes to:

- The almighty God, who made this thesis possible.
- My supervisor Dr Carina Eksteen. Without her, this study would not have happened. I thank you from the bottom of my heart.
- My partner Tinyiko and our sons (Muhluri and Ntshembho) for their sacrifices and emotional support throughout the duration of this study.
- My parents (Mbhazima Daniel and Mamaila Rose) for always believing in me.
- All the men and women who participated in this project: *Ndza mi khensa…ingi Hosi yi nga miendla hi tintswalo.*
- The National Research Foundation (NRF), the University of Pretoria and the South African Society of Physiotherapy (SASP) for funding this project.

ABSTRACT

The rehabilitation of children with disability (CWDs) in a rural area is difficult because of the multiple challenges associated with rural and under-resourced areas. These challenges include accessibility of health-care facilities, shortage of experienced rehabilitation professionals and limited rehabilitation models to direct how the rehabilitation of CWDs should be conducted within a rural South African context. The primary research question for this study was: how should a model for the rehabilitation of CWDs look like in Giyani?

The aim of the study was to develop a descriptive model for the rehabilitation of CWDs by health-care workers. The objectives of the study were to: (1) synthesise concepts, (2) synthesise non-relational statements, (3) organise relational statements, and (4) present the theory as a model with an ultimate goal of improving the health, function, and participation of CWDs.

A qualitative, theory-generating, exploratory, descriptive and contextual approach was used.

Data collection was divided into two phases. The primary objective of Phase 1 was to generate data through face-to-face interviews with caregivers of CWDs, rehabilitation professionals and community rehabilitation workers (CRWs) in order to develop concepts. The objective of Phase 2 was to expand data gathering from caregivers and rehabilitation professionals through focus group discussions (FGDs).

Data from the interviews and FGDs was transcribed verbatim, translated into English, and analysed using an inductive approach.

Ten caregivers participated in the interviews. Participants were predominantly mothers and unemployed. The CWDs whose caregivers participated in the interviews were under the age of six and had mostly a cerebral palsy diagnosis (80%). Eight rehabilitation professionals and two CRWs participated in the interviews.

A total of ten caregivers participated in three FGDs. Participants were predominantly mothers. The CWDs whose caregivers participated in FGDs were less than or equal to two years of age and were diagnosed with cerebral palsy (80%). Six rehabilitation professionals participated in one FGD.

Sixteen concepts and non-relational statements were developed:

1) cause of childhood disability
2) available services
3) role of caregivers
4) caregivers' source of support
5) caregivers' coping strategy
6) caregivers' level of satisfaction
7) caregivers' expectations
8) role of rehabilitation professionals
9) rehabilitation professionals' competency
10) factors that affect the rehabilitation professionals' work ethic
11) rehabilitation professionals' plan of action
12) role of CRWs
13) role of the municipality towards people with disabilities
14) role of Pfunanani Special School
15) challenges experienced
16) societal perception of CWDs

Seven relational statements were developed to show the relationship between the sixteen concepts. Lastly, a model for the rehabilitation of CWDs was presented.

The implication of the model is that the rehabilitation professionals and CRWs have a responsibility to reduce child-related, family-caregiver related, and health-care related challenges. In addition, the local government and the education sector have a responsibility to reduce community related challenges. The assumption of the model is that a reduction in child-related, family-caregiver related, health-care related, and community related challenges is likely to improve the caregivers' ability to support the CWD and ensure that there is continuity of care or treatment.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF TERMINOLOGY

Caregiver of a child with a disability

Caregiver of a child with disability is a parent who provide long-term care to a child with disability that requires physical, emotional, social and financial resources as well as to co-ordinate their child's numerous and multifaceted medical, education and developmental interventions while balancing competing family needs (Silver, Westbrook & Stein, 1998; Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu & Wood, 2005). A caregiver of a child with a disability is interchangeable used with the word caregiver in this research. For the purpose of this study, a caregiver is a male or female relative or any appointed individual who helps the child with disabilities with the activities of daily living such as feeding or bathing.

Child

According to the South African Children's Act of 2005, a child is any person below the age of 18.

Children with disabilities

Children with disabilities refer to persons below the age of 18 who have a physical, mental, intellectual and sensory impairment which in interaction with barriers may hinder their full and effective participation in society on equal basis with other children (WHO, 2007). Children with disabilities include children with health conditions such as cerebral palsy, hydrocephalus, developmental delay, achondroplasia, spina bifida and Down syndrome.

Community rehabilitation workers

Community rehabilitation workers are health-care workers trained in the field of occupational therapy, but registered with the Health Professions Council of South Africa as occupational therapy assistants. Community rehabilitation workers are meant to provide rehabilitation services to people with disabilities and in particular children in the community.

Concept

A concept is a basic building block of a theory which presents a mental image of a phenomenon, an idea, or a construct in the mind about a thing or an action (Walker & Avant, 2005, p. 26).

Disability

Disability is an interaction between the health condition, environmental factors and personal factors (WHO, 2007). Disability can occur as impairment in body function or structure; as a limitation in performing activities or a restriction in participation (WHO, 2012).

Genetic clinic

Genetic clinic refers to an area within the Nkhensani Hospital's private ward in Giyani, Limpopo Province where a nurse who had specialised training in genetics assesses and assists children with disabilities and their caregivers.

Model

A model is a graphic representation of a theory that is presented schematically by using symbols and arrows (Walker & Avant, 2005).

Non-relational statement

A non-relational statement is a statement that shows the existence of a concept or defines a concept (McEwen & Willis, 2002).

Rehabilitation

The *World Report on Disability* defines rehabilitation as a set of measures that assist individuals who experience or are likely to experience disability to achieve and maintain optimal functioning in interaction with their environment (WHO, 2011). For the purpose of this study, rehabilitation refers to a series of action or steps taken, with the aim at helping children who acquired disabilities before, during and after birth to enable them to regain maximal functioning. Rehabilitation of children with disabilities is a complex matter which involves multiple sectors such as health, education and social services (Wiart, Church, Darrah, Ray, Magill-Evans, & Andersen, 2010).

Rehabilitation clinic

A rehabilitation clinic refers to an area within the Nkhensani Hospital's allied health block in Giyani, Limpopo Province where children with disabilities are rehabilitated by rehabilitation professionals.

Rehabilitation professionals

Rehabilitation professionals are professionals such as physiotherapists, occupational therapists and speech-therapists who are responsible for the restoration and compensation for the loss of function in children with disabilities (WHO, 2011). For the purpose of this study, rehabilitation professionals refer to both therapists and therapy assistants.

Relational statement

Relational statements are statements that shows the relationship between two or more concepts and are used to connect ideas in an attempt to describe the real world or to develop a theory (McEwen & Willis, 2002; Walker & Avant, 2005).

Rural area

Rural area is defined as a geographic area that is located outside the cities and towns. For the purpose of this study, a rural area refers to a former Bantustan area.

Theory

Theory is defined as a group of relational statements that presents a systematic view about a phenomenon and it is used descriptive, explanatory, predictive and prescriptive purposes (Walker & Avant, 2005, p. 28).

LIST OF ABBREVIATIONS AND ACRONYMS

CBR: Community-based rehabilitation

CEO: Chief executive officer

CRW: Community rehabilitation worker

CWDs: Children with disabilities

DHSD: Limpopo Department of Health and Social Development

DOH: Department of Health

FGD: Focus group discussion

HIC: High-income countries

HPCSA: Health Professionals Council of South Africa

ICF-CY: International Classification of Functioning, Disability and Health; Children and Youth Version

LMIC: Low and middle-income countries

PHC: Primary health-care

PWD: Persons with disabilities

QDA: Quantitative data analysis

STATSSA: Statistics South Africa

UNICEF: United Nations Children’s Fund

WCPT: World Confederation of Physical Therapy

WHO: World Health Organization

CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

The current study seeks to develop a model for the rehabilitation of children with disabilities in Giyani. In Chapter 1, the background of the study, problem statement, research question, research framework, aim, objectives, significance and chapter outline are presented.

According to the International Classification of Functioning, Disability and Health, Children and Youth Version's (ICF-CY), disability is an interaction between the health condition, environmental factors and personal factors. Disability is neither purely biological nor social but lies between the two (WHO, 2007). The United Nation Children Fund‘s (UNICEF) discussion paper on early childhood development and disability, define children with disability (CWD) as children with health conditions such as cerebral palsy, spina bifida, muscular dystrophy, traumatic spinal cord injury, Down's syndrome, as well as with hearing impairment, visual impairment, physical impairment, communication impairment and intellectual impairment (WHO, 2012).

According to the World Report on Disability, childhood disability is a phenomenon found in both low-middle-income countries (LMIC), as well as high-income countries (HIC) (WHO, 2011). The estimated number of CWDs in LMIC is high (Grantham-McGregor, Cheung, & Cueto, 2007). The higher numbers of CWDs in LMIC imply that the existence of such children should be acknowledged, and their needs addressed (Scherzer, Chhagan, Kauchali, & Susser, 2012). In addition, CWDs require access to good quality health services in the form of early identification of a disabling condition as well as intervention (Bonnier, 2008; Reithmuller, Jones, & Okely, 2009).

The early identification of CWDs may be achieved through the use of a surveillance process (Scherzer et al. 2012). Surveillance method is primarily used in a primary health-care (PHC) clinic or a paediatric clinic where routine observation of early childhood milestones is performed (Brothers, Glascoe, & Robertshaw, 2008). An example of early childhood milestone observation is the South African Road to Health Chart. The South African Road to Health Chat monitors the growth of the child, immunisation, vitamin A supplementation, deworming medicine and other illnesses (Kitenge & Govender, 2013). In the event that developmental delay or suspected genetic abnormality is detected from the milestone observation based on developmental guidelines. A formal medical examination such as a physical and laboratory tests may be performed in order to confirm an underlying pathology resulting in disability (Scherzer *et al*, 2012). As soon as CWDs are identified, intervention that is mainly in the form of rehabilitation is required (Nair & Radhakrishnan, 2004; Penny, Zulianello, Dreise, & Steenbeek, 2007).

1.1.1 Rehabilitation of Children with Disability

The rehabilitation of CWDs may be conducted by the private health sector, public health sector or Non-Governmental Organisations (NGOs) (McIntyre, Thiede, Nkosi, Mutyambizi, Castillo-Riquelme, Goudge, Gilson, & Erasmus, 2007; Dawad & Jobson, 2011; Zhaokang, Yuxi, Yong, Yunchang, Yuanjum, & Harris, 2012). Sometimes the provision of rehabilitation services by NGOs is classified as private health sector (Berendes, Heywood, Oliver, & Garner, 2011). Rehabilitation by the private health sector is mostly reserved for those who can afford as well as those with medical insurance or medical aid. On the other hand, the rehabilitation by the public health sector is mainly for the poor who cannot afford a private health sector (McIntyre *et al*, 2007). Nonetheless, the provision of rehabilitation services by NGOs has been reported to be affordable even to the poor population in South Africa (Leonald, 2002).

The focus of the current study is on the provision of rehabilitation for CWDs in the public health sector.The rehabilitation of CWDs within the public health sector may be provided in an inpatient or outpatient basis (Simons, Sieberg, Pielech, Conroy, & Logan, 2013).

The inpatient rehabilitation is often used in children whose disabilities are physical and injury-related such as spinal injuries, traumatic brain injury and burns (Trovato, Bradley, Slomine, Salorio, Christensen, & Suskauer, 2013; Zonfrillo, Durbin, Winston, Zhao, & Stineman, 2013). On the other hand outpatient rehabilitation is often used for developmental and neurological conditions such as cerebral palsy (Adelugba, Ayodiipo, Ogunbameru, Oni, Akinsiku, & Akinrem, 2011; Chang, Lin, Tung, Chiang, & Hsu, 2014; Majnemer, Shikako-Thomas, Lach, Shevell, Law, Schmitz, Pouline, & QUALA Group, 2014).

The outpatient rehabilitation of CWDs may be provided either in a hospital-based setting or a community-based setting (WHO, 2011). Irrespective of the rehabilitation setting, collaboration between rehabilitation professionals and caregivers of CWDs is required (Egilson, 2011; An & Palisano, 2014). The lack of collaboration between rehabilitation professionals and caregivers negatively affects how caregivers perceive the services that CWDs receive. As such, there is a possibility that caregivers could lose interest and default from rehabilitation sessions (Egilson, 2011). In order to ensure that healthy collaboration between rehabilitation professionals and caregivers exist, rehabilitation professionals should not only promote their own views of the child to the caregiver. Instead, rehabilitation professionals join the caregiver in viewing the CWDs from a multidimensional perspective so as to generate strategies that will eventually assist the child and the family during the rehabilitation process (Meisels & Atkins-Burnett, 2000, p. 235; An & Palisano, 2014; Brewer, Pollock, & Wright, 2014).

Rehabilitation professionals such as physiotherapists and occupational therapists, have multiple roles to play during the rehabilitation of CWDs (Egilson, 2011). These tasks include monitoring of assistive device usage, the provision of information and advice to the caregivers, the improvement of physical function, and the promotion of participation of CWDs in society. Other authors have also suggested that the role of physiotherapists and occupational therapists is to: optimise motor function of CWDs, prevent the development of secondary conditions such as musculoskeletal deformities, and promote participation in daily life (Chiarello, Palisano, Bartlett, & McCoy, 2011; Bartlett, Chiarello, McCoy, Palisano, Jeffries, Fiss, & Wilk, 2014).

However, the role that rehabilitation professionals play during the rehabilitation of CWDs is influenced by their chosen team approach such as the multidisciplinary, interdisciplinary and transdisciplinary approach (Fawcett, 2013; Ted & Brett, 2013).

According to Butt and Caplan (2010), multidisciplinary, interdisciplinary and transdisciplinary approaches are the three commonly used team approaches within the rehabilitation field. The multidisciplinary, interdisciplinary and transdisciplinary team approaches are unique in terms of; (1) the role played by rehabilitation professionals, (2) how rehabilitation professionals assess CWDs, (3) how the goals of rehabilitation are set, (4) the strength of the methods, and (5) the limitations of the approaches (Rosen, Miller, Pit-ten Cate, Bicchieri, Gordon, & Daniele, 1998; Haig & LeBreck, 2000; Kilgo, Aldridge, Benton, Vogtel, Burke, & Unanue, 2003; Butt & Caplan, 2010; Nandiwada & Dang-Vu, 2010; Bartlett *et al*. 2014).

Besides the selected team approach, rehabilitation professionals' role in the rehabilitation of CWDs is also influenced by the chosen rehabilitation model or approach. According to Wilson (2002), rehabilitation models are used to enable rehabilitation professionals to conceptualise the rehabilitation process, think about the treatment or rehabilitation to be given to the CWD, and explain the impairments and functional status to the caregiver or the child.

In the twentieth century the rehabilitation of CWDs was influenced by a medical model of disability that sought to 'fix' something wrong with the child through the expertise of rehabilitation professionals and treatment (Stiker, 2002). The focus was on the impairment of the child that was viewed as the child's source of social exclusion. However, the emergence of the social model of disability makes an explicit distinction between impairment and disability. It rejects medical categories, focusing on the elimination of prejudice, discrimination and defends self-determination, social integration, and the civil rights of CWDs (Loja, Costa, Hughes, & Menezes, 2013).

Most of the existing models for the rehabilitation of CWDs are based on both the medical and social models of disability (Pless & Granlund, 2012), together with other theories, models and approaches such as: (1) The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), (2) Community-based rehabilitation (CBR) (WHO, 1982, 2002, 2010), (3) family-centred approach (Rosenbaum, King, Law, King, & Evans, 1998; Law, Hanna, King, Hurley, King, Kertoy, Rosenbaum, 2003; Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012), (4) human ecology, theory of human development and systems theory (Bronfenbrenner, 1979; Garbarino & Ganzel, 2000), (5) model of therapeutic recreation (Dattilo & Kleiber, 1993; Dattilo, Kleiber, & Williams, 1998), (6) the primary health-care approach (PHC) (WHO, 1978, 2008), (7) the community-based service delivery model (Stricklin, 1997; Rosenberg, 2000; McPherson, Weissman, Strickland, Van Dyck, Blumberg, & Newacheck, 2004; Perrin, Romm, Bloom, Homer, Kuhlthau, Cooley, Duncan, Roberts, Sloyer, Wells, Newacheck, 2007), (8) the resource-based approach (Trivette, Dunst, & Deal, 1997), and (9) stress and coping theories (Aranda & Knight, 1997; Knight & Sayegh, 2010).

Despite the fact that almost 90 per cent of CWDs in the world reside in LMIC (UNICEF, 2008), most of the existing models of rehabilitation of CWDs were developed in HIC such as Canada and the USA, where the rehabilitation of CWDs is well supported by the abundance of economic and social advantages. It is also known that the characteristics of HIC and LMIC are different (Sumner, 2010).

An example of the models developed in HIC are: (1) the life need model of paediatric service delivery (King, Tucker, Baldwin, Lowry, LaPorta, & Martens, 2002), (2) the model of determinants of change in gross-motor abilities and engagement in self-care and play (Chiarello *et al*. 2011), (3) the ecological model of community-focused therapeutic recreation and life skills services (King, Curran, & McPherson, 2012), and (4) solution-focused coaching in paediatric rehabilitation (Baldwin, King, Evans, McDougall, Tucker, & Servais, 2013).

It has also been shown in the literature that disability is linked to poverty where disability is thought to increase the risk of poverty and poverty thought to increase the risk of disability (Fujiura & Yamaki, 2000; Emerson & Hatton, 2009; Sen, 2009). The implication of poverty in LMIC is that the models of rehabilitation as developed in HIC will not necessarily be useful in the LMIC context such as South Africa (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014).

The rehabilitation professionals in Limpopo Province and particular Giyani experience similar challenges as other rehabilitation professionals in the rural areas of Eastern Cape and the Kwazulu-Natal provinces in South Africa (Bateman (2012).

Bateman (2012) highlighted that rehabilitation professionals in some of the rural parts of the Eastern Cape and KwaZulu-Natal encountered multiple challenges during the rehabilitation of CWDs such as an unclear operational mandates from the health departments, lack of multi-sectoral collaboration as well as the lack of appropriate rehabilitation protocols or standards to enable them to provide efficient and effective rehabilitation services to CWDs.

1.2 BACKGROUND

In the background subsection discussions on the following topics are presented: (1) introduction of the research setting, (2) the population of South Africa, (3) CWDs, (4) the rehabilitation team that is responsible for the rehabilitation of CWDs, (5) rehabilitation of CWDs within a hospital-based setting, (6) rehabilitation of CWDs within a community-based setting, (7) additional needs of CWDs, (8) rehabilitation models and strategies used in the world, and (9) rehabilitation models and approaches used in South Africa.

1.2.1 Introduction of the Research Setting

The current study was conducted in Giyani[1], which is the heart of the Greater Giyani Municipality in the Limpopo Province of the Republic of South Africa. Limpopo Province has five district municipalities: Mopani, Vhembe, Capricorn, Waterberg, and Sekhukhune (STATSSA, 2012; GCIS, 2013). Mopani district has five local municipalities: Greater Giyani, Ba-Phalaborwa, Greater Tzaneen, Greater Letaba, and Maruleng (STATSSA, 2012; GCIS, 2013). Giyani is a township that used to be the capital of the former Gazankulu Government, and it is currently the administrative and commercial centre of both the Mopani District and the Greater Giyani Municipality. The Greater Giyani is a rural municipality comprising only one town which is Giyani, ten traditional authorities and 91 villages (LGHSA, 2013).

---

[1] Giyani is a Xitsonga word meaning to dance.

There is only one hospital in the Greater Giyani Municipality called Nkhensani, and it is situated in the town of Giyani. For the purpose of the present study, Giyani refers to the town and the surrounding villages.

1.2.2 South African Population

The Republic of South Africa has nine provinces, eight metropolitan municipalities, 44 district municipalities and 226 local municipalities (GCIS, 2013). According to Census 2011, the population of South Africa is about 51.8 million (STATSSA, 2012). Limpopo Province has a population of 5.4 million (GCIS, 2013). Mopani district and the Greater Giyani Municipality has a population of one million and 244 217 respectively (STATSSA, 2012). Out of the 51.8 million people in South Africa, 29.2 per cent are children below the age of 15 years. Limpopo Province, Mopani district and the Greater Giyani Municipality respectively has a population that comprises 34.0, 33.8 and 36.8 per cent of children below the age of 15 years (STATSSA, 2012).

1.2.3 Children with Disabilities

In this subsection, the prevalence of childhood disabilities and the causes of childhood disabilities are discussed.

1.2.3.1 Prevalence of childhood disabilities

The prevalence of CWDs in the world is not known (WHO, 2011). However, the Global Burden of Disease commissioned in 2004 estimated that the number of children living with moderate to severe disabilities between the ages of zero to 14 years is about 93 million, which is 5.1 per cent of the global population (WHO, 2008). UNICEF estimated that the number of CWDs below the age of 18 years is about 150 million (UNICEF, 2005). A review of the literature in LMIC indicated that the prevalence of childhood disability ranged between 0.4 and 12.7 per cent (Maulik & Darmstadt, 2007). Two studies conducted in Ghana and South Africa respectively suggested that the prevalence of childhood disability is at 1.8 and 6 per cent (Biritwum, Devres, Ofosu-Amaah, Marfo, & Essah, 2001; Couper, 2002).

According to Census 2001, the prevalence of childhood disability in South Africa was 2.1 per cent for children aged zero to nine and three per cent for children aged 10 to 17. Limpopo Province was found to have the fourth highest number of people with disabilities (PWDs) out of the nine South African provinces, although the exact percentage of CWDs was not specified (STATSSA, 2005, p. 12).

1.2.3.2 Causes of childhood disabilities

It is commonly accepted amongst researchers in paediatrics that the aetiology of childhood disability is attributed to prenatal, perinatal and postnatal factors (Shevell, Majnemer, Rosenbaum, & Abrahamowicz, 2001; Goyen & Lui, 2009; Gladstone, 2010; Maimburg, Bech, Vaeth, Møller-Madsen, & Olsen, 2010; Jauhari, Boggula, Bhave, Bhargava, Singh, Kohli, Yadav, & Kumar, 2011). Prenatal factors include physical, chemical, biological, and psychological hazards that the foetus is subjected to during the prenatal development stage, such as a woman who excessively consumes alcohol and smoke during pregnancy. Perinatal factors include physical, chemical, biological, and psychological hazards that the developing foetus/baby is subjected to at the time of birth such as asphyxia. Postnatal factors include physical, chemical, biological, and psychological hazards that the child is subjected to after birth such as trauma, meningitis or cerebral malaria (Giza, Mink, & Madikians, 2007; Gladstone, 2010; Paley & O'Connor, 2011; Karthikeyan & Ramalingam, 2012).

In LMIC poverty, poor health, and poor nutrition of pregnant or lactating mothers as well as infants and young children is also thought to increase the risk of childhood disabilities (Grantham-McGregor, Cheung, & Cueto, 2007). However, caregivers of CWDs often have varying perceptions on the potential causes of the children’s disabilities. A study on Pakistani families in the UK reported that the caregiver’s perceived causes of the children’s disabilities were religious in origin. These caregivers believed that: (1) the child was a gift from God, (2) the child was a test from God, (3) they were chosen, and (4) they were being punished or even cursed for having a CWD (Croot, Grant, Cooper, & Mathers, 2008). In addition, other Pakistani families’ associated biomedical reasons and their individual behaviours such as the types of food they consumed to be some of the possible causes of childhood disabilities.

1.2.4 Rehabilitation Team for Children with Disabilities

Rehabilitation professionals perform the rehabilitation of CWDs in collaboration with caregivers of CWDs (Law *et al*, 2003; Dempsey & Keen, 2008). A study conducted in Tanzania which is a LMIC found that apart from collaboration with caregivers, rehabilitation professionals also collaborate with community rehabilitation workers (CRWs) in the rehabilitation of CWDs (Hansen, Chaki, & Mlay, 2013). In addition, CWDs themselves can achieve their own rehabilitation or self-management in the form of exercises depending on their age, cognitive capacity, and their level of function (Tsai, Wu, & Huang, 2008; Jankowicz-Szymanska, Mikolajczyk, & Wojtanowski, 2012).

1.2.4.1 Rehabilitation professionals

Traditionally, the term ‘rehabilitation professional’ refers to therapists such as physiotherapists, occupational therapists, and speech-therapists (Levin, 2006; Chiarello *et al*, 2011). However, during the course of the current study the speech-therapists were found not to play any significant role in the rehabilitation of CWDs in Giyani.

Physiotherapy is a health profession which is concerned with identifying and maximising quality of life and functional movement potential, within the spheres of promotion, prevention, maintenance, intervention/treatment, habilitation and rehabilitation. Physiotherapy encompasses physical, psychological, emotional and social well-being of the client (WCPT, 2011a). The World Confederation of Physical Therapy (WCPT) recommends that physiotherapy professional entry-level educational programmes be based on university level studies, of a minimum of four years, independently validated and accredited as being at a standard that accords graduates full statutory and professional recognition (WCPT, 2011b).

Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life.

Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement (WFOT, 2012). A majority of the member countries of the World Federation of Occupational Therapy (WFOT) require a four-year university qualification before registering as an independent occupational therapist (WFOT, 2010).

Physiotherapists and occupational therapists play various roles in the rehabilitation of CWDs. They do not only assist CWDs with rehabilitation but also assist families and caregivers of CWDs with necessary skills to enable the CWD to participate in society (Chiarello *et al*, 2011). Of all the rehabilitation professionals rendering rehabilitation services to CWDs in Brazil, physiotherapists and occupational therapists were found to perform the most comprehensive assessments of children and treatment, making them the most relevant professionals to conduct rehabilitation of CWDs (Andrade, Ferreira, Mendonca, & Haase, 2012).

Rehabilitation professionals are best known for the 'hands-on' role that they play in the rehabilitation of CWDs such as soft tissue mobilisation, joint mobilisation and positioning (Levin, 2006). The WCPT recommended that rehabilitation professionals should play other roles in addition to the traditional hands-on role that they play when working with CWDs and their caregivers (WCPT, 2003). By only focusing on the 'hands-on' role, rehabilitation professionals do not sufficiently address the broader challenges facing CWDs and their families such as their educational needs and social security (Levin, 2006; Saloojee, Phohole, Saloojee, & IJsselmuiden, 2007; Egilson, 2011).

According to Chiarello, Huntington, and Bundy (2006), the goal of rehabilitation professionals should be: (1) to optimize motor function of CWDs, (2) to prevent the development of secondary conditions such as musculoskeletal deformities and contractures, and (3) to promote participation in daily life. Nonetheless, rehabilitation professionals are being criticised for not using outcome measures to assess the effectiveness of their intervention on CWDs and their caregivers (King, Wright, & Russell, 2011).

1.2.4.2 Community rehabilitation workers

The use of CRWs in rehabilitation programmes was introduced by the World Health Organization (WHO) as a strategy for the provision of services that focused on PHC issues and the rehabilitation of both adults and CWDs in their own communities (WHO, 1995). The use of CRWs was meant to improve the accessibility of health-care services by both adults and CWDs through the use of CBR.

CRWs are health workers who had undergone two years certificate training in basic occupational therapy skills, physiotherapy skills, speech therapy skills and community development skills (Lorenzo, 1994). In South Africa CRWs are employed by the Department of Health as specialised auxiliary services officers to work in the communities and are mainly stationed in the community clinics (Twine, 2007). The primary role of CRWs is to: (1) implement CBR, (2) empower PWDs and CWDs, (3) promote inclusion of PWDs and CWDs, (4) provide basic occupational therapy, physiotherapy, and speech therapy in the community, and (5) refer clients to the hospital when the need arises (Concha, 1993).

A study by Dolan, Concha, and Nyathi (1995) highlighted that CRWs' training is not sufficient enough to meet the needs of people and children with different disabilities. Similarly a study by Mannan, Boostrom, MacLachlan, McAuliffe, Khasnabis, and Gupta (2012) suggest that there is no sufficient evidence in the literature to suggest that CRWs are effective when working with PWDs as well as CWDs. These findings are similar to those of WHO (2002) where it was reported that a review of CBR programmes run by CRWs mainly increased awareness of disability among non-disabled people, as well as an improved financial income of PWDs through improved access to social security funds. Robertson, Emerson, Hatton and Yasamy (2012), also said that CBR programmes for children with intellectual disabilities in LMIC showed that there was insufficient evidence to suggest that CBR programmes were efficient or effective in the rehabilitation of CWDs.

According to Rule, Lorenzo, and Wolmarans (2006), CRWs' training comprises 80 per cent of occupational therapy skills, 10 per cent of community development skills and 10 per cent of physiotherapy and speech therapy.

It is likely that the inability of the CRWs in South Africa to meet the needs of people with different types of disability as suggested by Lorenzo (1994) and Concha (1993) is as a result of the CRWs training which is centred on the field of occupational therapy and not the other rehabilitation professions (Twine, 2007). CRWs are currently registered with the Health Professions Council of South Africa (HPCSA) as occupational therapy assistants (Ramakumba, Holland & Beukes, 2006 cited in Twine, 2007). A study in Tanzania has also showed the CRWs are more in line with the profession of occupational therapy than with other rehabilitation professions such as physiotherapy and or speech therapy (Hansen, Chaki, & Mlay, 2013).

1.2.4.3 Caregivers of children with disability

It is generally accepted amongst the community of paediatric rehabilitation professionals around the world that caregivers play a vital role in the rehabilitation of CWDs but the role that caregivers should play has not been sufficiently explored in the literature (O'Neil, Palisano, & Westcott, 2001; Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu, & Wood, 2005; Levin, 2006; Graungaard & Skov, 2007; Saloojee *et al*, 2007). A review of literature on the role of family during the rehabilitation of children with cerebral palsy showed that the role that a child's family plays is diverse – ranging from being decision makers, playing the role of therapist and playing other non-specific roles (Dirks & Hadders-Algra, 2011). According to a study conducted by Braga, Da Paz Junior and Ylvisaker (2005), caregiver-instituted rehabilitation of CWDs was found to produce superior results as compared to professional-instituted rehabilitation. The reason for such excellent results is that caregivers spend more time with the child and know the child more than the rehabilitation professionals. It is fundamental that rehabilitation professionals should recognise caregivers as equal partners in the decision-making process and not just passive recipients of service. Should rehabilitation professionals not recognise caregivers as equal partners, there is likelihood that caregivers will rebel, and not perceive their children's rehabilitation by rehabilitation professionals as important (Carter & Markham, 2001; Dalzell, Nelson, Haigh, Williams, & Monti, 2007).

1.2.5 Rehabilitation within a Hospital-Based Setting

According to the *World Report on Disability*, rehabilitation services for PWDs and in particular CWDs are still based in a hospital setting or community setting (WHO, 2011). The rehabilitation of CWDs in South Africa and, in particular, Limpopo Province is hospital based. This fact was confirmed by a study, which was conducted in Gauteng and Limpopo Province where it was found that rehabilitation services for CWDs was mainly rendered in a public hospital setting (Saloojee, Rosenbaum, Westaway, & Stewart, 2009). Nonetheless, hospital-based rehabilitation is associated with challenges such as poor accessibility of health-care facilities, economic and transport barriers, and health-care related barrier as discussed in the following sub-section.

1.2.5.1 Challenges associated with hospital-based rehabilitation

In this sub-section, discussions are on the challenges associated with hospital-based rehabilitation services.

Poor accessibility of health-care facilities

Rural communities in some of the South African provinces are located in remote geographical areas where there are no formal roads between the areas of residence and the nearest town with health-care services (Porter, 2002). People living in those types of settlements tend to make limited use of the health-care services as a result of the long distances and inaccessible roads between home dwellings and health-care facilities (Porter, 2002; Saloojee *et al,* 2007).

A study by Egilson (2011) in Iceland highlighted that caregivers and CWDs had to travel as much as 20 kilometres to access hospital-based rehabilitation services in towns and cities. The distance between the hospital and the child’s place of residence often put pressure on the caregiver because of the disruptions in family routines such as cooking, cleaning or even fetching firewood and water from communal taps.

At times caregivers have to walk long distances and carry the child on their backs to catch a mini-bus taxi to get to the nearest health-care facility (Masasa, Irwin-Carruthers, & Faure, 2005; Monson, Hall, Smith, & Shung-King, 2006).

Economic and transport barriers

A study conducted in Orange Farm in the Gauteng Province of South Africa, highlighted financial hardship as an obstacle that hampered caregivers' compliance with the rehabilitation of CWDs (Saloojee *et al*, 2007). With the unemployment rate of 29.8 per cent amongst the general population in South Africa and 38.9 per cent in Limpopo Province as reported in Census 2011. It is expected that families will not necessarily be able to afford to bring their children to the rehabilitation clinics on a regular basis because of high transport costs. Furthermore, a province such as Limpopo is considered to be one of the poorest provinces in South Africa, with an average household annual income of R 57 000 per annum (STATSA, 2012). As a result of their socio-economic background families of CWDs find themselves in a situation where they have to decide whether to use the little money that they have to buy essential food commodities or use it for transport to take the child to a clinic for treatment (Monson *et al*, 2006).

Having to use public transport is also not a simple matter for the caregiver and the child. Using public transport, particularly mini-bus taxis for a child in a wheelchair or "Madiba buggy"[2], can be a costly exercise as taxi drivers expect to be paid for the wheelchair or Madiba buggy and the child because both occupy space in the taxi (Masasa *et al*, 2005).

Health-care related barriers

Overcrowding and long queues are common phenomena in South African public hospitals (Saloojee *et al*, 2007). Health-care users find themselves in a situation where they have to wait for an extended length of time before they are attended to by health professionals.

---

[2] Is a manually propelled modular postural seating device for CWDs

The overcrowding and long queues are often attributed to the serious shortage of health professionals in South Africa, particularly in poorly resourced areas (Tumbo, Couper, & Hugo, 2009; Campbell, 2011; DHSD, 2011).

According to Levin (2006) rural-based public hospitals are mainly served by inexperienced health professionals doing their compulsory one year of community service. According to a study conducted in Limpopo, community service professionals were found to have received inadequate supervision during their term as community service practitioners (Nemutandani, Maluleke, & Rudolph, 2006). With limited supervision of community service practitioners or lack thereof, caregivers and CWDs suffer due to the limited skills and competences that professional would have acquired during the mandatory community service year.

1.2.6 Rehabilitation within Community-Based Setting

CBR was introduced three decades ago by the WHO as a strategy for the rehabilitation of PWDs in the communities. CBR is defined as an approach within a general community development to promote rehabilitation, equalisation of opportunities, poverty reduction, and social inclusion of all PWDs, including CWDs (WHO, UNESCO, ILO, & IDDC, 2010a). According to Chappell and Johannsmeier (2009), the South African government has adopted the CBR model in the Integrated National Disability Strategy White Paper as the basis of the national rehabilitation policy. The Integrated National Disability Strategy White Paper incorporates challenges that all PWDs encounter, the existing practises in the field of disability, as well as recommendations of the implementation of disability plans. However, the White Paper has not yet been implemented into law (Chappell & Johannsmeier, 2009). South Africa is also lacking behind its European counterparts in terms of disability management strategies, which include the availability of medical specialists in physical and rehabilitation medicine (Haig, Im, Adewole, Nelson, & Krabak, 2009).

Just like the hospital-based rehabilitation, community-based rehabilitation is also associated with challenges. These challenges include heavy reliance on CRWs and the lack of collaboration between stakeholders.

1.2.6.1 Challenges associated with community-based rehabilitation

Challenges associated with community-based rehabilitation are discussed in this sub-section.

Reliance on CRWs

The implementation of CBR relies on the use of CRWs and or other mid-level workers. The training of CRWs remains a contentious issue more especially in South Africa (Rule, Lorenzo, & Wolmarans, 2006). As reported earlier, CRWs training comprises 80 per cent of occupational therapy skills, 10 per cent of community development and 10 per cent of physiotherapy and speech therapy. The current practice implies that CRWs are occupational therapy assistants based in the community with limited knowledge in community development, social skills, physiotherapy skills and speech therapy skills (Rule, Lorenzo, & Wolmarans, 2006). It is therefore not surprising that CBR has been reported not to be effective in meeting the needs of PWDs and in particular CWDs (Dolan, Concha, & Nyathi, 1995; Mannan, Boostrom, Kuyini, Alhassan, & Mahama, 2011; MacLachlan, McAuliffe, Khasnabis, & Gupta, 2012).

Lack of collaboration between stakeholders

Rule, Lorenzo, and Wolmarans (2006) indicated that there is a lack of collaboration between the different stakeholders during the implementation of CBR. The rehabilitation professionals and the CRWs are said not to be collaborating during the rehabilitation of CWDs. On the other hand the Department of Education together with the HPCSA has not concluded on the required curriculum or the institutions which will be responsible for training of CRWs (Rule, Lorenzo, & Wolmarans, 2006).

1.2.7 Additional Needs of Children with Disabilities

Besides the health-care and rehabilitation services that CWDs receive in the hospital as well as in the community, there are other services that they are in need of.

The United Nation's conversion on the rights of PWDs requires nations to ensure that PWDs and CWDs have access on equal basis with non-disabled people or children to physical environment such as buildings, transportation, information, and communication (UN, 2006). However, a European study by Colves, Dickinson, Parkinson, Arnaud, Beckung, Fauconnier, Marcelli, Mcmanus, Michelsen, Parkes, and Thyen (2011) suggested that CWDs are not having access to physical environment like stairs and ablution facilities in their homes, schools, and community like their non-disabled counterparts. In addition Colves *et al,* (2011) also reported that CWDs were not receiving social support in their homes and community.

According to Resch, Mireles, Benz, Grenwelge, Peterson, and Zhang (2010) CWDs are in need of access to: (1) necessary information and services, (2) financial services, (3) school and community inclusion, and (4) family support. Other studies have also found that CWDs are in need of: (1) education and educational facilities, (2) rehabilitation, (3) social assistance grants, (4) equipments, and (5) assistive devices (Saloojee *et al*, 2007; Bourke-Taylor, Cotter, & Stephan, 2014; Tornbom, Jonsson, & Sunnerhagen, 2013).

1.2.8 Rehabilitation Models and Approaches Used Internationally

Five rehabilitation models and approaches as used in other parts of the world are discussed in this subsection.

1.2.8.1 A life need model of paediatric service delivery

The aim of a life need model is to guide rehabilitation professionals, caregivers, board members and community partners on how paediatric service delivery should be conducted in order to enhance the community participation of CWDs as well as their quality of life (King *et al*, 2002). This model was developed for the Canadian context where paediatric rehabilitation services are provided by regional or locally-based centres. The emphasis of rehabilitation services in Canada is on coordination of health, social and educational services for CWDs (King *et al*, 2002).

According to King *et al* (2002), there are five major types of needs that the life need model seeks to address. The five types of needs focuses on: (1) the foundational skills needs of the CWD such as mobility, (2) the applied skills of the CWD such as skills that enables the child to perform day-to-day function, (3) the child's needs for support and information such as mentorship, vocational exploration and sexuality, (4) the parents' and other family members' needs for support, information and skills development, and (5) community members' needs for information and education on disability issues.

Seeing that the life need model was developed for the Canadian context which is a HIC and different to the African context and in particular South Africa. The relevance of the life needs model in a South African context is questionable considering that: (1) it was designed for a HIC context where the rehabilitation of CWDs emphasis on the coordination of health, social and educational services which is not the case in rural South Africa (Twine, Collinson, Polzer, & Kahn, 2007), and (2) the model relies on the use of a transdisciplinary approach which requires collaboration between rehabilitation professionals and caregivers as equal partners, but this still seems to be lacking in the South African context (Vorster & Kruger, 2007; Theron & Theron, 2010).

1.2.8.2 Model of determinants of change in gross-motor abilities and engagement in self-care

The aim of the model is to provide physiotherapists and occupational therapists with a framework for decisions to be taken about intervention and support for young children with cerebral palsy and their families (Chiarello *et al,* 2011). The model encourages rehabilitation professionals to broaden the focus of rehabilitation services for young children with cerebral palsy to include not only development of motor abilities but also comprehensive intervention and support to enhance participation in daily activities and routine. The assumption underlying this model is that through activity and participation, CWDs gain experience and learn skills that promote self-determination and prepare them for the transition through the education system into adulthood. The model requires the rehabilitation professionals to gather comprehensive information on the child and family as well as considering options for rehabilitation services, community services and support. The rehabilitation professionals are encouraged to consider how the child, family and, the different available services complement each other when planning intervention and evaluating outcomes. The decisions about intervention are made in collaboration with the family while taking into consideration the: (1) available options, (2) family preferences, (3) research evidence, and (4) the knowledge and professional judgement of the therapists.

Just like the life needs model, this model was created and tested in the USA and Canada, which are considered to be HIC with adequate monetary resources.

1.2.8.3 An ecological model of community-focused therapeutic recreation and life skills services

The ecological model of community-focused therapeutic recreation and life skills services was developed for the Canadian context. The model is intended to be used by managers and service organisations seeking to develop an integrated programme of community-focused therapeutic recreation and life skills services based on a collaborative capacity-building approach (King, Curran, & McPherson, 2012). The four pillars of the model are a set of integrated services and principles designed to support the participation of children and youth with disabilities in community activities. The pillars are meant to: (1) provide community outreach services, (2) provide community development services, (3) facilitate the sharing of physical and educational resources with community partners, and (4) promote the organisation that is rendering rehabilitation services as a community facility that provides adapted physical space and specialized instruction. The overall expectation of the model is that community members will take the responsibility and can ensure that CWDs participate in society.

1.2.8.4 Solution-focused coaching in paediatric rehabilitation

The model was developed for the western context, and it is meant to be used by paediatric rehabilitation professionals of all disciplines, the youth, the caregivers, and the key decision makers such as managers. The model addresses the how paediatric rehabilitation services should be provided as well as to enable the therapists’ to work with key decision-makers such as managers in order to enhance the well-being and the participation of CWDs in society (Baldwin *et al*, 2013). The model is strength-based and goal-oriented where positive reframing and strategic questions are used to assist clients in envisioning the preferred future or goal. This model focuses on the client's expertise, strengths and resources.

The model consists of seven elements. (1) The first element is the setting of the stage. The setting of the stage is a point where a client such as a caregiver enters into a relationship with therapists, and each party is expected to bring it's strengths and resources from their life experiences or training. The therapist must pay attention to the caregivers' ideas in order to explore and expand their knowledge and choices. (2) The second element is the forming of caregiver-therapist relationship where the therapist must ensure that s/he connect with the caregiver as a person, through respect, warmth and openness. The therapist must also explore the caregiver's needs, priorities and preferences regarding the CWD. (3) The third element is envisioning a preferred future. The caregivers' preferred future for the child provides a lens through which the goal of therapy is aligned with the caregivers' long-term vision. (4) The fourth element is target discovery where caregivers are expected to consider own goals as well as the therapists' information and assessment findings, so that mutual goals can be developed. (5) The fifth element is strategy creation which is based on the goals of both the caregiver and the therapist. The strategy should focus on increasing the caregiver's awareness and integrating knowledge based on learning and practising of new skills, and using of equipment. (6) The sixth element is plan confirmation. At this stage, the therapist uses strategic questions and positive feedback to confirm, clarify and explore any needed refinement to the goals and plans regarding the CWD (DeJong & Berg, 2002). (7) The last part is called action and reflection cycle. At this stage, the therapist informs the caregiver of what went well, as well as failures while highlighting the strengths of the caregiver.

1.2.8.5 Model for community health service development

The model introduces the concept of community health services with the aim of strengthening the capacity of health-care facilities in townships and villages. This model is not specific for the rehabilitation of CWDs but is a generic model for all children with health-care needs in under-resourced areas in China.

The model advocates for the introduction of public health clinics in the townships. The introduction of public health clinics is followed by the development of the role of health management, supervision of doctors as well as education of doctors in rural health services (Zhaokang *et al*, 2012). In the villages, the model advocates for the introduction of special clinics for maternal health, child health, immunisation and chronic diseases. This step is followed the promotion of health education by using health materials and outreach programmes in villages.

The provision of services within this model is provided by both public and private health-care providers. It is said that the success of the model requires the commitment of the government as well as the use of many health professionals in the form of doctors and nurses (Zhaokang *et al*, 2012). Even though the economic condition of China is more or less the same as that of South Africa, health professionals are in short supply in South African under-resourced areas and there is poor cooperation between private and public health professionals (George, Quinlan, Reardon, & Aguilera, 2012).

1.2.9 Rehabilitation Models and Approaches Used in South Africa

A literature search on how the rehabilitation of CWDs is conducted in Limpopo Province did not reveal any particular method. However one study was found in the literature which was done in the Bushbuckridge district which used to be part of Limpopo Province at the time (Kromberg, Zwane, Manga, Venter, Rosen, & Christianson, 2008). Bushbuckridge has since been incorporated into Mpumalanga Province. The Bushbuckridge study mainly highlighted that the rehabilitation of CWDs in Limpopo involved the use of both health professionals/CRWs and traditional healers (Kromberg *et al*, 2008). As a result of the limited research on how the rehabilitation of CWDs is conducted in Limpopo Province, this subsection will focus on South Africa as a whole.

Rehabilitation models and approaches as used in South Africa are discussed in this subsection.

1.2.9.1 Primary health-care approach

The provision of health-care services in public institutions in South Africa post 1994 is based on the PHC approach (Rispel, Doherty, Makiwane, & Webb, 1996; Levin, 2006). The PHC approach has a particular focus of preventing diseases, injuries, and disability at primary-, secondary- and tertiary levels of care (WHO, 1995). The main objective of PHC is to decentralise health-care services from the town- and city-based hospitals into local community clinics so as to promote the accessibility of people to health-care. With regard to the provision of services for PWDs and CWDs, the South African government has formulated the Integrated National Disability Strategy White Paper in which it is recognised that the medical approach to disability is not the best approach to use when working with PWDs and CWDs (Presidency, 1997).

The medical approach to disability emphasises that the cause of disability is an anatomical or physiological deviation from normal function that has to be fixed or cured. This approach conceptualises disability from an impairment viewpoint and has been associated with measurement of deficits and counting of specific diagnoses or problems' (McDermott & Turk, 2011, p. 1). The condition of PWDs or CWDs is seen as the cause of the social limitations that the disabled person may experience. According to Thomas (2007) the medical approach suggests that PWDs and CWDs will forever depend on others for care and support, implying that they will never be able to be independent. Health-care delivery based on this approach is heavily reliant on specialised professionals (Roush & Sharby, 2011). Based on this approach, health-care professionals such as medical practitioners, physiotherapists, occupational therapists and psychologist are viewed as experts with authority to diagnose and prescribe treatment, care or rehabilitation (Lutz & Bowers, 2003; Shakespeare, Lezzoni, & Groce, 2009). The provision of rehabilitation services using the medical approach is provided by 'able-bodied' professionals without the input of PWDs and families. This suggests that the medical approach does not take into consideration the value of family-professional collaboration as integral part of health-care delivery (Rosenbaum *et al*, 1998; Woodside, Rosenbaum, King, & King, 2001; Law *et al*, 2003). Furthermore, the medical approach does not take into consideration: (1) the family's satisfaction associated with family-centred care, (2) the decrease in parental stress associated with family centred care, and (3) the improvement of the CWD or the outcomes of therapy associated with family care (King, King, & Rosenbaum, 2004).

Unlike the medical approach which suggests that disability is situated within an individual, the social approach to disability shifts the perspective from the disabled individual to the environment and its role in defining, amplifying, and ameliorating the effects of impairments (Roush & Sharby, 2011, p. 1717). The social approach suggests that it is the society that fails and creates barriers that limit the participation of PWDs (Anastasiou & Kauffman, 2011).

According to Anastasiou and Kauffman (2013), the social approach to disability differentiates between disability and impairment, where ‘impairment is defined as the functional limitation within the individual caused by physical, mental or sensory impairment. Disability on the other hand is defined as the loss or limitation of opportunities to take part in the ordinary life of the community on an equal level with others due to physical and social barriers’ (Barnes, 1991, p. 2; Barnes, 1999). The goal of rehabilitation or intervention within a social approach of disability is:
(1) political in nature, (2) economic in nature, (3) to improve the social status of PWDs and their families, (4) to improve general accessibility of PWDs, and (5) to improve social inclusion (DOH, 2000; Roush & Sharby, 2011).

The medical or social approach to disability alone is not more important than the other, but the combination of the two is. The understanding that the medical approach is not superior to the social approach and vice versa has led to the emergence of a biopsychosocial approach. The biopsychosocial approach suggests that the child’s ability to function depends on a complex interaction between a child’s biological condition, psychological status and social factors (Falvo, 2014).

1.2.9.2 Community-oriented primary care (COPC)

The South African version of the COPC is also called the Tshwane health post model. This model was designed around a service unit called health post that is situated in the community with teams of health-care practitioners such as professional nurses and community health workers. The role of the teams is to:

(1) promote health, (2) prevent disease and early detection of disease, and (3) support treatment, rehabilitation and palliation in a way that develops capacity and shared responsibility for health-care between service providers and service users (Bam, Marcus, Hugo, & Kinkel, 2013). The health posts are entry points into the health and social care systems focusing on continuous, comprehensive, integrated, and informed health-care. However, this model is not specific for CWDs but all people with health-care needs. In addition, the model is developed for an urban setting which tends to have more resources as compared to the rural counterparts (Lemie're, Herbst, Dolea, Zurn, & Soucat, 2013).

1.2.9.3 A model for community mental health services

This model is designed to estimate human resource needs for community-based mental health in South Africa. The model involves a number of steps that includes determining: population size, age distribution, prevalence of mental health conditions, comorbidity, levels of coverage, ambulatory care workloads, and health-care staff profile (Lund & Flisher, 2009) . However, the model is mainly meant for the population aged 15 and above. In addition, it focuses on estimating the human resource needs and not the rehabilitation of CWDs.

1.2.9.4 Community-based rehabilitation strategy

The South African government through the National Rehabilitation Policy has adopted CBR as a rehabilitation strategy for both adults and CWDs (DOH, 2000). The goal of CBR as stipulated in the South African National Rehabilitation Policy is to make rehabilitation accessible to all who need it, irrespective of the user’s location and economic circumstances.

CBR, as an integral part of PHC, should ensure accessibility and affordability of appropriate and acceptable services to the target community. For CBR to be effective there should be a consented effort between PWDs or CWDs, their families, disability organisations, community members, non-governmental organisations and various government departments which include education and social services (ILO, UNISCO, & WHO, 2004).

The WHO, UNESCO, ILO, and IDDC (2010b) have identified five domains of rehabilitation needs for PWDs/CWDs through the CBR matrix. The CBR matrix is a visual presentation of the different sectors which makes up the CBR strategy. The five critical domains are health, education, livelihood, social and empowerment. Each of the five domains is divided into five key elements.

The health domain is divided into: promotion, prevention, medical care, rehabilitation and assistive devices. Even though the promotion of health does not require expensive drugs and technology, it requires expertise of health-care workers. Similarly the prevention, medical care, rehabilitation and assistive devices require the availability of skilled health-care workers and rehabilitation professionals (WHO, UNESCO, ILO, & IDDC, 2010c). The implication on the health domain is that there should be enough health-care workers and rehabilitation professionals to ensure that the CBR strategy is efficient and effective. However, it has been documented in literature that in the rural areas people experience serious shortage of health-care workers and rehabilitation professionals (Dovlo, 2007; Lehmann, 2008; Scheffler, Mahoney, Fulton, Dal Poz, & Preker, 2009). The shortage of health professionals makes it difficult to achieve the objectives of the health domain as part of the CBR matrix. The shortage of health-care workers was also confirmed in all parts of South Africa. It is suggested that the number of health-care workers in both public and private sector has decreased between 2001 and 2010 (George *et al*, 2012).

The education domain is divided into early childhood, primary, secondary/higher, non-formal and lifelong learning. The education component advocates that PWDs and CWDs in particular should receive education at all levels. Education is important considering that many of the CWDs in South Africa do not have access to educational services (Fleisch, Shindler, & Perry, 2012).

The livelihood domain is divided into skills development, self-employment, wage employment, financial services and social protection. The social domain is divided into personal assistance; relationships, marriage and family; culture and arts; recreation, leisure and sports; and justice. The empowerment domain is divided into: advocacy and communication; community mobilisation; political-participation; self-help group; and disabled people organisations.

Therefore, out of the five domains of the CBR matrix it seems that the health and education domains are primarily concerned with both CWDs and adult PWDs while the livelihood, social and empowerment are primarily concerned with adult PWDs.

1.2.9.5 Malamulele Onward Outreach model

Malamulele Onward Outreach is an initiative of Gillian Saloojee, who is a researcher in the field of childhood disabilities in South Africa. The project was started at Malamulele in the Vhembe district of Limpopo Province of South Africa, which is 35 kilometres north of Giyani. Malamulele Onward Outreach has also been introduced in the Eastern Cape Province of South Africa and Lesotho (Saloojee, 2012).

According to Saloojee (2012), the model consists of three components: (1) the identification of an outreach visit site such a cerebral palsy clinic in a public hospital, (2) the provision of therapy to CWDs and training, empowerment and capacity-building of caregivers of CWDs, and (3) the strengthening of existing rehabilitation services CWDs within a chosen site.

Each outreach visit involves a number of steps or phases as indicated in Figure 1.1 (on page 28) starting with the identification of a public hospital site in a poorly resourced rural area where there is a rehabilitation service for children with cerebral palsy. The aim of the project is not to start a new service, but rather to strengthen and expand an existing service.

Once the site has been identified, an introductory and screening visit is done by neuro-developmental-therapy (NDT) trained members of the Malamulele Onward NPC, followed by the planning phase. Children with cerebral palsy at each site receive an annual intervention consisting of five-day intensive block of therapy including physiotherapy, occupational therapy and speech therapy. During the five days of therapy, 25 to 50 children are treated daily by about 10 to 15 volunteer rehabilitation therapists from Malamulele Onward NPC. The five-day treatment is complemented with caregiver training, training of local rehabilitation professionals, and the provision of assistive devices. After the five-day block therapy, a follow-up visit is done two months later where the children are reassessed. Another follow-up is held in a year’s time where intervention is also based on a five-day block therapy which includes hands-on therapy, caregiver training, the provision of equipment as well as training of the local rehabilitation therapists. The annual visits are then conducted for the next coming two years.

The Malamulele Onward Outreach is conducted by volunteer rehabilitation professionals who often rely on the use of local interpreters. In addition, the model implies that caregivers of CWDs have to be away from their families for five days during the time when the Malamulele Onward Outreach is held. This model does not take into account that South African women in rural areas are expected fetch drinking water, fetch firewood, cook and even wash clothes for the entire family (Kehler, 2001; Kongolo & Bamgose, 2002). At times these women assume the role of the head of the family in the absence of males due to death and or work-related migration (Schatz, Madhavan, & Williams, 2011). Based on this information, one can conclude that the caregivers' absence for five days is not necessarily in the best interest of the entire family.

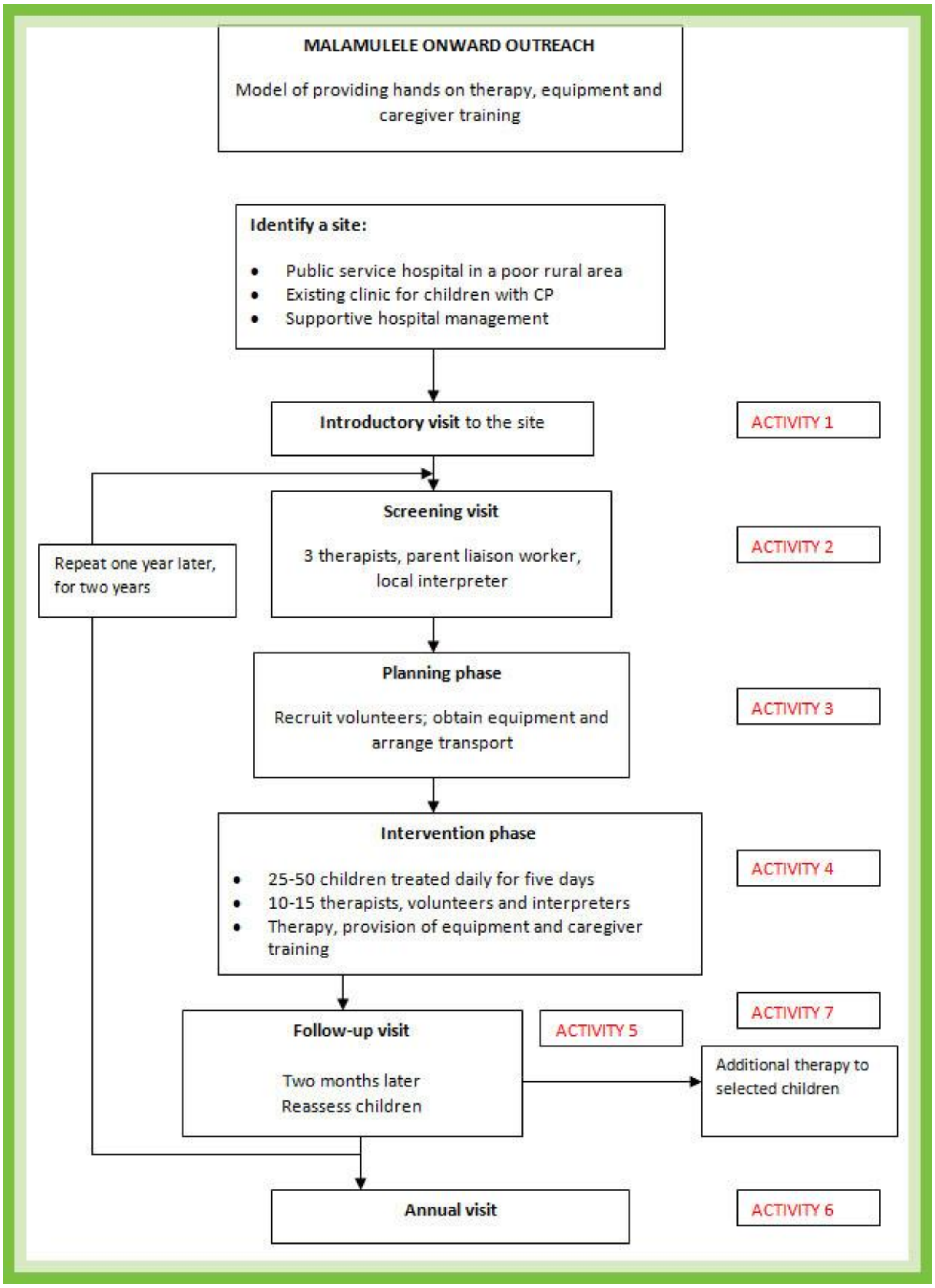


Figure 1.1 Malamulele onward outreach model

1.3 PROBLEM STATEMENT

Different models and approaches for the rehabilitation of CWDs exist in both HIC and LMIC. Some of the models are exclusively used in HIC whereas others have been modified to suit LMIC.

Models which seems to be more relevant in a HIC context than a LMIC context include: (1) A life need model of paediatric service delivery, (2) Model of determinants of change in gross-motor abilities and engagement in self-care, (3) An ecological model of community-focused therapeutic recreation and life skills services, and (4) Solution-focused coaching in paediatric rehabilitation (King *et al*, 2002; Chiarello *et al*, 2011; King, Curran, & McPherson, 2012; Baldwin *et al*, 2013). These models were developed in well-resourced countries where there is an abundance of monetary and human resources as opposed to poorly resources countries like South Africa.

On the other hand models which have been developed and or modified for use in LMIC include: (1) A model for community health service development, (2) PHC approach, (3) COPC, (4) a model for community mental health services, (5) CBR strategy, and (6) Malamulele outreach model (Rispel *et al*, 1996; ILO, UNISCO, & WHO, 2004; Levin, 2006; Lund & Flisher, 2009; Saloojee *et al*, 2009; Saloojee, 2012; Zhaokang *et al*, 2012; Bam *et al*, 2013). Even though these models have been designed or modified for use in rural and poor LMIC, they have limitations that are likely to make them inappropriate for use in a rural South African context like Giyani.

In the next subsection, limitations of the models and approaches as used LMIC is discussed.

Limitations of the models for the rehabilitation of children with disabilities

- A model for community health service development requires a large number of health professionals to be available which is not the case in South Africa while considering the serious shortage of health-care workers and rehabilitation professionals (Dovlo, 2007; Lehmann, 2008; Scheffler *et al*, 2009; George *et al*, 2012). Similarly, it has also been reported in Limpopo Province that the allied health professions such as physiotherapy and occupational therapy had a vacancy rate of 67.4 per cent and 72.8 per cent respectively (DHSD, 2011).

- The COPC is a South African health post model based on the PHC approach. The model is not necessarily meant for CWDs but all people with health-care needs. However, this model was developed for an urban setting which tends to have more resources as compared to the rural areas (Lemie're *et al*, 2013).
- The model for community mental health services is designed to estimate human resource needs for community-based mental health service focusing on children above the age of 15 years (Lund & Flisher, 2009). This model excludes young children with physical and neurological disabilities and is not meant to guide or direct the rehabilitation of CWDs but to estimate the human resource needs.
- CBR was adopted by the South African Government as a rehabilitation strategy for PWDs and CWDs. Earlier studies have showed that the rehabilitation of CWDs still takes place in hospital-based rehabilitation clinics and follows the medical model of disability, which is contrary to the principles of CBR (Levin, 2006; Saloojee *et al*, 2007; Roush & Sharby, 2011). In addition, a review of the literature on CBR programmes for children with intellectual disabilities in LMIC showed that there is insufficient evidence to suggest that CBR is efficient or effective as a rehabilitation approach (Robertson *et al*, 2012).
- The Malamulele onward outreach model which was developed for the rural South African context relies on volunteer rehabilitation professionals, making its sustainability questionable. These volunteer rehabilitation professionals tend to use local health-care workers as interpreters, which is also likely to affect other services that the ‘interpreters’ are responsible for in the hospital. In addition, the Malamulele onward outreach is run for five consecutive days with the same clients and that puts a lot of pressure on the caregivers, considering that they have other roles to play in their families such as fetching firewood, water and preparing food for their households. Lastly, the Malamulele onward outreach only focuses on the health setting and does not integrate or collaborate with other sectors within the community, such as the education sector.

Despite the availability of rehabilitation models and approaches, CWDs in LMIC still do not have access to the useful range of interventions which are available in HIC (Patel, Kieling, Maulik, & Divan, 2013). According to Patel *et al,* (2013), CWDs in a LMIC such as the rural parts of South Africa do not have access to effective intervention mainly due to: (1) lack of evidence on the delivery of treatment, (2) low levels of the identification of CWDs, and (3) shortage of skilled rehabilitation professionals. The researcher has also witnessed during an informal meeting in Giyani that the rehabilitation professionals often complain of caregivers' non-compliance with the children's rehabilitation programme. These rehabilitation professionals often blame caregivers for the poor attendance of the rehabilitation clinic without understanding the caregivers' reasons for non-compliance.

Some of the western developed rehabilitation models for CWDs were not tested in LMIC such as South African. Models that have been adapted to be used in LMIC have been found not be effective (Robertson et al, 2012). Mckenzie, McConkey, and Adnams (2013) suggested that there is a need to understand CWDs in an African context because the information and models obtained from western-based research are not necessarily applicable in Africa.

It seems to the researcher that models for the rehabilitation of CWDs that have been discussed up to now are not sufficiently suitable for use in the rural community of Giyani. Furthermore the role that rehabilitation professionals, CRWs and caregivers play in the rehabilitation of CWDs in Giyani is not known.
Secondly, the challenges that CWDs experience within the family, health-care facility and community has not been investigated.
Thirdly, it is not known what other services do CWDs, and caregivers need in addition to the health and rehabilitation services.
Fourthly, it is not known what kind of support structures does CWDs, and caregivers need.
Lastly, it is not known to which extent the present services meet the expectations of the caregivers in Giyani.
For these reasons, it seems necessary to develop a rehabilitation model for CWDs in Giyani.

1.4 RESEARCH QUESTION

The primary question asked in the current study is: How should a model for the rehabilitation of CWDs look like in the rural area of the Greater Giyani Municipality?

1.5 RESEARCH FRAMEWORK

In order to address the research question, a conceptual framework was used. The purpose of a conceptual framework is to “explain either graphically, or in narrative form, the main things to be studied such as the critical factors, concepts or variables together with the presumed relationship among them” (Miles & Huberman, 1994, p. 18). The conceptual framework provides an explicit logic underpinning the design of the study to both the researcher and the reader of the research (Burns & Grove, 2003).

According to the conceptual framework of the ICF, the goal of rehabilitation of CWDs is to: (1) alleviate the effect of impaired body structures and systems or optimise health, (2) reinforce environmental facilitators by educating families and adapting physical environment, (3) foster development of the child’s capacities or function, and (4) facilitate participation in society (WHO, 2001). For this reason, the ultimate goal of the proposed model of rehabilitation is to optimise health, improve function and promote participation.

There are two conceptual frameworks underpinning this research: (1) Dunst and Trivette’s resource-based model (Trivette, Dunst, & Deal, 1997), and (2) Guralnick’s early development and risk factor model (Guralnick, 1997b).

Dunst and Trivette’s resource-based model has three components: (1) sources of support, (2) community resource mapping, and (3) building community capacity as shown in Figure 1.2 (on page 33). In the current research, the focus is on sources of support and community resource mapping. Wolery (2000, p.196) reported that the resource-based approach is often used by selecting individual elements of it and not using all three components.

The sources of support component is divided into four categories: (1) personal social network such as friends or relatives,(2) associational groups such as a church or a support group, (3) community programmes and professionals such as a hospital, clinic or rehabilitation professionals, and (4) specialised services such as referral services (Trivette, Dunst, & Deal, 1997; Wolery, 2000).

Community resource mapping “ involves identifying various kinds of resources that exist in a given locale” (Wolery, 2000, p. 196).

Figure 1.2 Dunst and Trivette’s resource-based model

Guralnick’s model has three components: family patterns, family characteristics and potential stressors or challenges (Guralnick, 1997b) as depicted in Figure 1.3 (on page 34). Guralnick’s model implies that the characteristics of the family such as the caregiver’s financial background, social status, educational level, and potential stressors or challenges have a bearing on the family patterns (Wolery, 2000). Family patterns include how the caregiver/family interacts with the child, how they provide for the child and what they do to the child to promote health and safety (Guralnick,1997b). Family patterns also include how caregivers participate in the rehabilitation of a CWD.

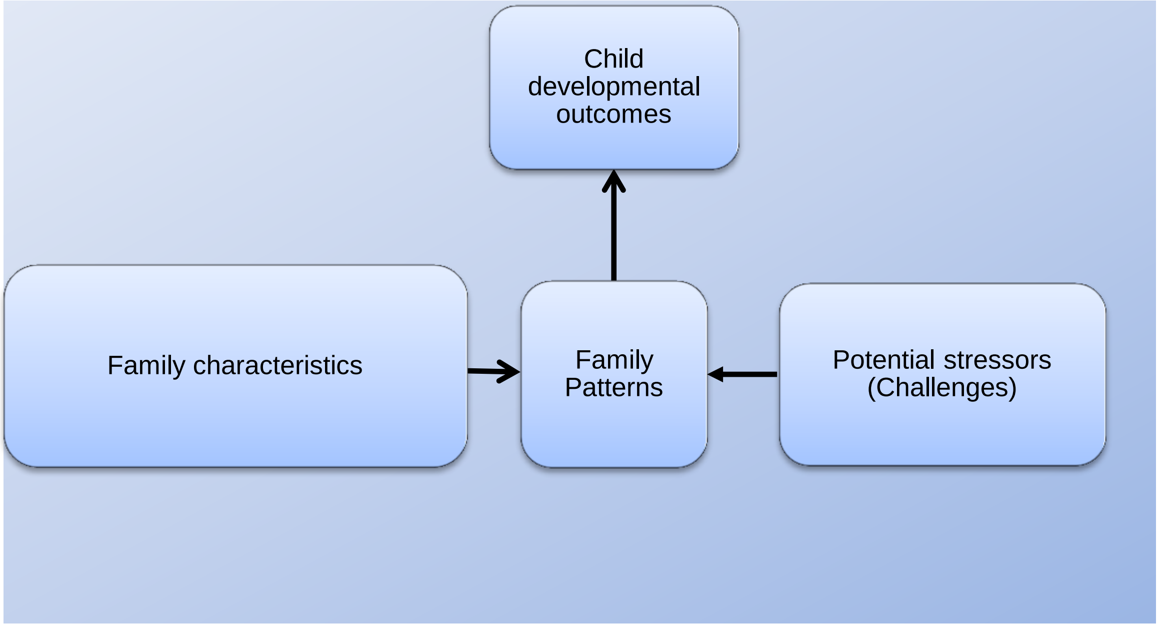


Figure 1.3 Guralnick's early development and risks factor model

Dunst and Trivette's resource-based model and Guralnick's model both acknowledges the family or a caregiver as a major role player in the life of a CWD. However, Guralnick's model also suggests that the challenges that caregivers or CWDs encounter affect how the caregivers interact with the child. The rehabilitation professionals, CRWs and other health workers are recognised by the Dunst and Trivette's resource-based model (Trivette, Dunst, & Deal, 1997) as primary sources of support for CWDs. Furthermore, Dunst and Trivette values community resources like hospital, rehabilitation clinics and schools as an important component in bettering the lives of CWDs. Equally so the community in the form of local government has an important role to play in the lives of CWDs.

Based on Dunst and Trivette's resource-based model (Trivette, Dunst, & Deal, 1997) and Guralnick's (1997b) model, a conceptual framework for this research was developed as shown in Figure 1.4.

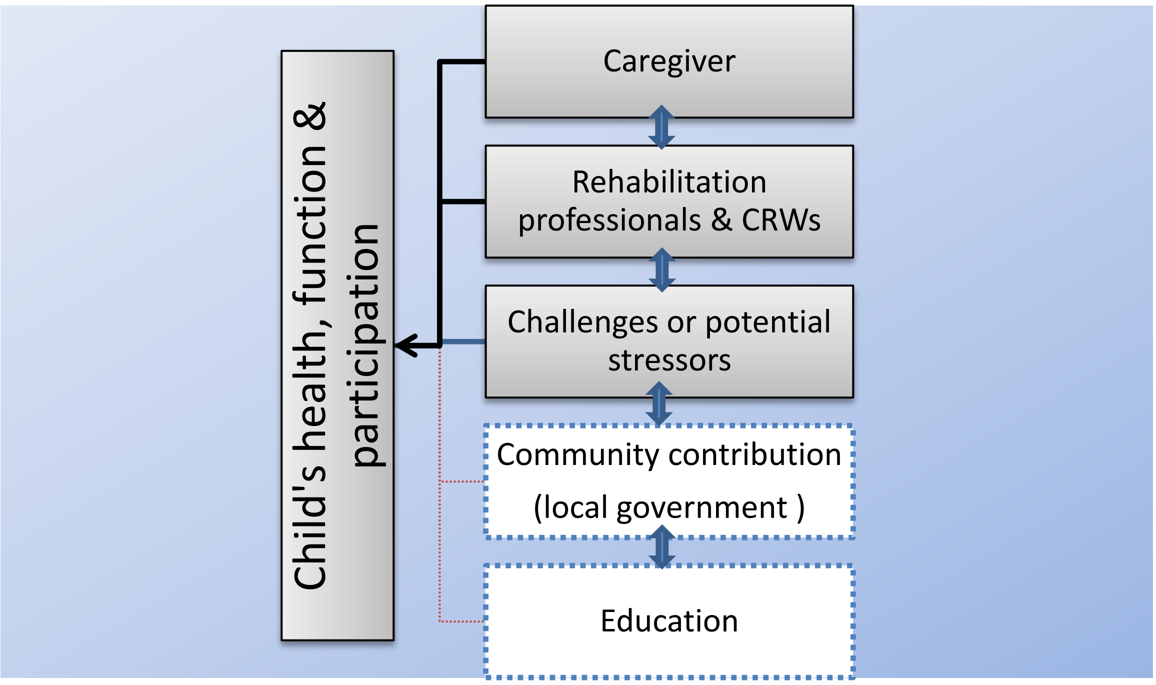


Figure 1.4 Conceptual framework of the study

The broken or dotted lines on community contribution and education as shown in Figure 1.4 imply that the contribution from this research on those areas is new.

1.6 AIMS

The aim of the study is to develop a descriptive model for the rehabilitation of CWDs by rehabilitation professionals and other health-care workers such as CRWs in the rural municipality of the Greater Giyani in Limpopo Province. In order to develop a model for the rehabilitation of CWDs, a middle-range theory comprising concepts and suggested relationship among the concepts in the form of statements is generated (Smith & Liehr, 2014). Middle-range theories have a narrower scope than grand theories and encompass limited concepts and aspect of the real world (Speziale & Carpenter, 2007).

1.7 OBJECTIVES

The objectives of the study were:

1) To synthesise, clarify, refine and sharpen concepts on:
    - The role of caregivers, rehabilitation professionals and CRWs in the rehabilitation of CWDs
    - Challenges that CWDs and caregivers encounter
    - Other specialised and available services for CWDs
    - Support structure for CWDs and caregivers
    - Caregivers' satisfaction and expectations of services
2) To synthesise non-relational theoretical statements
3) To systemize and organise the relational statements
4) To present the theory diagrammatically as a model

1.8 SIGNIFICANCE OF THE STUDY

If implemented, the model for the rehabilitation of CWDs will guide or direct rehabilitation professionals and other health-care workers in rural communities on how to provide rehabilitation services to CWDs and caregivers. The model may also form part of rehabilitation policy in Limpopo Province as well as to assist in improving the quality of services that CWDs and caregivers receive in public health facilities. The study has also contributed to the body of knowledge in physiotherapy and other rehabilitation disciplines as well as creating a room for further studies to be conducted based on the findings of the current study.

1.9 CHAPTER OUTLINE

In this section, the visual map in the form of a flow diagram is used to show the steps followed in this research. The visual map is then followed by an outline of all the chapters in this thesis.

A logic model as shown in Figure 1.5 (on page 39) is used to provide a visual map of how the different components of the study are related to the desired outcome (Schalock, Keith, Verdugo, & Gomez, 2011). This model links the research inputs (participants), the research activities (research methodology), the research output (results), the outcome (other objectives) and the impact (model of rehabilitation) (Kellogs, 2004).

Chapter 1: Introduction

In Chapter 1 the background of the study, problem statement, research question, research framework, aim, objectives, significance and chapter outline are presented.

Chapter 2: Methodology

In Chapter 2, the research approach, research design, study location, strategies to enhance trustworthiness, ethical considerations, Phase 1 of the study, Phase 2 of the study, and the summary of the chapter are discussed.

Chapter 3: Results of Phase 1

In Chapter 3, the results of Phase 1 of the study are presented. This chapter, is divided into subsections where information obtained from: (1) caregivers, (2) rehabilitation professionals, (3) CRWs, and (4) the launch of the Greater Giyani Disability Forum (GGDF) are shown.

Chapter 4: Results of Phase 2

In Chapter 4, the results of Phase 2 of the study are presented. Chapter 4 is divided into subsections where information obtained through the use of focus group discussions with caregivers and rehabilitation professionals are given.

Chapter 5: Discussion of results

In Chapter 5, the results from Phase 1 and Phase 2 of the study are jointly discussed and substantiated with findings from the literature review in order to refine and clarify concepts. Synthesis of non-relational statements follows the refinement and clarification of concepts

Chapter 6: Synthesis of relational statements

In Chapter 6, relational statements are synthesised and presented.

Chapter 7: Conclusion and recommendations

In Chapter 7, the model for the rehabilitation of CWDs in the Greater Giyani Municipality is presented and compared with other models for the rehabilitation of CWDs. The recommendation for the dissemination of the results, the limitations of the study and suggestions for future studies are also discussed.

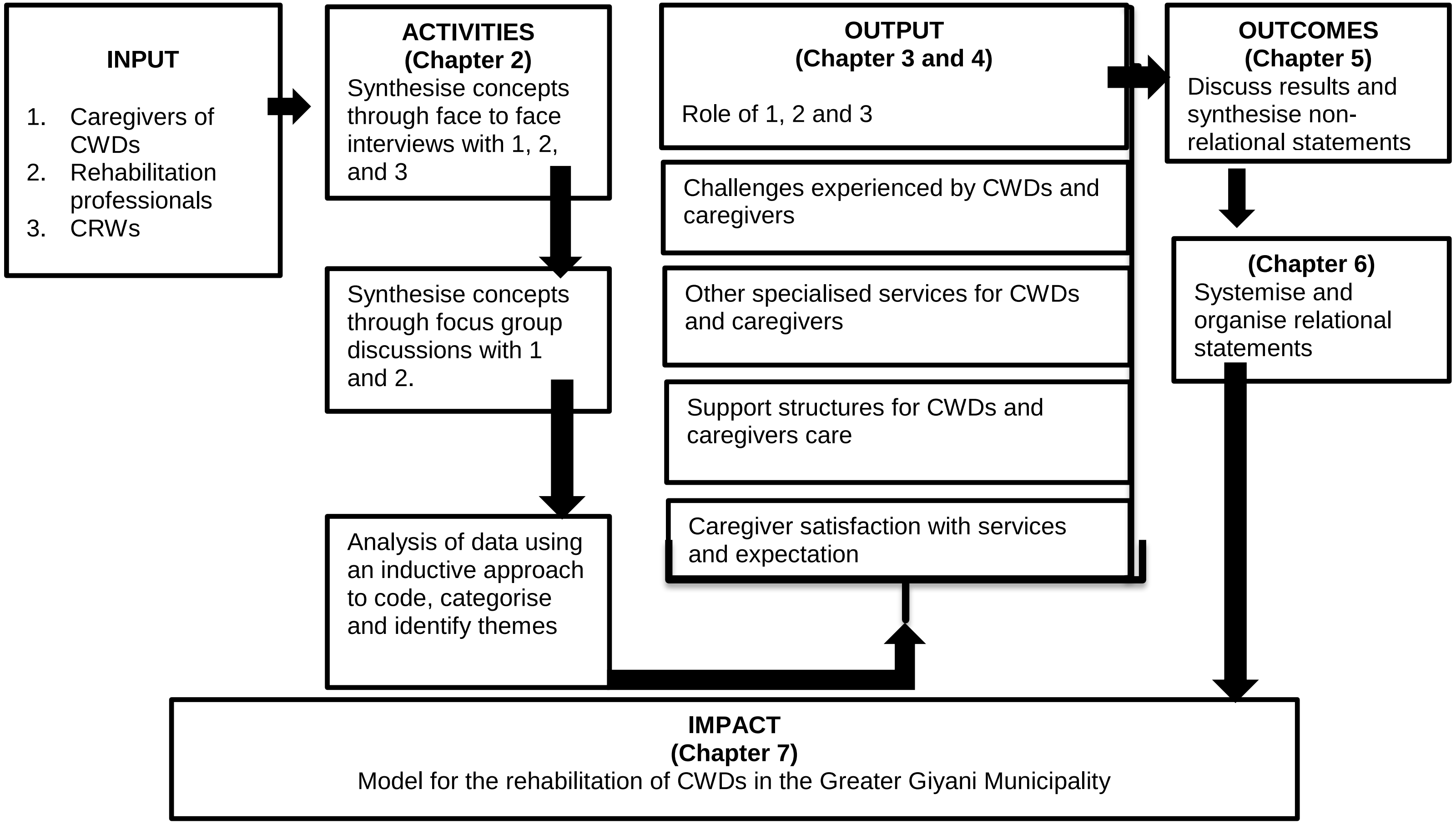


Figure 1.5 Flow diagram of the steps followed in the research

CHAPTER 2

METHODOLOGY

2.1 INTRODUCTION

In Chapter 2 the research approach, research design, study location, strategies to enhance trustworthiness, ethical considerations, Phase 1 of the study, and Phase 2 of the study are discussed.

2.2 RESEARCH APPROACH

A qualitative, theory-generating, exploratory, descriptive and contextual approach was used to address the research question.

According to Babbie and Mouton (2001, p. 270) qualitative research always attempt to study human action from the perspectives of the social actors themselves. Qualitative research offers the opportunity to focus on finding answers to questions centred on the social experience, how it is created, and how it gives meaning to human life (Denzin & Lincoln, 1994).

According to Speziale and Carpenter (2007, p. 21) qualitative researchers should ensure that their research: (1) belief in multiple realities, (2) identify an approach to understand the phenomenon being studied, (3) promote participants' viewpoint, (4) limit disruption of the natural context of the phenomena of interest, (5) acknowledge participation of the researcher in the research process, and (6) report data in a literary style rich with participant commentaries.

In a qualitative research data is collected in a face-to-face situation by interacting with participants in their own setting or context, with the aim of understanding the participants' meaning of events from their own perspectives (McMillan & Schumacher, 2006).

Considering that the aim of this qualitative study was to develop a model, the entire process through which a model was developed is referred to as theory-generation (McEwen & Willis, 2002).

According to Babbie and Mouton (2001) social research comprises three main purposes: exploration, description and explanation. However, qualitative researchers explore, understand and describe events within their concrete and natural context in which they occur rather than explaining them (Babbie & Mouton, 2001, p. 272).

An exploratory and descriptive approach is used in a qualitative study when the researcher seeks to examine little-understood phenomena or to develop a detailed concept such as a model as it was the case with the current study (Babbie & Mouton, 2001; McMillan & Schumacher, 2006, pp. 315-17).

In the present study a qualitative paradigm was chosen in order to explore how the rehabilitation of CWDs was conducted within its natural context at Nkhensani Hospital's rehabilitation clinic where the rehabilitation of CWDs in the Greater Giyani Municipality mainly takes place. The exploration was based on the perspectives of the caregivers of CWDs, rehabilitation professionals and CRWs.

2.3 RESEARCH DESIGN

The selected research design in the current study is theory-generation, which is based on a process described by Walker and Avant (2005). According to McEwen and Willis (2002, p. 70) theory construction, theory development, theory building, and theory-generation are some of the terms which are used interchangeably or synonymously in nursing literature to refer to the creation of theory. However, some authors prefer to use one word from the theory-generation process such as theory development to refer to the entire process of the creation of theory (Walker & Avant, 1995; Cesario, 1997; Walker & Avant, 2005). For the purpose of the present study, theory-generation is the term used to refer to the creation of the theory.

In social sciences, grounded theory is one of the commonly used methods of theory-generation (Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990; Strauss, 1991; Glaser, 1992; Strauss & Corbin, 1994). Grounded theory is defined as the discovery of the theory from data systematically obtained from social research (Glaser & Strauss, 1967, p. 2). Grounded theory is ideal for exploring integral social relationships and the behaviour of groups where there has been little exploration of the contextual factors that affect individual's lives (Crooks, 2001).

Nonetheless, there are as many versions of grounded theory as there are grounded theorists (Dey, 1999). There are three common types of grounded theory:
(1) Glaserian or traditional grounded theory (Glaser & Strauss, 1967; Glaser,1978; Strauss & Corbin, 1998), (2) Straussian or evolved grounded theory (Strauss & Corbin, 1994), and (3) constructivist grounded theory (Charmaz, 2006). Regardless of the grounded theory school of thought that a researcher chooses, Charmaz (2002) identified a number of similarities between all grounded theories. These similarities include: (1) simultaneous collection and analysis of data, (2) creation of analytic codes and categories developed from data and not by pre-existing conceptualisations (theoretical sensitivity), (3) discovery of fundamental social processes in the data, (4) inductive construction of abstract categories, (5) theoretical sampling to refine categories, (6) writing analytical memos as the stage between coding and writing, and (7) the integration of categories into a theoretical framework.

Grounded theory was not used to develop the model for the rehabilitation of CWDs in the current study because the literature on grounded theory suggest that the researcher should not substantively review any literature due to the fear of contaminating, constraining, inhibiting, and impeding the researcher's analysis of codes emerging from the data (Glaser, 1992). Secondly, grounded theory also suggests that there must be simultaneous collection and analysis of data (Charmaz, 2002) which was not possible in the current study due to the shortage of resources.

There are other methods of theory-generation beside grounded theory such as the Herbert Blumer's idea of sensitising concepts (Blumer, 1969; Baugh, 1990; Van den Hoonard, 1997), the case study method (Eisenhardt, 1989; Yin, 1994) and the Dubin's eight-phase methodology of theory building (Dubin, 1978).

Five of the eight-phases of Dubin's method which are primarily concerned with theory building, state that there should be: (1) units or concepts of the theory, (2) laws of interaction among concepts, (3) boundaries within which the theory is expected to apply to, (4) conditions under which the theory is in operation, and (5) logical deductions about the theory in action (Torraco, 1997). Even though Dubin's (1998) method is primarily used within management disciplines, such as human resources or human resource development (Lynham, 2002), it is similar to the theory-generation process as proposed by Walker and Avant (2005).

Theory-generation is a complex and time-consuming process with a number of stages (Powers & Knapp, 1995). These stages comprise concepts development, statements development and theory development where the latter is graphical presented as a model (Walker & Avant, 2005).

Theory-generation process in the current study began with concept development, followed by statement development and theory development as depicted in Figure 2.1.

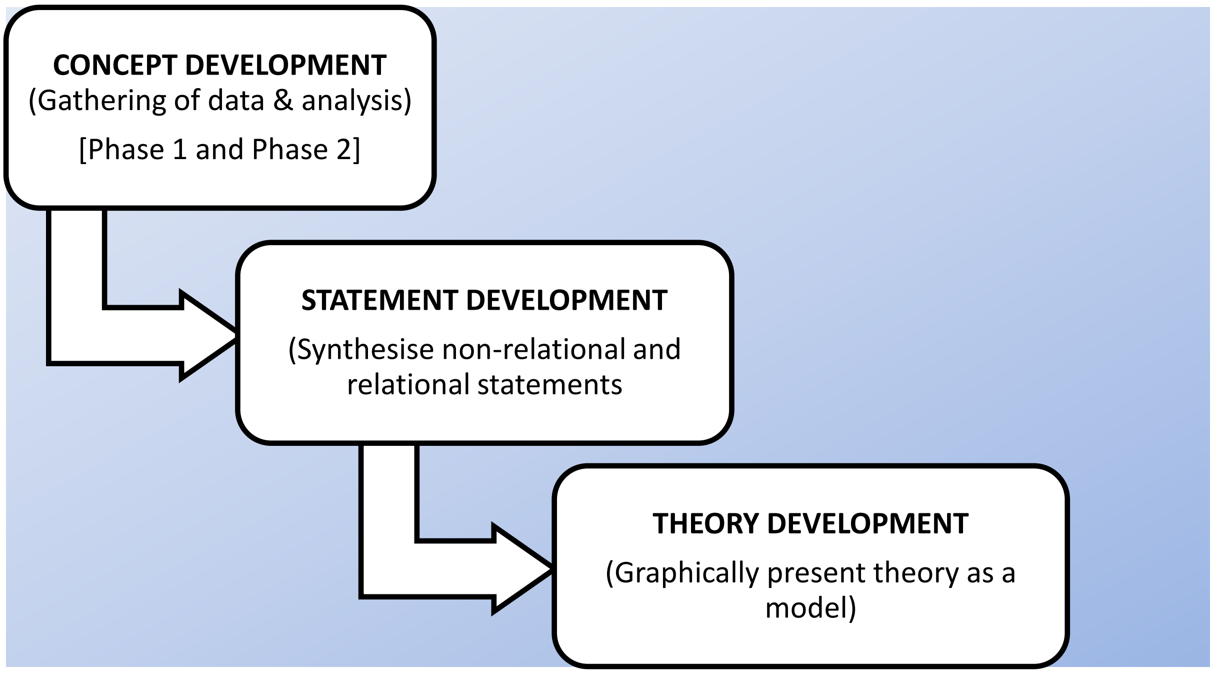


Figure 2.1 Theory-generation process

2.3.1 Concept Development

A concept is a label that is assigned to the phenomenon, object or an event. It is often referred to as the basic building block of theory (McEwen & Willis, 2002; Walker & Avant, 2005). Several approaches may be used to initiate the process of concept development such as: (1) theory-practice-theory, (2) practice-theory, (3) research-theory, and (4) theory-research-theory (Meleis, 1997; McEwen & Willis, 2002). In the current study, a research-theory approach was used where the development of concepts was based on research.

The concept development stage is divided into concept synthesis, concept derivation and concept analysis (Walker & Avant, 2005, p. 30).

2.3.1.1 Concept synthesis

According to Walker and Avant (2005, p. 30) information based on the body of collected data and or set of observations may be used to synthesise or construct a new concept. Furthermore, concept synthesis is said to allow the researcher to combine isolated pieces of information that are as yet theoretically unconnected through data analysis (Walker & Avant, 2005).

In the current study, concepts on: (1) the role of caregivers, the role of rehabilitation professionals, and the role of CRWs in the rehabilitation of CWDs, (2) challenges that CWDs and their caregivers encounter, (3) other specialized services for CWDs, (4) support structure for CWDs and caregivers, and (5) caregivers' satisfaction and expectations of services, were synthesised in Phase 1. Data was gathered through interviews with: (1) caregivers of CWDs, (2) rehabilitation professionals, and (3) CRWs. In addition concepts were synthesised in Phase 2 through focus group discussions (FGDs) with: (1) caregivers of CWDs who were not part of Phase 1, and (2) rehabilitation professionals who were part of Phase 1.

2.3.1.2 Concept derivation

Concept derivation is based on analogy or metaphor where the researcher redefines concepts from one context to another. However, the concept derivation approach to theory-generation is mainly applicable where theory base does not exist in the literature (Walker & Avant, 2005, p. 31) but it does exist with regards to the current study. As a result, the concept derivation method was not used in the current study.

2.3.1.3 Concept analysis

Concept analysis is a process where the researcher clarifies, refines and sharpens concepts through the use of the existing body of theoretical literature (Walker & Avant, 2005). Clarification, refinement and sharpening of concepts mainly took place in Chapter 5.

2.3.2 Statement Development

Statement development is another essential ingredient of the theory-generation process (Walker & Avant, 2005). There are two types of statements: non-relational and relational statements. Non-relational statements are either existence statements that show the existence of a concept or theoretical statements that define concepts. On the other hand, relational statements are about the relationship between two or more concepts and are used to connect ideas in an attempt to describe the real world or to develop a theory (McEwen & Willis, 2002; Walker & Avant, 2005).

Just like concept development, statement development follows the synthesis, derivation and analysis approach. As it was also the case with concept development, statement development in the current study focused on statement synthesis and analysis.

2.3.2.1 Statement synthesis and analysis

In this subsection synthesis and analysis of non-relational and relational statements are discussed.

Non-relational statements

Non-relational statements in the form of existence statements were developed in Chapter 5 of the study as part of the initial stage of statement synthesis. Existence statements are simple statements of assertion about a concept. These statements enable a reader to understand a concept whose existence was not known before the study. The researcher introduced a reader to the existence of a concept using a theoretical definition which is usually abstract and may not be measurable (Walker & Avant, 2005). Through the use of existing body of literature, existence statements were clarified, refined and sharpened in the current study (Speziale & Carpenter, 2007).

Relational statements

Relational statements are those statements that demonstrate the association (correlation) between concepts or the cause and effect relationship (causality) between concepts (McEwen & Willis, 2002; Walker & Avant, 2005). Relational statements were developed in Chapter 6 of the study.

2.3.3 Theory Development

According Walker and Avant (2005, p. 28) theory is an internally consistent group of relational statements that represent a systematic view about a phenomenon. Theory is useful for description, explanation, prediction, and prescription or control purposes. In addition, theory is associated with definitions that are specific to concepts in the theory.

Meleis (2012, p. 29) defines theory as a conceptualisation of some aspect of reality communicated for the purpose of describing phenomena, explaining relationships between phenomena, predicting consequences, or prescribing care. Ideally theory should have a descriptive, explanatory, predictive and prescriptive component (McEwen & Willis, 2002), but having all four component is not possible (Walker & Avant, 2005) as it was the case in the current study.

Theory was graphically shown as a model (McEwen & Willis, 2002; Walker & Avant, 2005) in Chapter 7 together with theory analysis based on the available literature on models of rehabilitation. A model is a graphic representation of the theory, which can either be presented mathematically as an equation or schematically by using symbols and arrows (Walker & Avant, 2005).

2.4 STUDY LOCATION

The study was conducted in the Greater Giyani municipal area in the Mopani district of Limpopo Province, South Africa as shown in Figure 2.2 (on page 48). The primary research site was the allied health block of Nkhensani Hospital where the rehabilitation clinic for CWDs was held every Tuesday. Nkhensani Hospital is located in Section-A of Giyani Township within the following geographic coordinates:

23° 19' 03.6" S, 30° 42' 38.0" E.

Nkhensani is the only hospital in the Greater Giyani Municipality serving a population of about 244 217 (STATSSA, 2012), and has a bed capacity of about 330. It is a level-one district hospital which has been designated to support PHC clinics, provide generalist services to inpatients and outpatients as well as rehabilitation services to both adults and children (DOH, 2002). There is no private hospital in Giyani, but there are health professionals’ stand-alone private practices serving clients with health insurance/ medical aids or those who can afford to pay. There are two private hospitals in the Mopani district in Tzaneen, which is about 100 kilometres south of Giyani and Phalaborwa, which is about 100 kilometres east of Giyani.

At the time of data collection, all the rehabilitation professionals at Nkhensani Hospital were employed by the Limpopo Department of Health and were headed by a Deputy Manager of Clinical Support Services who was also based in the hospital. The physiotherapy department had four physiotherapists, one community-service physiotherapist and a physiotherapy assistant. The occupational therapy department had an occupational therapist, a community-service occupational therapist, and three occupational therapy assistants. The speech therapy department had one speech-therapist.

There were five CRWs employed by the Limpopo Department of Health in the Greater Giyani Municipality, and they were based in the PHC offices in Giyani. CRWs were supervised by the occupational therapists from Nkhensani Hospital.

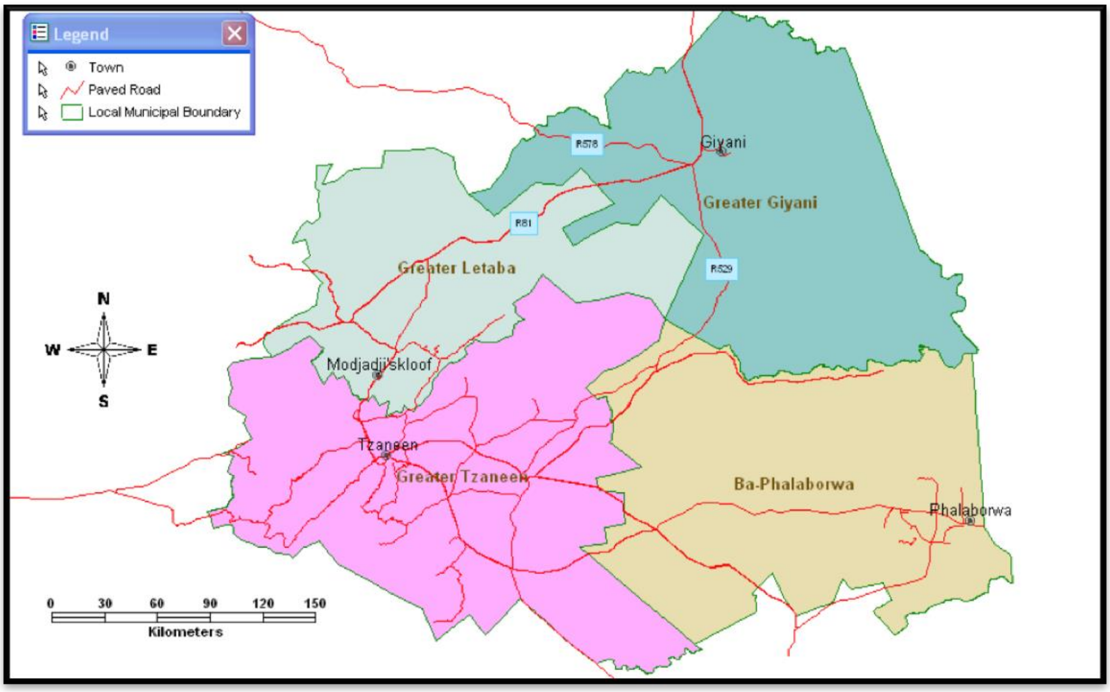


Figure 2.2 Map of the Mopani District Municipality in Limpopo

The researcher established during the course of the study that there is a special school for children with mild to moderate intellectual disability in Giyani called Pfunanani. Permission was obtained from the principal (Appendix R) in order to obtain further information about Pfunanani Special School. The school was established in the early 2000s and is located in Giyani Section A, east of the Central Business District (CBD). There were about 430 learners and 68 staff members. Out of the 68 staff members, 35 were teaching staff and 33 were non-teaching staff. Only eight out of the 35 teaching staff had specialised training in special needs education. The other 27 teaching staff only had a basic teacher's training.

The school does not use children's age as an admission criterion and admits children with varying degrees of intellectual impairment. The curriculum is based on vocational training and not mainstream education. The type of classes and the number of pupils per class are as summarised in Figure 2.3.

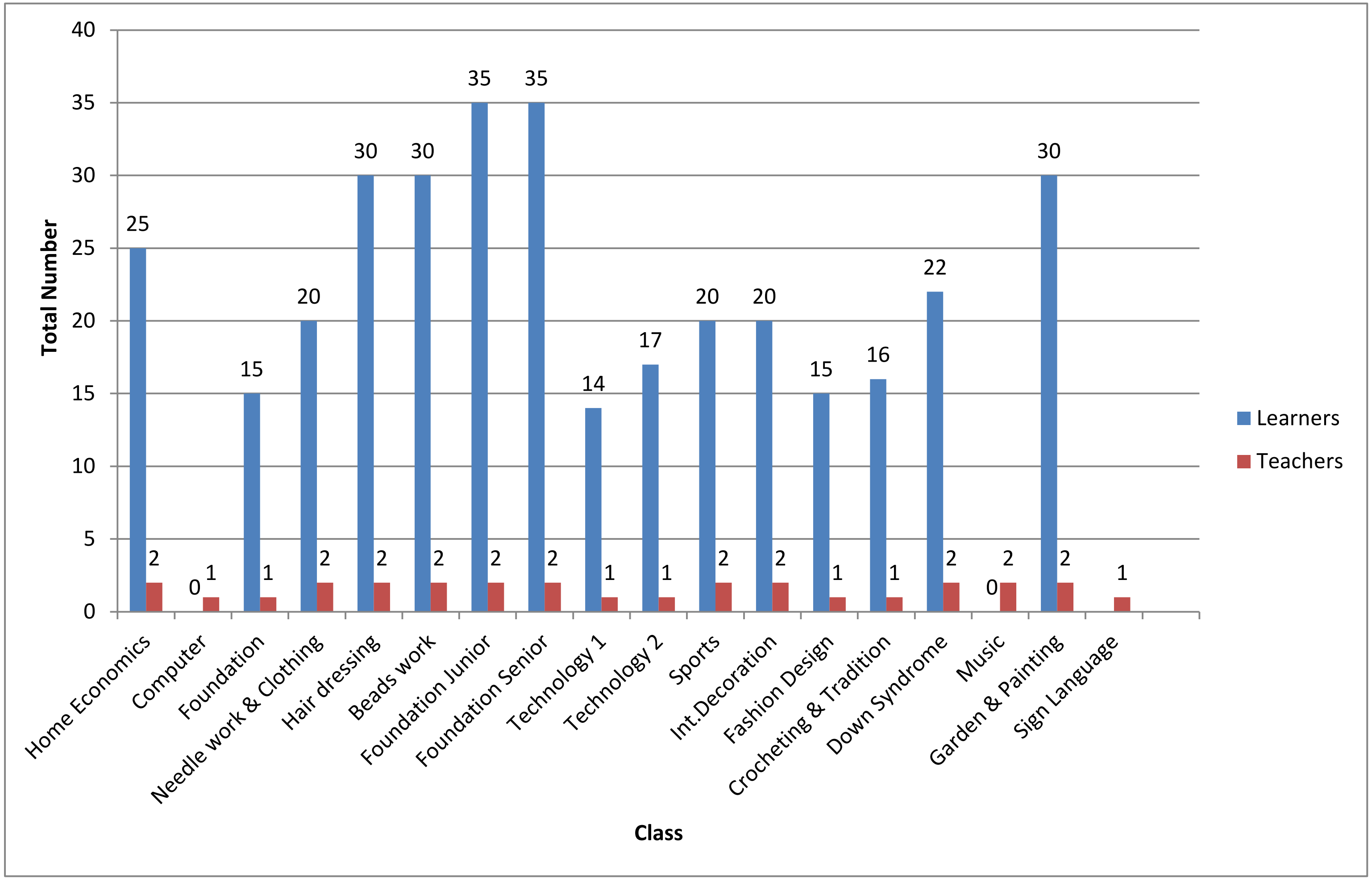


Figure 2.3 Types of classes and the number of pupils at Pfunanani Special School

2.5 STRATEGIES TO ENSURE TRUSTWORTHINESS

Trustworthiness is a term that is used to describe rigour or goodness of qualitative research (Speziale & Carpenter, 2007). Trustworthiness refers to the activities that were implemented to ensure that data was gathered and analysed rigorously so as to ensure that the outcome of the research is correct. Credibility, dependability, confirmability, and transferability are the four criteria used to demonstrate trustworthiness of qualitative research (Lincoln & Guba, 1985).

2.5.1 Credibility

According Lincoln and Guba (1985), credibility includes activities that increase the probability that credible findings are produced in the study. As suggested by Shenton (2004), the activities set out in the following subsections were used to enhance the credibility of the current study.

2.5.1.1 Background, the qualifications and experience of the investigator

The researcher’s credibility in qualitative research is essential, especially if the researcher participated in collecting and analysing data. The readers of the research findings should at least trust the researcher to be able to conduct a study so as to produce credible findings (Patton, 1980; Shenton, 2004).data collection

The researcher has been living in Giyani for over ten years and understood the local culture. The researcher is also a Xitsonga first-language speaker, and Xitsonga is the most dominant spoken language in Giyani. Furthermore, the researcher has over ten years of experience working as a physiotherapist in both public- and private-health-care settings, where the focus of his practice was the rehabilitation of both adults and CWDs. He obtained a Masters’ in Early Childhood Intervention, majoring in severe disabilities, at the University of Pretoria. He has also undergone training in electronic qualitative data analysis (Atlas.ti) at the University of Pretoria to optimise his skills to apply electronic strategies to qualitative data analysis.

2.5.1.2 Development of an early familiarity with the culture of Nkhensani Hospital

The researcher had a prolonged engagement (Lincoln & Guba, 1985) at Nkhensani Hospital since he started practising as a physiotherapist in Giyani in the year 2002. However, the researcher's engagement at the study site mainly familiarised him with the rehabilitation professionals and CRWs but not caregivers. Prior to the start of data collection, the researcher had meetings with the rehabilitation professionals where he presented the aims and the objectives of the study as discussed later in this chapter.

2.5.1.3 Triangulation

Similar data was collected from multiple perspectives such as caregivers, rehabilitation professionals and CRWs. In addition, various data collection strategies were used, such as individual face-to-face semi-structured interviews and FGDs. The use of triangulation is said to compensate for the weaknesses of collecting data from a single perspective (Shenton, 2004).

2.5.1.4 The researcher's reflective commentary

One of the distinguishing facts between qualitative and quantitative research is the subjectivity of qualitative studies (Speziale & Carpenter, 2007, p. 20). The researcher kept a reflective journal in the form of field notes so as to ensure that he was constantly aware of his prejudgements and subjectivity during data collection. The use of field notes helped the researcher to give an account of the detailed procedure followed during the data collection process.

2.5.1.5 Examination of previous research findings

A literature review was conducted after data analysis so as to assess the degree to which the research results are congruent with the results from the latest literature.

2.5.2 Dependability

According to Speziale and Carpenter (2007, p. 49), dependability is a criterion met when the researcher has demonstrated the credibility of the findings.

One way of contributing to the dependability of the study is through the use of triangulation of methods (Sharts-Hopko, 2002). The researcher used a multi-method data collection strategy from multiple sources and an in-depth methodological description to allow the study to be repeated (Shenton, 2004).

2.5.3 Confirmability

By definition confirmability refers to a process criterion where the researcher leaves an audit trail which can be followed by the readers of the research report (Lincoln & Guba, 1985). The researcher attempted to give a detailed audit trail to show how the study's conclusion was reached. The audit trail showed an in-depth methodological description to allow integrity of the research results to be scrutinised (Shenton, 2004). An accompanying CD has been submitted with this these in order to enhance the confirmability of the study.

2.5.4 Transferability

According to Babbie and Mouton (2001, p. 277) transferability is the extent to which the findings of the study can be applied in other contexts or with other participants. The aim of the current study was not to generalise the findings. Nonetheless, it is expected that the findings will have meaning to participants in a similar situation (Speziale & Carpenter, 2007). A detailed presentation of the methodology of the study will enable the reader to find meaning of the present study in the studies of a similar context.

2.6 ETHICAL CONSIDERATIONS

- The study was approved by the Ethics Committee of the Faculty of Health Sciences of the University of Pretoria (Protocol 109/2009) (Appendix A).
- Permission to conduct the study in Limpopo was granted by the Limpopo Provincial Department of Health and Social Development's Research Ethics Committee (Ref: 4/2/2) (Appendix B).

- Written permission to conduct a study at Nkhensani Hospital was obtained from the hospital's CEO (Appendix C).
- Nkhensani Hospital's deputy manager of clinical support services who is responsible for the rehabilitation services was informed of the researcher's intention to conduct a study and issued written permission (Appendix D).
- The researcher was granted permission by the Mopani District Senior Manager: PHC to conduct the interviews with CRWs (Appendix E).
- All participants were requested to sign an informed consent form before participating in the study (Appendix F, G and H).

2.7 PHASE 1 OF THE STUDY

The primary objectives of Phase 1 of the study were to generate data based on the perspectives of caregivers of CWDs, rehabilitation professionals and CRWs in order to contribute toward the development of concepts on: (1) the role of caregivers, rehabilitation professionals and CRWs in the rehabilitation of CWDs, (2) challenges that CWDs and their caregivers encounter, (3) other specialised services for CWDs, (4) support structure for CWDs and caregivers, and (5) caregivers' satisfaction and expectations of services.

The secondary objectives of Phase 1 were to collect data from the launch of the Greater Giyani Disability Forum (GGDF) and Pfunanani Special School. The GGDF and Pfunanani Special School are some of the available services for CWDs in Giyani. The data from the GGDF was collected in order to develop concepts on: (1) the role of the municipality towards PWDs/CWDs, (2) other specialised services for CWDs, and (3) challenges that CWDs and their caregivers encounter. Data collected from Pfunanani Special School was used to describe the services that the school offered to CWDs.

2.7.1 Gathering of Data from Participants

In Phase 1 of the study, data was collected mainly through individual face-to-face interviews with caregivers of CWDs, rehabilitation professionals, and CRWs. In the next subsections the inclusion criteria, sampling of participants, sampling method, sample size, researcher's role, data collection techniques used, data collection using face-to-face interviews, data collection using field notes, refreshment for participants, analysis of data, limitations of data gathering and conclusion are discussed.

2.7.1.1 Inclusion criteria

To be included as participants in Phase 1 of the current study, caregivers of CWDs, rehabilitation professionals and CRWs had to meet certain inclusion criteria as discussed in this sub-section.

Caregivers had to: (1) be an information-rich caregiver of a CWD aged zero to15 years and attending a rehabilitation clinic at Nkhensani Hospital, (2) have attended at least three rehabilitation sessions at the rehabilitation clinic at Nkhensani Hospital, (3) be willing to sign an informed consent form to participate in the study, and (4) be older than 18 years of age. Caregivers below the age of 18 years were not considered because they are legally classified as children according to the South African Children's Act number 38 of 2005.

Rehabilitation professionals had to: (1) be registered with the HPCSA as a physiotherapist, occupational therapist, speech-therapist or therapy assistant, (2) be working at the rehabilitation clinic Nkhensani Hospital for over 3 months, and (3) be willing to sign an informed consent form.

CRWs had to: (1) be working as a CRW in the Greater Giyani Municipal area and (2) be willing to sign an informed consent form.

2.7.1.2 Sampling of participants

Sampling in qualitative studies differs from that of quantitative studies in the sense that qualitative study sampling is viewed as a dynamic process that is not governed by statistical rules; instead guidelines of between one to 40 participants or more are used, depending on: the purpose of the study, the data collection strategy, the availability of participants, and the redundancy of data or data saturation (McMillan & Schumacher, 2006).

The sampling of caregivers of CWDs was informed by a large estimated numbers of caregivers attending the rehabilitation clinic at Nkhensani Hospital as reported by the rehabilitation professionals. Caregivers were sampled with the aim of achieving redundancy of data. However, the sampling of rehabilitation professionals and CRWs was conducted based on the small number of available participants.

In the next sub-section, the sampling of caregivers', rehabilitation professionals' and CRWs' is discussed.

Caregivers

The researcher made an appointment with the deputy manager of clinical support services at Nkhensani Hospital on Friday 07 May 2010 in order to formally introduce himself to the rehabilitation professionals and familiarise them with the study. The researcher met with the rehabilitation professionals on three consecutive days to explain the aims and objectives of the study. The rehabilitation professionals were given the opportunity to ask questions.

Rehabilitation professionals (i.e. therapists and therapy assistants) working in the rehabilitation clinic were requested to assist the researcher in identifying and recruiting caregivers who met the study's inclusion criteria. The sampling objective for caregivers was to recruit information-rich caregivers or key informants. Information-rich caregivers were those caregivers who were familiar with the processes of the rehabilitation clinic at Nkhensani Hospital. Rehabilitation professionals knew their clients/caregivers and for this reason, rehabilitation professionals were asked to assist the researcher in recruiting participants. Caregivers who were willing to participate in the study were expected to sign an informed consent form (Appendix F).

Rehabilitation professionals

On 11, 12 and 13 May 2010, the researcher circulated the study information leaflets directly and indirectly (through others) to all rehabilitation professionals in the physiotherapy, occupational therapy and speech therapy departments. The rehabilitation professionals who received the information leaflets in person were given the opportunity to ask questions. Rehabilitation professionals who received the information leaflet from their colleagues had an option of calling or texting the researcher if they needed clarity.

Rehabilitation professionals who were willing to participate in the face-to-face interviews were expected to sign an informed consent form (Appendix G).

Community rehabilitation workers

Through the assistance of occupational therapy staff members, the researcher made an appointment to meet CRWs on 13 July 2010. The appointment was scheduled for 08:00 at Giyani PHC offices with the aim of explaining the aims and objectives of the research study to the CRWs and recruiting them to participate in the study. As soon as the researcher arrived at the PHC offices, one of the CRWs introduced him to the nursing sister in charge. However, the nursing sister indicated that the researcher could not interview the CRWs without the permission of the district PHC senior manager. Nonetheless, the researcher went ahead and presented the aims and objectives of the study to four CRWs at around 08:30 on 13 July 2010. CRWs who were willing to participate in the study were expected to sign an informed consent form (Appendix H).

2.7.1.3 Sampling method

The sampling method used for caregivers was different to that of rehabilitation professionals and CRWs. Purposeful sampling was used to select caregivers who could give information-rich data. These caregivers had to be knowledgeable or had experience and insight about the phenomenon being investigated (McMillan and Schumacher, 2006; Speziale & Carpenter, 2007). The sampling of caregivers was conducted until data saturation was reached. Data saturation is a point where there is a repetition of discovered information and confirmation of previously collected data. It is a point where analysis of data does not yield any new information (Morse, 1994a).

A convenience sample of rehabilitation professionals and CRWs was selected to participate in the study. According to McMillan and Schumacher (2006), convenience sampling is a process of selecting participants in a particular setting who are available and willing to participate in the study. There were a limited number of rehabilitation professionals, and CRWs in Giyani and as such a convenience sample of participants was chosen.

2.7.1.4 Sample size

Considering that the aim of this qualitative study was not to generalise the findings to the general population, a sample of nine caregivers who met the inclusion criteria was recruited to participate in the interviews through the assistance of the rehabilitation professionals. Caregivers were not all recruited on the same day. They were recruited on an ongoing basis where one caregiver was recruited after another until the researcher was convinced that the analysis of data was not yielding any new information (Morse, 1994b).

As the researcher collected data from caregivers, he received an invitation from the Greater Giyani Municipality to attend the launch of the GGDF. At the launch, the researcher established that the chairperson of the disability forum who was also disabled and had two CWDs. He was also knowledgeable in disability issues. As a result, the researcher considered him to be a key informant and invited him to participate in the face-to-face interviews which the chairperson agreed. The chairperson's data was categorised with data collected from caregivers because of the similarities between the two. Therefore, a total of ten caregivers including of the chairperson participated in the current study.

Seven rehabilitation professionals agreed to participate in the face-to-face interviews. Five of the rehabilitation professionals were working in the occupational therapy department, and two were from the physiotherapy department. From the face-to-face interviews with caregivers, the researcher determined while analysing data that a nurse had referred CWDs and their caregivers to the rehabilitation clinic. The researcher later proved that the nurse had been trained in the field of genetics and had a Master's degree in nursing. The nurse was also responsible for the running of the "genetic clinic" in the hospital. The "genetic clinic" was used by the nurse to assess CWDs, offer counselling to caregivers of CWDs and other support services. What the nurse did at the "genetic clinic" was more or less the same as what was done at the rehabilitation clinic. The researcher considered the nurse to be a key informant because she was knowledgeable and experienced in the field of childhood disabilities. As a result, the nurse was invited to participate in the face-to-face interviews, which she agreed. The similarities between the nurse and the rehabilitation professionals, as well as the genetic clinic and the rehabilitation clinic, led the researcher to group the nurse in genetics under rehabilitation professionals. Therefore, seven rehabilitation professionals from the occupational therapy and physiotherapy departments and one rehabilitation professional from the nursing unit participated in the face-to-face interviews. A total of eight rehabilitation professionals participated in the interviews.

2.7.1.5 Researcher's role

In a qualitative research, the researcher plays an active role during the collection and analysis of data. According to Speziale and Carpenter (2007, p. 140), the researcher must not attempt to remove himself or herself from the study, but must openly recognise his or her role in the investigation.

The researcher played three major roles when data was being collected from the caregivers, rehabilitation professionals and CRWs. The researcher: (1) Collected all the data from participants and seemed to be the best person to conduct the investigation because of his prolonged exposure in the field of childhood disabilities, his knowledge of the local language and culture, and the fact that he had been living in Giyani for over 10 years. (2) Acted as an interviewer throughout the interviews with participants. (3) Analysed of all the data collected.

There are two schools of thoughts regarding analysis of data by an individual researcher. There are authors who are against analysis by an individual researcher (Denzin, 1978; Mays & Pope, 1995; Patton, 1999; Pope, Ziebland, & Mays, 2000) but there are those who support it because it is said to be sufficient and preferred (Morse, 1994a; Morse & Richards, 2002; Janesick, 2003).

2.7.1.6 Data collection techniques used with participants

Data collection techniques are methods and strategies used to collect data. Two data collection methods were used: (1) Face-to-face interviews were used with caregivers, rehabilitation professionals and CRWs. (2) Field notes were used with all participants.

2.7.1.7 Data collection using face-to-face interviews

In the next subsections, the face-to-face interviews with caregivers, rehabilitation professionals and CRWs are discussed.

Caregivers

According to Holstein and Gubrium (1995, p. 1), interviews are regarded as the universal mode of systematic enquiry in qualitative research. Interviews are used to understand the closed worlds of individuals through extracting and transmitting information from the interviewee to the interviewer (De Vos, 1998, p. 297).

Semi-structured face-to-face interviews with guiding questions were used to interview caregivers (Appendix I). Semi-structured interviews are the kind of interviews where the interviewer follows an interview guide, based on the objectives of the study. The interviewer does not necessarily ask the questions to the interviewees in the same sequence all the time but ensures that all the guiding questions have been addressed during the interview. The topics of the interview are predetermined, but the researcher decides the sequence of the questions during the interview (McMillan & Schumacher, 2006).

The use of guided questions during the interview does not mean that the interviews will be rigid and only address those guiding questions. It is expected and accepted in qualitative studies that further questions will evolve as the interviews are being conducted (Birks & Mills, 2011). In a qualitative study the researcher has to play an active role and ensure that he coordinates the conversation with the aim to generate data for the developing theory (Corbin & Strauss, 2008; Birks and Mills, 2011, p. 75).

As soon as a caregiver was recruited, the researcher was given a private room at the occupational therapy kitchen to sit and explain the aims and objectives of the study to the caregiver. The caregiver was then given an opportunity to ask questions. The researcher emphasised to the caregivers that participation in the study was voluntary, and it was expected from participants to sign an informed consent form, which was read and explained in Xitsonga. A caregiver was interviewed after signing an informed consent form.

The researcher took about a minute to set up the interview area and prepare the recording devices and microphones before the interview commenced. The researchers' greeting and self-introduction followed this process. Probing was used to stimulate caregivers to elaborate on what they said.

Two digital audio recorders were used simultaneously to record all interviews. This method was used to ensure that uninterrupted records were obtained in case of mechanical failure of one of the audio recorders. All face-to-face interviews with caregivers were conducted in Xitsonga and were scheduled for a maximum of 45 minutes.

According to Glaser (1998), it is unnecessary to record interviews in qualitative research. However, for the purpose of the current study audio records were used and kept as evidence during data analysis and to enhance the trustworthiness of the study’s findings (Devers & Robinson, 2002).

At the end of the interview, the researcher thanked the caregiver and made an appointment for a follow-up interview. Face-to-face interviews with caregivers were stopped when data saturation was reached after about 14 interviews.

The first three caregivers who had an appointment with the researcher for follow-up interviews did not honour their appointments. After realising that Caregiver 1 (CG 1), Caregiver 2 (CG 2) and Caregiver 3 (CG 3) had defaulted on their follow-up interview appointments, the researcher suspected that caregivers were experiencing financial difficulties. For this reason, the researcher decided to compensate caregivers for their transport fares on condition that follow-up interviews were organised. Immediately afterwards, Caregiver 4 (CG 4), Caregiver 5 (CG 5), Caregiver 6 (CG 6) and Caregiver 7 (CG 7) had their first face-to-face interviews. They were provided with transport fare based on what they said it cost to get to the hospital. One caregiver was provided with twenty Rand (R20); two caregivers were provided with twenty-five Rand (R25) each, whereas the other caregiver was provided with forty Rand (R40).

CG 5 did not show-up on the day of the scheduled appointment despite having been given transport fare and it was never established why she failed to come because she didn’t answer her mobile phone when the researcher contacted her. In addition, she did not show up for her child’s next rehabilitation clinic appointment.

CG 3 did not show up on her scheduled date of appointment but came on another date at which time her follow-up interview was conducted. Immediately after her follow-up interview, CG 3 was provided with transport fare of forty Rand (R40) because all the caregivers who had had follow-up interviews before her had been compensated for their transportation costs.

Out of the nine caregivers who had scheduled follow-up interviews, only four caregivers (CG3, CG 4, CG 6 and CG 7) honoured their appointments by coming back to be interviewed.

Rehabilitation professionals

All rehabilitation professionals had to sign informed consent forms. Before the interviews began, the researcher asked all rehabilitation professionals who had signed informed consent forms to indicate when they preferred to be interviewed. On the day of the interview, the researcher ensured that the rehabilitation professionals were free and comfortable by cracking some jokes as he began setting up the recording devices.

The researcher started the interview by greeting and introducing himself. Semi-structured face-to-face interviews with guiding questions were used to interview rehabilitation professionals (Appendix K).

Two digital audio recorders were used simultaneously to record all interviews. Interviews were conducted in Xitsonga and English depending on the rehabilitation professional’s preference. However, some of the rehabilitation professionals’ responses were in Tshivenda. All interviews were scheduled for a maximum of 45 minutes per interview and were held in the hospital. At the end of the interview, the researcher thanked the rehabilitation professional and made an appointment for a follow-up interview based on the preference of the rehabilitation professional. Follow-up interviews were conducted with the seven rehabilitation professionals from the physiotherapy and occupational therapy department between 05 and 08 July 2010.

The nurse in genetics was not followed-up because data analysis did not warrant further clarification.

Community rehabilitation workers

The two CRWs, who agreed to participate in a face-to-face interview, had to sign an informed consent form and the researcher emphasised to all participants that participation in the study was voluntary. Before the interviews began, the researcher asked all CRWs who signed informed consent forms to indicate when they preferred to be interviewed. The two CRWs chose 17 September 2010.

Two digital audio recorders were used simultaneously to record all interviews, which were conducted in Xitsonga. Semi-structured face-to-face interviews with guiding questions were used to interview CRWs (Appendix L). Interviews were scheduled for a maximum of 45 minutes per interview and were conducted at Nkhensani Hospital.

Follow-up interviews were not conducted after the researcher had established that CRWs were, in fact, occupational therapy assistants based in the community. They were trained at the same institution as some of the rehabilitation professionals who were interviewed earlier. Secondly, analysis of the two CRWs' interviews yielded similar information. As a result, the researcher felt that follow-up interviews would not yield any new information.

2.7.1.8 Data collection from using field notes

Field notes were taken during all interviews and served as records of what the researcher observed, thought, or experienced during the course of the caregiver interviews (McMillan & Schumacher, 2006). The researcher's personal belief about the topic was also documented in the field notes in order to alert him to his possible judgements or presuppositions (Speziale & Carpenter, 2007). A total of two notebooks were used to record field notes, which would not typically be captured on audio-recorded data.

2.7.1.9 Refreshments for participants

After the conclusion of each interview, participants were provided with lunch as a gesture of appreciation that is in-line with the culture and practises of Va-Tsonga people. As the researcher was not sure of the number of people who would consent to participate at a given date, meals for 10 to 15 people were prepared. Caregivers and rehabilitation professionals who refused to participate in the study were also provided with a meal, but priority was given to those participants who were willing to be interviewed. The menu included protein (chicken and sausage), carbohydrates (rolls), salad (chakalaka) and soft drinks (coca cola products and 100 per cent juice).

2.7.2 Analysis of Data

Analysis of qualitative data is a process where data is organised by coding, categorising and identifying relationships among categories (McMillan & Schumacher, 2006).

Considering the amount of data that was collected from the caregivers, the researcher recruited two senior university students to be trained as data transcribers. The two students were doing a third year of social work and a final year of medicine respectively. The exposure that social work and medical students have to patients while studying/training ensures that they have a better understanding of the concept of confidentiality. As such, the researcher was satisfied that the students would not compromise the participants' confidentiality in any way. In addition, the students were requested to sign a letter of confidentiality as soon as they agreed on how they would be compensated (Appendix J).

The researcher individually trained the students on how to conduct verbatim transcription of the recorded data. Training was conducted on 15 June 2010 and lasted for 90 minutes. During training, the researcher began by playing an audio clip and transcribed it verbatim after which the student was asked to do the same. After the 90-minute training session, the researcher checked how the students transcribed their allocated audio clips. The researcher was satisfied that the students were competent in conducting the verbatim transcriptions.

Two days later, Students were allocated recorded data in audio clip format to transcribe verbatim. All of the transcripts that the students produced were verified and corrected by the researcher before the researcher translated them into English. All translated transcripts were typed into a Microsoft Word document format before being loaded into Atlas.ti version 6 for coding. Similarly data generated from other sources such as field notes was typed and uploaded into Atlas.ti program.

Preliminary analysis of data was conducted even before transcripts were uploaded into Atlas.ti program. Preliminary analysis of data is a process undertaken every time data is collected. It is a simple process of checking and tracking the data to see what is coming out of it, identifying areas that require follow-up (Grbich, 2013, p. 21).

An inductive approach to qualitative data analysis was used in the current study (Thomas, 2006).The inductive approach is not associated with any individual qualitative approach such as grounded theory or phenomenology but is generic in nature and may be applied to different types of research approaches (Silverman, 2000; Ezzy, 2002). Inductive approach to qualitative data analysis is similar to grounded theory but does not explicitly separate the coding process into open coding and axial coding (Thomas, 2006, p. 241). However, Strauss and Corbin (1998) suggest that the theory that is generated should emerge from the data (Strauss & Corbin, 1998).

The Atlas.ti program was used to store efficiently, organise, and reconfigure data to enable human analytic reflection. The Atlas.ti program did not code the data, but the researcher did (Saldana, 2013, p. 28). According to Galman (2007) coding in most qualitative studies is a solitary act. The researcher alone was responsible for the coding of data. Collaborative coding or solo coding have their advantages and disadvantages. However, the availability of resources and the distance between the researcher and the study leader was not conducive for collaborative coding.

In-vivo and open coding was used to generate codes. In vivo coding is the creation of a code from the selected text, such as the uploaded transcripts (Muhr, 2004). Saldana (2013) defines in-vivo coding as a code that is taken directly from the participant using his/her own words. On the other hand, open coding is when a qualitative researcher creates, names and lists a code (Muhr, 2004).

Coding was mainly conducted on Atlas.ti program, and an audit trail presented in the CD. However, the Atlas.ti program used for analysis of data in this research was affected by computer malware. As such coding on the CD is not the final product as the malware prevented the refinements of codes.

The presentation on the CD is in terms of quotations, code families (categories) and super code families (theme). Coding on the CD was further refined and rearranged into quotations, codes, subcategories and categories as presented in chapters 3 and 4.

Even though the terminology that is used in Atlas.ti is unique, with terms such as code families and super code families, the analysis of data follows the same process of coding, categorisation (code families) and identification of a theme (super code families) as described by Speziale and Carpenter (2007). A summary of the data analysis process is depicted in Figure 2.4 below.

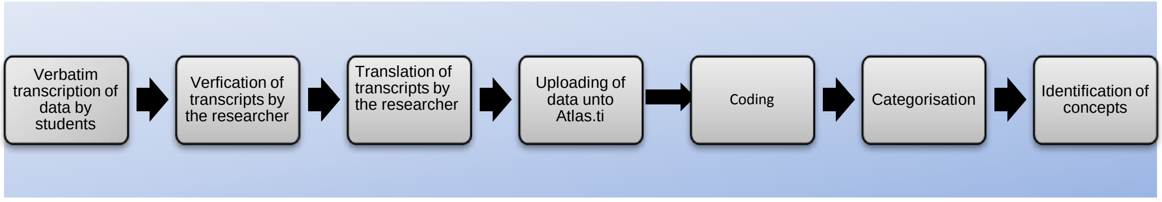


Figure 2.4 Data analysis process

2.7.3 Limitations of Data Gathering

- It was initially planned that follow-up interviews with caregivers would be conducted in the communities where caregivers reside on condition that their partners or parents approve. Conducting the interviews where caregivers reside would have given the researcher an opportunity to see how CWDs are rehabilitated at home. However, the first three caregivers who were interviewed in this study declined to be interviewed in their homes and, as such, interviews in the communities were abandoned and all the remaining interviews were conducted in the hospital.
- To identify caregivers who could give information rich data through purposeful sampling, the researcher relied on rehabilitation professionals.
- Nine out of ten caregivers who participated in Phase 1 of the study only experienced disability as they saw it in their children because they were not disabled themselves.
- The speech-therapist and three experienced physiotherapists did not consent to be interviewed and, as such, they did not take part in the study. Similarly, only two of the five CRWs agreed to participate in the study.

2.7.4 Conclusion

Face-to-face interviews were used to gather data from caregivers, rehabilitation professionals, and CRWs. A total of fourteen face-to-face interviews were conducted with ten caregivers, fifteen interviews were conducted with eight rehabilitation professionals and two interviews were conducted with two CRWs. The researcher also observed four rehabilitation sessions where the rehabilitation professionals were treating CWDs in the presence of their caregivers. Two senior university students were trained by the researcher in order to assist with the verbatim transcription of data before data was analysed by the researcher using of an Atlas.ti program.

2.7.5 Gathering of Data from the Greater Giyani Disability Forum Launch

During the face-to-face interviews with rehabilitation professionals, the researcher received an invitation to attend the launch of the GGDF at the local community hall on 27 May 2010. The researcher was interested in attending the launch and obtained the contact details of the municipal councillor who was coordinating the function to make a reservation.

2.7.5.1 Ethical considerations

- Permission to utilise information gathered from the launch was requested from the chairperson of the GGDF (Appendix M).
- The mayor’s speech was in the public domain (website) hence permission was not sought to utilise it.

2.7.5.2 Data collection from the launch

Observation and field notes were used as data collection techniques during the launch. The researcher spent about four hours at the Giyani community hall where the launch took place. He watched all the activities of the day as indicated in the programme (Appendix N). A notebook was used for field notes purposes in order to document all that the researcher observed and thought, as well as what was said during the programme. The researcher also had the opportunity to direct questions to the mayor of the Greater Giyani Municipality. Additional information was obtained from the mayor’s written speech, which was accessed from the municipality’s website. Analysis of data was conducted as in Section 2.3.1.2.

2.7.5.3 Conclusion

During the launch of the GGDF, the researcher listened attentively to all the speakers of the day and recorded what was being said in his notebook. He also had the opportunity to ask questions after the Greater Giyani Municipality mayor spoke. The mayors’ speech was also available on the municipality’s website.

2.7.6 Gathering of Data from Pfunanani Special School

The availability of a Pfunanani Special School in Giyani was mentioned during the face-to-face interviews with caregivers and rehabilitation professionals. Pfunanani Special School is a school for children with mild-to-moderate intellectual impairment. The researcher visited the school on 15 July 2010 with the hope of getting permission from the principal to gather information about the school. A letter requesting permission was left with the acting principal as the principal was not available. The researcher was informed by the acting principal to come back to the school on 21 July 2010 as the principal would be back by then.

2.7.6.1 Ethical considerations

Permission to gather information from the school was obtained from the principal on 21 July 2010.

2.7.6.2 Data collection from Pfunanani Special School

Observation and field notes were used to collect data at the school. On 21 July 2010 the principal of Pfunanani Special School introduced the researcher to a female educator who was asked to show him around the school. The educator was one of the researcher’s clients in his private practice. The researcher was taken from one class to another class where he was shown and told of the activities performed in those classes. The researcher also had the opportunity to ask questions. A notebook was used to document what the researcher was told and what he observed. Analysis of data was conducted as in Section 2.3.1.2.

2.7.6.3 Conclusion

The researcher obtained permission from Pfunanani Special School to enable him to observe what was done at the school. On the day of his visit to the school, the researcher was taken from one class to another where he was shown what each class did and was given the opportunity to ask questions.

2.8 PHASE 2 OF THE STUDY

The objectives of Phase 2 of the study were to gather more data from caregivers and rehabilitation professionals through FGD in order to develop concepts on: (1) the role of caregivers, rehabilitation professionals and CRWs in the rehabilitation of CWDs, (2) challenges that CWDs and their caregivers encounter, (3) other specialised services for CWDs, (4) support structure for CWDs and caregivers, and (5) caregivers' satisfaction and expectations of services.

2.8.1 Gathering of Data from Participants

In the next subsection the inclusion criteria, sampling of participants, sampling method, sample size, researcher's role, data collection from participants, analysis of data, and conclusions are discussed.

2.8.1.1 Inclusion criteria

Caregivers

Caregivers had to meet the following inclusion criteria to be included in FGDs: (1) they had to be between the ages of 18 and 70, (2) they should have been a caregiver of a CWD between the ages of 0 to 15 with a neurological, physical or intellectual disability, (3) they should have attended at least three treatment sessions at Nkhensani Hospital's rehabilitation clinic, and (4) they had to be willing to sign an informed consent form. Caregivers who participated in the face-to-face interviews in Phase 1 of the study were excluded from participating in the FGDs.

Rehabilitation professionals

Rehabilitation professionals had to meet the following criteria to be included in the FGD: (1) they had to be registered with the HPCSA as a physiotherapist, occupational therapist, speech & language therapist or therapy assistant, (2) they had to be working at Nkhensani's Hospital's rehabilitation clinic, and (3) they had to be willing to sign the informed consent form.

2.8.1.2 Sampling of participants

The researcher requested the rehabilitation professionals to assist in identifying and recruiting caregivers who met the inclusion criteria for Phase 2 of the study. Rehabilitation professionals who participated in Phase 1 of the study were invited to participate in Phase 2.

2.8.1.3 Sampling method

Purposeful sampling was used to select information-rich caregivers to participate in the FGDs.

A convenient sample of rehabilitation professionals who participated in the face-to-face interviews in Phase 1 of the study were selected to participate in the FGD.

2.8.1.4 Sample size

The researcher's plan was to conduct FGDs consisting of between eight and ten participants. However, caregivers did not consent to participate in the study as anticipated. As a result, the researcher had FGDs with three groups comprising a total of ten caregivers. The first group comprised two caregivers; the second group comprised three caregivers, and the last group comprised five participants.

A total of eight rehabilitation professionals agreed to participate in the FGD by signing informed consent forms. However, only six rehabilitation professionals presented themselves to the venue where the FGD was conducted. Four of the participants were from the occupational therapy department (two occupational therapists and two occupational therapy assistants), and two were from the physiotherapy department (one physiotherapist and one physiotherapy assistant).

2.8.1.5 Researcher’s role

The role of the researcher in Phase 2 of the study was to facilitate the FGDs, act as an interviewer and to analyse the data.

2.8.1.6 Data collection from participants

FGDs were used as the primary data collection strategy from caregivers and rehabilitation professionals in Phase 2 of the study supplemented with field notes. According to Birks and Mills (2011, p. 76) a FGD can be an extension of interviews where two or more participants engage in a specified topic of discussion led by a facilitator and or interviewer.

Caregivers

As soon as the caregivers signed an informed consent, they were led into a private area where the FGD was conducted. The researcher started the FGD by introducing himself and greeting participants. All FGD participants were informed of the ground rules, such as not speaking at the same time. Caregivers who participated in the FGDs were assigned a number that they were expected to call out before they spoke during the discussion. The numbers assisted the researcher to identify a participant during the transcription of data and data analysis.

The FGDs with caregivers followed a guiding question (Appendix P). Probing was used to stimulate participants to elaborate on their responses. The FGDs were scheduled for a maximum of 30 minutes. At the end of each FGD, participants were thanked by the researcher and provided with lunch.

A total of three FGDs were conducted at Nkhensani Hospital in the morning as highlighted in the next paragraph.

- The first FGD (FGD 1) was conducted on 05 October 2010. The group comprised two participants who were Xitsonga-speaking and as such the FGD was conducted in Xitsonga. FGD 1 lasted for about 20 minutes and 32 seconds.
- The second FGD (FGD 2) was held on 12 October 2010. FGD 2 comprised three participants who were all Xitsonga-speaking, and the FGD was conducted in Xitsonga. FGD 2 lasted for about 19 minutes and 18 seconds.

- The third FGD (FGD 3) was conducted on 19 October 2010. FGD 3 comprised five participants. Four of the five participants were Xitsonga-speaking, and one was Sepedi speaking. The Sepedi-speaking participant understood Xitsonga and as such the FGD was conducted in Xitsonga. However, the Sepedi-speaking participant responded in Sepedi throughout the discussion. The language difference was not of any concern because the Sepedi-speaking participant participated freely in the discussions. The FGD facilitator and all other participants understood what the Sepedi speaking participant said. FGD 3 lasted for about 23 minutes and 17 seconds.

Rehabilitation professionals

Rehabilitation professionals who agreed to participate in the FGD were informed of the date and venue of the FGD by the researcher. Rehabilitation professionals who did not have their own transport to the FGD venue were provided with transport. The FGD was scheduled to start at 18:00 on 26 October 2010. A total of six rehabilitation professionals presented themselves at a privately rented venue in Giyani Section A on the date of the FGD.

The researcher started by greeting all participants and introduced himself. The researcher assigned numbers to each participant and reiterated that participants would have to call out their respective number before speaking during the FGD. The FGD followed guiding questions (Appendix Q) and was conducted in English but responses were sometimes in African languages such as Xitsonga and Tshivenda. The researcher accepted the use of any language that the participants were comfortable to use. The FGD was pre-scheduled to last for a maximum of 60 minutes. However, it lasted for just over 60 minutes.

2.8.1.7 Analysis of data

Analysis of data was conducted as it was the case in Section 2.7.2 of the study.

2.8.1.8 Conclusion

FGDs were used in Phase 2 of the study to collect additional data from caregivers of CWDs and rehabilitation professionals. Three FGDs were conducted with a total of ten caregivers. One FGD was conducted with six rehabilitation professionals at around 18:00 in a private hall in Giyani Section A.

FGD with rehabilitation professionals was scheduled for a maximum of 60 minutes but lasted for about 61 minutes. Field notes were also used as supplemental data collection strategy.

2.9 SUMMARY OF CHAPTER 2

Chapter 2 was divided into nine sections where the following were discussed: (1) introduction into the chapter, (2) research approach, (3) research design, (4) study location, (5) strategies to ensure trustworthiness, (6) ethical consideration, (7) Phase 1 of the study, (8) Phase 2 of the study, and (9) summary of Chapter 2.

Phase 1 and Phase 2 of the study were presented in Chapter 2 as part of concept development based Walker and Avant's (2005) theory-generation process. A total of ten caregivers, eight rehabilitation professionals and two CRWs participated in the face-to-face interviews in Phase 1. The researcher also attended the launch of the GGDF and visited Pfunanani Special School where data about the local disability forum and special needs education was collected respectively. In Phase 2 of the study, a total of ten caregivers participated in three FGDs. One FGD with six rehabilitation professionals was also conducted as part of Phase 2.

Results from Phase 1 and Phase 2 of the study are respectively presented in Chapter 3 and Chapter 4 of the thesis.

CHAPTER 3

RESULTS OF PHASE 1

3.1 INTRODUCTION

In this chapter, the results of Phase 1 of the study are presented. Chapter 3 is divided into subsections where information obtained from: (1) caregivers, (2) rehabilitation professionals, (3) CRWs, and (4) the launch of the Greater Giyani Disability Forum (GGDF) are discussed.

The primary objectives of Phase 1 of the study were to generate data based on the perspectives of caregivers of CWDs, rehabilitation professionals and CRWs in order to contribute toward the development of concepts on : (1) the role of caregivers, rehabilitation professionals and CRWs in the rehabilitation of CWDs, (2) challenges that CWDs and their caregivers encounter, (3) other specialised services for CWDs, (4) support structure for CWDs and caregivers, and (5) caregivers' satisfaction and expectations of services. The secondary objective of Phase 1 was to collect data from the launch of the GGDF.

3.1.1 Presentation of Results

Concepts in this chapter are mainly presented in a tabular form comprising quotations, codes, subcategories and categories. In Atlas.ti concepts are referred to as supercodes. Quotation refers to the exact words or phrases as said or reported by the participant. Every quotation is followed by a letter and numbers such as (P5:42) where P5 means it is "primary" document number 5 as saved in Atlas.ti program's primary document manager and 42 means line number or paragraph number 42. Codes are either in-vivo or open codes as used during analysis of data. Similar codes are grouped together as subcategories and or categories which are referred to as code families in Atlas.ti.

3.2 INFORMATION OBTAINED FROM CAREGIVERS

In this section, results emanating from interviews with caregivers are presented. These results include caregivers' demographic information, demographic information of children whose caregivers participated in the study as well as the emerging concepts. Results on the following concepts are introduced: (1) cause of childhood disability, (2) the role of caregivers, (3) available services for CWDs, (4) challenges experienced by CWDs, (5) role of CRWs, (6) caregivers' level of satisfaction, (7) caregiver's expectation, (8) caregivers' coping strategy, (9) caregivers' source of support, and (10) societal perception of CWDs.

3.2.1 Caregivers' Demographic Information

A total of ten caregivers participated in the face-to-face interviews. Nine of the caregivers had CWDs below the age of 15 years who were still actively attending the rehabilitation clinic at Nkhensani Hospital. One caregiver was a father of two young adults living with disabilities and had been discharged from the rehabilitation clinic more than five years prior to the study. A data sheet (Appendix S) was used to collect the caregivers' age, gender, marital status, relationship with the child, number of dependent children, educational level, employment status, source of income, estimated family income, living arrangement or person living with the caregiver, the availability of electricity and the availability of water. A summary of the demographic information of all the caregivers who participated in the face-to-face interviews is presented in Table 3.1

Table 3.1 Caregivers' demographic information

Code	Age	Gender	Marital status	Relation to child	Dependents	Education	Employment status	Source of income	Family income	Living arrangements	Electricity	Water
CG1	29	Female	Single	Mother	2	Grade 8	Unemployed	Social grants	R 1200	Parents	Yes	No
CG2	28	Female	Married	Mother	4	Grade 8	Unemployed	Social grants + farm labourer	R 1500	Partner	Yes	Yes
CG3	38	Female	Married	Mother	3	Grade 11	Unemployed	Social grants + security guard	R 800	Partner	Yes	No
CG4	33	Female	Married	Mother	2	Grade 11	Unemployed	Social grants	R 1080	Parents	Yes	Yes
CG5	18	Female	Single	Mother	1	Grade 11	Unemployed	Social grants	R 1200	Parents	Yes	Yes
CG6	29	Female	Single	Mother	3	Grade 10	Unemployed	Social grants + domestic worker	R 700	Parents	Yes	Yes
CG7	29	Female	Married	Mother	2	Grade 11	Unemployed	Social grants + Occasional Artisan Jobs	R 1480	Parents	Yes	Yes
CG8	23	Female	Single	Mother	1	Grade 10	Unemployed	Social grants + Occasional Artisan Jobs	R 1200	Parents	Yes	Yes
CG9	23	Female	Married	Mother	2	Grade 11	Unemployed	Social grants	R 1000	Parents and partner (interchange)	Yes	No
CG10	55	Male	Married	Father	2	Grade 12	Unemployed	Social grants	R 1500	Partner	Yes	Yes

3.2.2 Demographic Information of Children with Disabilities whose Caregivers Participated in the Study

The data sheet (Appendix S) was used to collect the age, gender and the diagnoses of the CWDs whose caregivers participated in the face-to-face interviews. The age of the children ranged from one to three years. There were seven females and three males. Eight of the children had a cerebral palsy diagnosis. A summary of the demographic information of all the CWDs whose caregivers participated in the study is shown in Table 3.2.

Table 3.2 Demographic information of children with disabilities

Code	Age	Gender	Diagnosis
CG1	4	Female	Cerebral palsy
CG2	2	Female	Cerebral palsy
	2	Female	Cerebral palsy
CG3	2	Male	Achondroplasia
CG4	6	Male	Microcephalus
CG5	1	Female	Cerebral palsy
CG6	1	Female	Cerebral palsy
CG7	2	Female	Cerebral palsy
CG8	5	Male	Cerebral palsy
CG9	2	Female	Cerebral palsy

3.2.3 Development of Concepts from Caregivers of Children with Disabilities

In this subsection, the results from the face-to-face interviews with caregivers are presented. Results emanate from the perspectives of the caregivers following the face-to-face interviews which were based on ten guiding questions (Appendix I). The emerging concepts, question asked and the results consisting of quotations from participants, codes, subcategories and the categories are shown. However, results on some concepts do not have subcategories.

3.2.3.1 Question 1: What can you tell me about this child?

Concept: Cause of childhood disability

When Question 1 was asked, caregivers expressed how the child was born as well as what they perceived to be the cause of the child’s disability.

The building blocks of this concept were derived from ten codes, five subcategories, and three categories. Caregivers thought that the cause of childhood disability was related to religious beliefs, other beliefs and biomedical reasons. The religious beliefs include factors such witchcraft and God's decision. Other beliefs include misconceptions whereas the biomedical causes consist of head injury and hypoxia. A summary of the results related to the cause of childhood disabilities as perceived by the caregivers is presented in Table 3.3

Table 3.3 Cause of childhood disability

Category	**Subcategory**	**Code**	**Quotation**
Religious belief	Witchcraft	Bewitched	*…maybe she has been bewitched. (P5:42)*
	God's decision	I thank God for everything Gift from God God's will God's decision	*…my child's condition is not my fault. I thank God for everything…(P1:11)* *…when God gives you something you just have to accept because you did not choose…(P12:93)* *…there are those that accept that it is God's will.(P13:161)* *…disability is God's decision. It is not the mother fault; it is not the fathers fault, it is not other citizens' fault, it is not the government's fault…(P16:91)*
Other belief	Misconception	Her brain was all over the place Had holes in her brain. Baby had relieved herself	*…I was told that her brain was all over the place, and she had holes in her brain…(P7:19)* *…it seemed as if the baby had relieved herself whilst still inside the womb as the water that broke was green…(P11:16)*
Biomedical	Head injury	Head injuries	*…the midwife thought she had some head injuries (P5:15)*
	Hypoxia	Oxygen deprived	*…they then said the child is oxygen deprived…(P11:17)*

3.2.3.2 Question 2: What is your role as a caregiver during the rehabilitation of the child?

Concept: Role of caregivers

The building blocks of this concept were obtained from 12 codes, five subcategories, and two categories. Caregivers played two major roles during the rehabilitation of the child at the hospital and out of the hospital where they supported the child (passive care) and ensured that the child was continually care for (active care). Caregivers supported their children by loving them which was considered to be a passive role. In addition caregivers actively continued with the care of their children through learning of new skills, performing hands-on role, demonstrating the newly learned skills to rehabilitation professionals, and performing home programmes. A summary of the role of caregivers as derived from the face-to-face interviews with caregivers is presented in Table 3.4 (on page 75).

Table 3.4 Role of caregivers

Category	**Subcategory**	**Code**	**Quotation**
Support the child (Passive care)	Love	Accept the child Love the child Tolerate the child	*...to accept that the child is disabled, to love the child, to tolerate the child…They should not hide the child.(P16:114)*
Continuity of care (Active care)	Learn	They show me I watch I observe I look	*I am always with them, and they show me what do. (P1: 95)* *I look at what they do with her. (P5: 68)* *I watch them as they treat her…(P7:49)* *…to look at what they do and how they do it so that I can do it at home…(P9:36)* *They show me what to do…(P11:43)* *I just sit and watch… I just observe how they stretch her (P12: 39 & 41)* *I look at what they do so that I can continue doing it at home. (P13:101)*
	Hands-on	We work together Stretch	*I am always with them; we work together. (P11:43)* *…I help them stretch. (P12:39)*
	Demonstrate	I show them Demonstrate	*…I show them…(P1:91)* *…and expect me to demonstrate to them what they have just showed me... (P11:43)* *I show them what I think is better for me to do at home as I know what she likes. (P5:68)*
	Home programme	Do at home	*… I do what they showed me to do at home. (P1:93)* *…they showed me what to do at home, and I did it…(P4:28)* *…so that I can do it at home. (P7:49)* *…so that I can do it at home as well. (P9:36)* *…to do the very same thing when I get home. (P11:43)* *…so that I can do exactly that when I get home. (P12:41)* *…so that I can continue doing it at home…(P13:101)*

3.2.3.3 Question 3: What are the available services for children with disabilities and caregivers in Giyani?

Concept: Available services

This developing concept comprises of 11 codes, eight subcategories and three categories. The available services are divided into rehabilitation services, community-based services and social services. The rehabilitation services consist of physiotherapy, occupational therapy, speech therapy, and orthotics and prosthetics. Community-based services consist of home-based carers, CRWs, and special school. Social service consists of social grants. A summary of the available services for CWDs in Giyani is shown in Table 3.5.

Table 3.5 Available services

Category	**Subcategory**	**Code**	**Quotation**
Rehabilitation services	Physiotherapy Occupational therapy Speech therapy Orthotics and prosthetics	Physiotherapy Occupational therapy Speech-therapist Assistive devices	*…the physiotherapists…promote our independence…the Occupational therapists…teach us handwork…the Speech and hearing therapists…provide us with hearing aids also …we have assistive devices services…(P16:98)*
Community-based services	Home based carers	Carers	*There are caregivers [carers] who sometimes pass by and find my child sitting….They come from my own village… (P6:77-89)*
	CRWs	People in community	*…services of those people who goes around in the community and educate us about TB and HIV/AIDS…(P10:17-22)*
	Special schools	Dzumeri School Letaba Special School Pfunanani Special School Nthabiseng Special School	*…there is a school at Dzumeri health centre…(P11.101)* *…Letaba Special School. (P13:167)* *…we have got Pfunanani Special School, which was the first and the only, in Mopani District...we now have another school within Mopani District in Phalaborwa called Nthabiseng…(P16:97)*
Social service	Social grants	Grants	*The only thing that makes it easy to come here is the grant…(P11:119)* *She gets a grant. (P12:89)* *…at least they are giving us grants…(P16:95)*

3.2.3.4 Question 4: What are the challenges that you experience as you try to seek rehabilitation for the child?

Concept: Challenges experienced

The building blocks of this concept were derived from 46 codes, 15 subcategories and four categories. The four categories are child related (Table 3.6), family-caregiver related (Table 3.7, on page 82), health-care related (Table 3.8, on page 83), and community related (Table 3.9, on page 84).

Table 3.6 Challenges experienced (1)

Category	Subcategory	Code	Quotation
Child-related	Clothes	Nappies	*…I cannot get nappies that fit her… (P5:76)*
	Nutrition	Not feeding Did not suck Not eating Cannot afford food	*…at first she was not feeding at all but these days it is better…(P5:76)* *She did not suck the breast…she was not eating. (P7:11 & 17)* *I gave her a breast, and she sucked a bit…(P11:17)* *…could not suck the breast…the problem is she cannot feed herself…(P12:17, 139)* *The problem is that I am no longer breastfeeding her, and I have to buy her food but I cannot afford...(P13:105)*

Table 3.7 Challenges experienced (2)

Category	Subcategory	Code	Quotation
Family-caregiver related	Information	Do not know Do not understand Doubt	*I do not know where it will end…(P1:63)* *…since she was born, I did not understand a thing…I did not know anything…it took me time to notice that she had a problem…I just thought she was lazy as there was no one to advise me to go to the hospital (P5:15, 25, & 27)* *I do not understand what is wrong. (P7:55)* *…I did not know that there is a place called CP clinic. I stayed for a very long time not knowing until I asked someone who said that I should come here…(P9:94)* *...they said it is cerebral palsy, but I do not know what that is. (P11:33)* *…I doubt if she can see... (P12:33)*
	Social grants access	Unclear grant application (bureaucracy) Bribe for grant Inappropriate grant Inconsiderate staff	*I thought they were the one's [genetic clinic] who decide by writing a letter. (P13:47)* *…I was told to bring R900 as a bribe for the doctor but I decided to let go because I was only getting a R250 grant (P13:47)* *She is only getting the child grant. (P13:41)* *…It is difficult to access those social grants because the panel comprises of a doctor and an official from Social development. How do they decide who is eligible, what criteria do they use...(P16:35-38)*
	Affordability	Expensive No money Cannot afford	*…it is expensive… It is R20... (P1:25 &27)* *When I do not have money to take the child to the hospital, I just borrow from the neighbours…milk is expensive she need to bath and also need clothes. (P8:21 & 23). It is not easy because you have to budget money to enable you can come with the child to the hospital (P9:132)* *I cannot afford to buy what she is supposed to be eating… It is bad.. (P13:105 &115)*
	Appropriate transport	No mini-bus-taxi Transport problem Child big to be carried No disabled driving schools	*We use buses; there are no mini-bus-taxis where I stay…(P1:29)* *I have a transport problem. She is now big, and I cannot carry her on my back. I cannot take along that [Madiba buggy] because I am using a bus, and everybody uses the bus. You sometimes find that there is no enough space in the bus…(P6:25)* *…the issue of driver's licence…why are we not having driving schools…that teaches automatic cars (P16:80-83)*

Table 3.8 Challenges experienced (3)

Category	Subcategory	Code	Quotation
Health-care related	Accessibility of health facility	Distance to clinic	*…we struggle going to Khakhala village…I cannot say how far it is but its twenty Rands return…(P1: 25 & 27)*
		No clinic in the village	*…they must make these services available in the villages as well. (P11:115)*
	Hands-on role	They do not check the child	*I think they should check the child every time she comes for treatment... (P5:72)*
		They do not touch the child	*…they tell you to continue without even touching my child at all, and I am not happy about that. (P10:37)*
		They do not treat the child	*…they tell me to go home and continue doing it, and I am unhappy about that…I expect them to show me themselves (P11:57 & 59)* *…the other time I came here I felt like I was just wasting money because the professionals just touched her and told me to go…(P13:27)*
	Uniformity	They treat differently	*…they treat her differently…there are others who will just tell you what you should do at home without doing anything themselves… If their treatments were the same they would see us coming every time but now we are discouraged… I wish to see them treating my child in the same way…(P13:33-37 & 99)*
	Equipment and material	They do not have a machine	*…they have to give them [rehabilitation professionals] the machine in order to assist them to stretch with… I am asking them to help my children with the machine…(P2:23)* *I think they are still short of machines… they should add beds because they are only using two beds to stretch our children on… (P9:42-48)*

Table 3.9 Challenges experienced (4)

Category	Subcategory	Code	Quotation
Community related	Inadequate special schools	School not fit for child Other children will laugh Not suitable School not appropriate	*She does not go to crèche…because she cannot walk by herself…when other children play, she will not play with them. (P1:61)* *…I wanted to ask whether she is fit to go to a special school. I think other children will laugh at her if she goes to an ordinary school…(P4:52)* *…we have an ordinary school for everybody and a child like this is not fit to go there...(P5:60)* *…it is not suitable for a disabled child…(P9:76)* *…educational facilities for children like this one. We need schools in the villages. (P10:19). I expect to see a crèche and a school that is appropriate for a child like this…(P11:98)*
		One pre-school Two schools No crèche Dzumeri School School is far Letaba Special School	*…there is a pre-school…It is one. (P1:67 & 69)* *…there are two schools where parents can choose where to take their children to. (P8:11).There is only one crèche for every child whether disabled or not…there are two (P9:76 & 80)* *There is no crèche, but there is a school at Dzumeri health centre even though it is far…(P11:101)* *I have heard that there is another school for children like her; I think they said it was in Pretoria, but I am not sure…Moreover, it is far. (P12:145 & 147)* *I am planning to take her to Letaba Special School…(P13:167)*
	Houses	No access to RDP house	*…we do not have access to housing, but we also deserve to get the RDP houses…(P16:73)*
	Access to water	No water We buy water Cost of water	*…the service that we do not have is water sometimes we go for a month without water… We also get water from the river, but it is not clean, and we only use it for bathing purposes…(P1:39 & 41)* *We buy…It is one rand or 50 cents per 20 litres…(P1:43 & 45)* *We buy… It is 50 cents…(P13:135 &141)*
		Poor rural tap design	*…we have problem with tap water in the rural areas…how do I get to drink water from the tap when I am on a wheelchair as they have erected concrete basins that channels water? (P16:29 & 31)*
	Accessibility of infrastructure	Poor road accessibility Poor building accessibility Poor rural toilet accessibility	*… the main problem is accessibility…It is not only building accessibility, even on the roads we do not have access to walk like any other person…where are we supposed to walk...we do not have paths to walk…(P16:15-24)* *…we have got a problem with the toilets that the municipality is erecting for us…the Zink toilets…when I am in that toilet, I cannot bend my knees. I do not fit in there. For a person on a wheelchair it is amen, he cannot get in there. There are steps on those pit toilets and how do we access it? (P16:22-23)*
	Recreational facilities	No place for CWD to gather No sports facility	*I wish for a place where all CWDs can gather…a place where the children can be safe and be able to play …(P9:64)* *…we do not have sports facilities for PWDs. We can compete with our kind…We do not have facilities…. (P16:56-58)*

3.2.3.5 Question 5: What can you tell me about the role of community rehabilitation workers?

Concept: Role of CRWs

This concept was derived from 11 codes, five subcategories and three categories as shown in Table 3.10. The three categories include the adequate role that CRWs play, the inadequate role that they play as well as the absent role, where CRWs fail to play any meaningful role to CWDs. The adequate roles include continuous evaluation of the child, education of the caregivers, being the family-hospital link and issuing of assistive devices. The CRWs' inadequate role is related to the lack of hands-on roles. Some caregivers felt that CRWs were not playing any role hence the category is referred to as an absent role.

Table 3.10 Role of CRWs

Category	**Subcategory**	**Code**	**Quotation**
Adequate roles	Continuous evaluation	Check on us Visit the child	*…all we know is that they visit and check on us. (P6:63)*
	Education		*…they also come to visit the child. (P13:147)*
	Family-hospital link	Educate	*…educate us about TB and HIV/AIDS…they only help by educating us… (P10:17 & 27)*
	Assistive device	Bring soft porridge Bring porridge Bring Physio mat	*…when the child was not eating well, I told them that the child is not eating well, and they brought this other soft porridge for the child to eat…(P6:59)* *…they should also bring along the baby's pampers…they should also bring along a Physio mat… (P12:71-73)* *…I was told that they will also bring along pampers, but the government has not allowed them to…(P13:153)*
		Wheelchair	*…there is a man who brought the wheelchair. (P6:53)* *…they said they wanted to help the child get a wheelchair…(P13:159)*
Inadequate roles	Hands-on	They do not check the child They do not touch the child	*I wish those people who come to check on the child can actually check on the child and not just ask how the child is…when they come they ask whether the child is fine and if we say yes, they leave…they only ask how the child is…At times they, just ask how the child is from the street… (P12:57, 61 & 73)* *They do not do anything; they just look at the child and ask how she is doing. After that they sign and go…no they do not touch a child…(P13:151 &153)*
Absent roles		Never heard	*I have never heard of them. (P3:27)*
		Never seen	*Ever since I started coming here they have never visited me. (P8:37)*

3.2.3.6 Question 6: How is your general level of satisfaction about health-care services that you have received?

Concept: Caregivers' level of satisfaction

This concept was derived from seven codes, five subcategories and two categories. There are caregivers who were satisfied with certain services whilst others were not. The two categories include services that caregivers were satisfied with because they were adequate (Table 3.11, on page 87) and those services that caregivers were not satisfied with because they were inadequate (Table 3.12, on page 88). The adequate services that caregivers were satisfied with include the compassionate nature of the staff and the efficient service that the staff renders. As for inadequate service, caregivers were not satisfied with the quality of service they received, tedious bureaucracy they were subjected to when they were being sent from one department to another, as well as the staff attitude.

Table 3.11 Caregivers' level of satisfaction (1)

Category	**Subcategory**	**Code**	**Quotation**
Adequate service	Compassionate	Caring	*When I came with her on my back, they realised that she is big, and they arranged that thing so that I can push her around. (P6:39)*
	Effective service	Happy with results	*…my children are getting better; I can see that they are getting better as I come here…I am satisfied with the treatment; I do not have any problem with it…(P1: 17& 29)* *The child is fine…She can now walk. She can lift her feet off the ground and take three four steps and sit. She is trying, and I can see there is improvement...I am happy… I would have given up if there were problems… (P3:11, 13, 17 & 25)…I am grateful for the buggy that they have given me…(P4:36)* *…since I started coming here for treatment, she can now turn…It feels good... (P5:33-36). I came with her on my back they realised that she was big, and they arranged that thing so that I can push her around. (P6:39)* *…they have helped her because since she was born she would just look at you, but these days she can even laugh…I think the way they are rendering service is ok because there are some children who could not sit, but ended up sitting…(P7:55 & 81)* *… If it were not for the hospital, I would not know why my child cannot walk or stand. I would not know what is wrong with my child…the service is good (P8:15 & 31). I think what they are doing is good …I am happy…(P9:30 &140)* *...I think it helps because when they show me a particular activity to do they also tell me what the outcome would be, and it ends up happening like they suggested…(P11:41)* *It is good…(P12:125)* *…I found a particular woman who treated my child well and I was happy that I did not waste money…there is a change…she could not use her hands but now she can use the left one…(P13:29 & 103)*
		Grateful for service	

Table 3.12 Caregivers' level of satisfaction (2)

Category	Subcategory	Code	Quotation
Inadequate service	Quality of service	Very slow	*…they are very slow at the clinic…(P1:35)*
	Bureaucracy	Department to department	*…when I got there they created a hospital file for me and I went from department to department where I was telling them that my child is not sick but I have a problem because she is one year old and cannot do a thing. (P5:29)*
	Staff attitude	Poor work ethic Not caring	*When a person gets a job, he relaxes and tells himself that I am the man…(P1:37)* *…you can come here only to be told to come next month…(P10:37)* *…they do not care about helping people…(P1:37)* *…the other time I came here I felt like I was just wasting money because the professionals just touched her and told me to go. (P13:27)*

3.2.3.7 Question 7: What are your expectations from the available services?

Concept: Caregiver's expectation

The caregiver's expectation was derived from 18 codes and four categories. There are no subcategories for this concept. Caregivers had different expectations from the various services that they received. They had expectations from the health-care services, social services, educational services, and community-municipal services as summarised in Tables 3.13 (on page 89) and 3.14 (on page 90) respectively.

Table 3.13 Caregiver's expectation (1)

Category	**Code**	**Quotation**
Health-care services	Food Clothes Access to village services Hands-on role Quality of service Toys Improvement of condition Other specialised service	*…they must also give these children…food and clothes…(P4:46)* *…they must make these services available in the villages as well. (P11:115)* *…another thing that I come here for was to get her stretched… I am coming to Physio so that they can stretch and teach her to walk. (P4:22)* *I wish to see them treating my child in the same way. They should be serious with their treatment so that we can get used to it…(P13:99)* *…if there were things like toys maybe, she would hold them as he cannot hold at the moment. (P7:69)* *…I want my child to walk. There is nothing else…(P1:57)* *…there is nothing that I expected other than to help my child stand and walk… (P4:34)* *…I think they should get something to support her neck so as to strengthen it because she cannot control her neck… (P7:39)* *I would like to see her holding toys and play by herself. I wish her brain can start working so that she can know when and what to touch, what to eat…(P12:133)* *…if they operate on her she can try to walk. (P1:87)* *You must also come and stretch them because you are also a doctor. (P7:73)* *…I am asking them to help my children with the machine. There is a particular machine that can assist them to stretch with … my problem is that I want the workers to use the machine. (P2:23 & 29)* *…they should look at everything that they can and cannot do. They should not only focus on stretching. (P12:45)*

Table 3.14 Caregiver's expectation (2)

Category	**Code**	**Quotation**
Social services	Social grants Relevant appointments	*…they must also give these children grants…(P4:46)* *If I can get that grant, I will be able to do many things…(P13:127)* *…the panel should not only comprise of the doctor and an official. It would be proper if disabled people talked about disability… (P16: 38 & 109)*
Education services	Attend school Village schools Appropriate schools Inclusivity	*I wish to see her going to school when she grows up. I want her to be educated…the first thing that I want is seeing her go to school. (P4:50)* *…we need schools in the villages. (P10:19)* *…a suitable school where she can get helped. (P5:56)* *…I would like to see is educational facilities for children like this one… (P10:19). I expect to see a crèche and a school that is appropriate for a child like this…(P11:98)* *I think of that every day, she has to go to school but I do not know which school…(P12:153)* *…we humbly ask the government to print all information in Braille as well…we request that they make sign language a compulsory subject at school… (P16: 61-62).*
Community -municipal services	Housing Recreational facilities Societal acceptance Promotion of human rights	*…I wish they can build them houses…(P4:46)* *…what I want is a place where these children can gather. (P9:100)* *…we should just accept one another. (P16:91)* *…we are also human beings… when we talk of human rights, it affects us as we are also human…(P16:27 &32)*

3.2.3.8 Question 8: How do you cope with the pressures of having a CWD?

Concept: Caregivers' coping strategy

This concept was derived from eight codes and four categories as displayed in Table 3.15. There are no subcategories for this concept. Caregivers used different coping strategies such as acceptance, patience, *fait accompli* attitude, and religious beliefs.

Table 3.15 Caregivers' coping strategy

Category	Code	Quotation
Acceptance	Accept	*…I have since accepted it…I have accepted my child, and I am still accepting her…(P4:13)* *…I accepted what I was told because I had seen children with the same condition and even those who were worse than her. (P5:31)* *…we have to learn to accept that something like this happens. (P11:81)* *…when God gives you something you just have to accept because you did not choose…(P12:93)* *…it is nobody's fault. We should just accept it as is…(P16:91)*
Patience	Be patient	*…I just have to be patient like they said she would be slow... (P7:25)*
Fait accompli	Did not choose Did not request	*I did not feel bad because I did not choose to have a disabled child…what gives me courage is the fact that when God gives you something you just have to accept because you did not choose…(P12:21 & 93)* *…we should not forget that disability is not something that you can request or buy. (P16:93)*
Religious belief	I thank God Gift from God I was given God's decision	*…I thank God for everything…(P1:11)* *…I told myself that it was a gift from God; there are many people out there who need a child and are not getting any…(P4:13)* *…I just have to feel good because this is a gift that I was given. (P7:57)* *….when God gives you something… (P12:93)* *…disability is God's decision…(P16:91)*

3.2.5.9 Question 9: What are your sources of support?

Concept: Caregivers' source of support

This concept was derived from 20 codes, four subcategories and two categories. There are caregivers who reported having adequate sources of support (Tables 3.16 and 3.17) while others reported absence of support (Table 3.18).

The adequate support category comprises of religion, family and neighbors, health-care services, and community-based services. On the other hand, there are caregivers who reported not to have received any form of support from anybody.

Table 3.16 Caregivers' source of support (1)

Category	Subcategory	Code	Quotation
Adequate support	Religion	Belief in God Praying Church ZCC	*… I thank God for everything because I know that one day my child will eventually walk. (P1:11)* *…there is no other place where we can get help except for the hospital and praying. (P3:41)…I told myself that it was a gift from God…(P4:13)* *…I should not give up because God is the answer, and my child will walk and feed herself one day. (P6:73)* *Praying makes me strong. I put everything before the Lord; Bible gives me strength. (P11:94)* *What gives me courage is the fact that when God gives you something you just have to accept (P12:93)* *…it is only God and the professionals who know whether she will walk or not. (P13:15)* *…when I am at church they accept my child, and you can see that they love her, they play with her and try by all means to make her happy. They accept the child's condition…(P3:45)* *…I normally run to this other lady that we attend church together. We pray and fast for the child together. (P11:87)* *…I go to ZCC…they pray for her and sometimes stretch her…I take her to church…every Sunday. (P12:173. 177 & 181)*
	Family and neighbours	Home Child's father People I stay with Grand-parents Mom Parents	*…I am only getting support at home…the child's father…he is the one who is mainly supporting me… (P3:33 & 37)* *I get it from the people I stay with. (P6:69)* *…I am raising her with the help of all her grand-parents…(P7:27)* *My family has accepted the condition and has supported me a lot since the child was born. (P11:83)* *My mom used to bring her when I was not around…Regardless of whether they are angry at me they still care for the child. (P12:27 & 101)* *…If it was not for my parents, I would still be sitting at home not knowing what to do. (P13:117)*
		Neighbours	*…neighbours…they keep on telling me that I should not give up because God is the answer…(P6:71-73)* *…as of my neighbours I can see that they are hurting, they are concerned…(P:11:81)* *…I can say that even the children that play with her at home love her, they laugh with her, carry her, and you can see that they have accepted her. (P3:49)*

Table 3.17 Caregivers' source of support (2)

Category	Subcategory	Code family	Quotation
Adequate support	Health-care services	Hospital Professionals Physio	*…he says I should only come to the hospital because there is no other place where we can get help except for the hospital…(P3:41)* *There is no other form of assistance except for the hospital. (P6:15)* *I get much assistance from the hospital... (P: 8:15)* *I get support from the professionals in the hospital because they encourage me at times… (P10:43)* *…physio. That is where my hope is, and it is only God and the professionals who know whether she will walk or not. (P13:15)*
	Community-based services	Home based carers	*…they tell me that I am not the first one to have a disabled child, and I should not give up…(P6:77)*
		Support group	*…sister S had just started a support group for mothers of CWDs. (P9:102)*
		Other caregivers	*…there are many that we meet. I even ask them a question because my child is still small, and theirs are big, and they tell me. I did not know that there is a place called CP clinic…(P9:94)*

Table 3.18 Caregivers' source of support (3)

Category	Subcategory	Code family	Quotation
Absent support		No one There is nothing No support	*I do not think there is anything that they can do to help. (P1:19)* *…there was no one to advise me to go to the hospital…maybe it is just my imagination but there is nothing in my community as I am the only one with a child like this. (P5:27 & 98)* *…we only meet when we come for treatment. It is not good because we were supposed to be friends as our children have the same condition. (P7:85)* *…there is no support…(P13:117)*

3.2.3.10 Question 10: How are you and the child perceived in the community?

Concept: Societal perception of CWDs

This concept was derived from 18 codes, nine subcategories, and two categories as indicated in Table 3.19. The society had both positive and negative perceptions towards CWDs and their caregivers.

The positive perception consists of love, care and support. Negative perception consists of name-calling, hatred, ridicule, stare, gossip, and fear of CWDs.

Table 3.19 Societal perception of CWDs

Category	**Subcategory**	**Code**	**Quotation**
Positive perception	Love Care Support	Perception ok They stop They lift her They wave They love her Show love They are friendly to me and child They care They feel for you Not saying anything bad	*The perception is ok. It is just that we do not travel much… (P7:59)* *Even when people are in a hurry, and she calls them they stop to lift her or wave their hands to show that they love her. (P3:53)…show her love… (P4:13)* *…they are very friendly to me and the child. They care. (P5:80)* *…but there are those who feel for you. Those who say what if it was me, those who say why I should laugh… (P9:110)* *…those that are not saying anything bad appreciate the fact that I love my child… (P12:129)*
Negative perception	Name calling Hatred Ridicule Stare Gossip Fear of CWDs	Cripple Not considered normal Not seat next to child Laugh at the child Look at you Stare Talk behind your back Terrified	*…there are those who say I have given birth to a cripple…(P13:161)* *…they only give the so-called "normal people" and we are not considered normal…(P16:50)* *…there are those who do not want to sit next to your child…(P9:110)* *Many people in my community laugh at my child…(P1:19)* *They look at you but when you look at them, they turn (P6:45).* *…commuters in a taxi stare at my child and that makes me sad…(P10:33)* *…but there are stupid ones who talk because they do not know what tomorrow will bring, they do not know what tomorrow will bring to them…(P12:129)* *It terrifies them yet it is nobody's fault…(P16:91)*

3.3 INFORMATION OBTAINED FROM REHABILITATION PROFESSIONALS

In this section, results obtained during the interviews with rehabilitation professionals are presented. These results include rehabilitation professionals' demographic information and the emerging concepts. Results on the following emerging concepts are introduced: (1) role of caregivers, (2) available services for CWDs, (3) challenges experienced by CWDs, (4) role of rehabilitation professionals, (5) rehabilitation professionals' competency, and (6) factors affecting rehabilitation professionals' work ethic.

3.3.1 Rehabilitation Professionals’ Demographic Information

A total of eight rehabilitation professionals agreed to participate in the face-to-face interviews. They comprised seven staff members from the physiotherapy and the occupational therapy department as well as one nursing professional who had a special interest in the management of CWDs. A data sheet (Appendix T) was used to collect the rehabilitation professionals’ age, gender, profession, occupation, qualifications and their work experience. A summary of the demographic information is presented in Table 3.13.

Table 3.20 Rehabilitation professionals' demographic information

Code	Age	Gender	Profession	Occupation	Qualification	Experience
Prof 1	46	Male	Occupational therapy technician	Occupational therapy assistant	Diploma in Occupational Therapy Assistant (Community)	10 years
Prof 2	26	Female	Occupational therapy	Occupational therapist	Bachelor of Occupational Therapy	3 years
Prof 3	47	Male	Physiotherapy therapy assistant	Principal physiotherapy therapy assistant	Registered with HPCSA (No formal qualification)	25 years
Prof 4	23	Female	Occupational therapy	Occupational therapist (community-service)	Bachelor of Occupational Therapy	5 months
Prof 5	30	Male	Physiotherapy	physiotherapist (community-service)	Bachelor of Science in Physiotherapy	5 months
Prof 6	43	Female	Occupational therapy assistant	Occupational therapy assistant	Diploma in Occupational Therapy Assistant (Community)	10 years
Prof 7	26	Female	Occupational therapy technician	Occupational therapy assistant	Diploma in Occupational Therapy Assistant (Community)	4 years
Prof 8	56	Female	Nursing	Professional Nurse	Diploma in General Nursing, Paediatric Nursing, Community Health, Nursing Administration, Midwifery, and Nursing Education; Bachelor of Nursing Science, Master of Nursing Science	35 years

3.3.2 Development of Concepts from Rehabilitation Professionals

In this subsection, the results from the face-to-face interviews with rehabilitation professionals are presented. Results emanate from the perspectives of the rehabilitation professionals following the face-to-face interviews which were based on six guiding questions (Appendix K). The developing concepts, question asked and the results consisting of quotations from participants, codes, subcategories and the categories are presented.

3.3.2.1 Question 1: What is the role of caregivers during the rehabilitation of CWDs?

Concept: Role of caregivers

This concept was derived from 19 codes, eight subcategories and two categories. Caregivers played two leading roles where they supported the child (passive care) and ensured that there was continuity of care (active care). The caregivers showed support by loving and caring for the child as in Table 3.21. The caregivers ensured continuity of care by learning new skills, performing hands-on role, demonstrating their newly acquired skills to professionals, conducting home programme, and being the main role player throughout the rehabilitation as summarised in Table 3.22.

Table 3.21 Role of caregivers (1)

Category	Subcategory	Code	Quotation
Support the child (Passive)	Love	Be a mother Love the child	*…being mother, a caring mother, a loving mother… (P24:69)*
	Care	Care for the child	

Table 3.22 Role of caregivers (2)

Category	**Subcategory**	**Code**	**Quotation**
Continuity of care (Active)	Learn	They watch She looks Next to me	*…the mothers watch what we do…(P18:66)* *Their role is to watch everything that we do with the patient…(P20:91)* *She has to be standing right next to me and looking at what I am doing…(P26:52)* *…I want the mother right next to me…(P28:68)*
	Hands-on	To rehabilitate Play with child	*…they involve themselves in the rehabilitation of their children…(P20:93)* *…the role of the caregiver is to rehabilitate the child…(P24:69)* *I encourage those mothers to play and talk to the children as they treat…(P28:72)*
	Demonstrate	To show us Mimic To show me Verify	*We expect these mothers to show us what we just showed them…(P18:66)* *…to perform what we have shown them at the end of the day. (P20:91)* *…to mimic what I am doing with the child. (P26:58)* *…I ask the mothers to show me the home programme that they have been taught before…demonstrating to me… (P28:68)* *…we check if the caregivers are doing the whole programme correctly… (P30:92)*
	Home programme	Home programme	*… We then show them home programmes…(P18:66)* *…perform all the home programmes that they have been given in the clinic…(P20:93)* *…they do as part of their home programme…(P24:61)* *…I ask the mother to show me the home programme that they have been taught before… (P28:70)* *…If I feel like there is something that has to be changed on the home programme, I change it. (P30:94)*
	Assume professionals' role	Empower with professional skills Continue with treatment They do we do Do what professionals do	*…empower them with some of the skills that we have as professionals. (P20:99)* *…they should continue with the treatment that we give them… (P22:64)* *…they cannot be as good as I do it, but they do it at an acceptable pace…(P26:68)* *…the mother should learn to do what health professionals do…(P31:57)*
	Main role player	Spend more time with the child Mothers are main force	*…they are the ones who have a bigger role to play at home than us as they spend a lot more time with these children than us…(P22:58)* *As mothers, they are the ones who spend most of the time with the kids. The children can only get full rehabilitation at home because parents are the ones who spend most of the time with them…(P24:67)* *… These mothers are the main force but if they have attitude and don't want to do a thing then the child will only be treated once a month and will not benefit from the services we offer.(P29:21)* *The mother is the one who spends most of the time with the child. (P31:57)*

3.3.2.2 Question 2: What services are available for children with disabilities and their caregivers in Giyani?

Concept: Available services

This concept was derived from eight codes, five subcategories and three categories as shown in Table 3.23. The three categories are health-care service, community-based service, and social service. The health-care service consists of hospitals. Community-based service comprises of disability group, CRWs, and special schools. Social service consists of social grants.

Table 3.23 Available services

Category	**Subcategory**	**Code**	**Quotation**
Health-care services	Hospitals	Hospital Evuxakeni Hospital	*I am not sure what is available outside the hospital…(P23:14)* *…there is Evuxakeni…(P25:17)*
Community-based services	Disability group	Albinism group	*…except for the albinism group that is there but I do not know what is happening in that group.(P23:14)*
	CRWs	Community rehab people CRWs	*…there are also people working outside as rehab people. (P19:11)* *…or refer them to CRWs who will do home visits…(P22:48)*
	Special schools	Pfunanani Special School Special schools	*There is Pfunanani Special School, which is the school that many of the children that we discharged or those that are fit for school goes to. This school accommodates all categories of CP children…(P17:11)* *The special schools…(P21:21)* *…I do not know of any other available services except for the Pfunanani Special School…(P25:13)* *There is not much in Giyani except for the special school…Pfunanani Special School is for children with mental retardation only. (P27:13)*
Social services	Social grants	Disability grants	*…we also assist them in getting disability grants so that they can bring their children for treatment…However, now that there is SASSA, we refer them to doctors who will complete SASSA forms (P22:44 & 46)*

3.3.2.3 Question 3: What are the challenges that caregivers and CWDs experience?

Concept: Challenges experienced

This concept was derived from 43 codes, 22 subcategories and four categories. The four categories are child related, family-caregiver related (Table 3.24, on page 102), health-care related (Tables 3.25, on page 103; 3.26, on page 104 and 3.27, on page 105), and community related (Table 3.28, on page 106). The child related category consists of nutrition as a subcategory. Family-caregiver related subcategory contains information, family support, motivation and commitment, and transport. Health-care related subcategory comprises staff attitude, communication, teamwork and collaboration, staff burnout, Hands-on role, uniformity, staff continuity, leadership and management, therapist-assistants infighting, human resource planning, awareness campaigns, duration of treatment, caregiver support, infrastructure, equipment and material, and budgetary constraints. Community related category include inadequate special schools and recreational facilities.

Table 3.24 Challenges experienced (1)

Category	Subcategory	Code	Quotation
Child related	Nutrition	Struggling to feed	*…they are struggling to feed the children because some of those children cannot chew…(P30:118)*
Family-caregiver related	Information	Lack of information Do not understand Not informed	*…maybe it is because of the lack of information…(P18:88)* *…the one thing that they expect is to see improvement; they expect to see the child grabbing something. They expect this without checking the child's condition. (P20:89)* *…they do not understand their child or grandchild's condition…(P22:60)* *…they do not understand that CPs [cerebral palsy] are different even if you explain to them that the conditions are different...(P24:63)* *…the mother had no information about the child's condition… (P28:134)* *Those caregivers are not informed about the nutritious food that they should be giving to their children…(P30:118)*
	Family support	Victimisation of mothers Outcasting of mothers	*…many of those women had marital problems after giving birth to a child with disabilities. The in-laws would even tell them that we do not have a crippled child in our family…(P17:72)* *Some of the caregivers experience many problems after giving birth to a disabled child to the extent that they even lose their marriages…(P27:40)*
	Motivation and commitment	Not committed Not motivated Receiving bad treatment	*…When parents are committed, the child can go to school some even go to normal school even though they might have jerky movements…(P28:128)* *…It is not all parents who are like that, but there are those that are not committed. It hurts me when I see a child with potential; a child who stands a better chance of walking but the parent is not committed…(P29:28)* *…the caregivers tend not to have motivation because it is long that they have been coming to the clinic. (P20:157)* *…the mothers want quick results…(P24:63)* *…they used to come in large numbers, but these days they say they will not come because of the bad treatment that they get. (P28:80)* *We used to get hold of the old patients who benefited in the CP clinic to come and motivate those who are new…Some are demotivated…(P30:73 &140)*
	Transport	Transport	*…mothers complained of transport…(P28:112)*

Table 3.25 Challenges experienced (2)

Category	Subcategory	Code	Quotation
Health-care related	Staff attitude	Not willing to treat Not getting rural allowance Play computer game	*You sometimes find that you are not willing to treat the child and you just tell the mother to go and do what they have been taught to do without touching the child…some of them are just not willing to go to the villages. As assistants we used to go out but we stopped when some said they cannot go anymore because they were not getting rural allowance, those that get rural allowance should go…some of my colleagues just rush for the computer after seeing one child and say to the mother to continue with therapy at home… (P28:34, 84 & 134)*
	Communication	Not sure what colleagues do Discharging patients without MDT knowledge No discussions	*…if the colleagues that are responsible for doing the home visits do them, maybe they can come and report back…I'm not even sure whether they are going to the same homes of the people who are coming here…(P26:103)* *…some of my colleagues are even discharging patients without telling us and when you happen to meet those discharged patients and ask them why they are not coming they will tell you I have been discharged…we don't even have time where we sit and discuss about the patient (P28:76 & 134)*
	Teamwork and collaboration	No MDT No teamwork	*…I think it was going to be better if we involved all the other professions because it is a CP clinic of two active departments that is Physio and OT. The other professions are only seeing the patients when the Physio and OT refer to them. (P20:151)* *…there is a need for other disciplines to be part of the clinic because it is only Physio and OT. Physio and OT alone can not meet the needs of those children… (P21:32)* *…there is not enough of a multidisciplinary team (MDT)…Everybody had to be there; a dietician, a social worker, occupational therapist (OT) and physiotherapist (Physio) in order to discuss whether patients need their services or not (P25:51)* *…I think we are not working as a team with colleagues in the CP clinic. Where I used to work before, we worked as a team, and I enjoyed it but the way we do it here you'll end up hating CP clinic. (P29:24)…we used to work as a team comprising Physio, OT and other professionals…. I have been here for a year, and there is no such thing as MDT. (P30:51, 53).* *…we should integrate fully and work in one place. After assessing the child we should discuss what I have identified and talk about what we can do to address the needs of that child because at the moment I only write a referral for the child…(P31:85)*
	Staff burnout	Just stopped	*I cannot really say what happened it just happened. I think some of us who were in the forefront just stopped doing it. (P17:29)…*

Table 3.26 Challenges experienced (3)

Category	**Subcategory**	**Code**	**Quotation**
Health-care related	Hands-on role	Not willing to treat the child Without touching the child	*…you sometimes find that you are not willing to treat the child, and you just tell the mother to go and do what they have been taught to do without touching the child...When you do that it negatively affects the relationship that you have with the child's mother. It is not nice because the mother will think of the money that she has spent coming (P27:34)*
	Uniformity	We treat differently	*…we are now many, and we treat differently. Some mothers are not comfortable with the way in which they are treated by my colleagues and some of them never come back for therapy…(P28:76)* *…there was uniformity as well. I complained that a parent will be told in the CP clinic to do what they have been showed to do as their programme only to find that another professional has showed the very same parent a different activity to do and these parents ends up overwhelmed and confused…(P30:75)*
	Staff continuity	Therapist keeps changing	*…we do not see the same mothers every time because we rotate. (P24:71)* *Our therapists keep on changing, and they all come with their own styles. I think the older therapist should tell the new ones that this is how we work…(P28:88)*
	Leadership and management	No visionary leaders Unconcerned managers	*… if we had visionary leaders with compassion…there is no support at all…I don't think the clinical manager or the CEO knows that we have a clinic of this nature…(P18:93, 95 & 99)*
	Therapist-assistants infighting	Degree-certificate discrimination Not valuing assistants Not involving assistants	*…I cannot suggest what to do to a person with a degree while I only have a certificate. They think I have no value…they take it as if you are teaching them to do their job…when somebody comes here and do it his or her own way there is nothing that you can do, you just have to follow otherwise they will charge you with subordination… (P28:88 & 98)* *…the people that I worked with were passionate about work…they involved us…(P30:51)*
	Human resource planning	Insufficient staff Trained personnel not placed	*The first thing is human resources; we don't have enough staff as I'm alone. When I'm on leave or not around, nobody takes care of the kids…There is also a need to create posts because there are no posts we just work...The nurses that we have trained are not being placed... (P31:83, 94 & 129).*
	Awareness campaigns	No CP awareness No awareness campaigns	*The district used to have CP awareness in Giyani…We also used to have our own awareness...the last CP awareness that we had was…two years back. (P18:83 & 85)* *We used to go out to the communities to have awareness campaigns and educate people out there, but all of sudden PHC is doing that…(P31:96)*
	Duration of treatment	Time not enough	*The time that we use is not enough; one day is not enough to see all those children and caregivers…(P21:13-14)*

Table 3.27 Challenges experienced (4)

Category	Subcategory	Code	Quotation
Health-care related	Caregiver support	No support group No home visits No support visits	*… we should also have support groups for those mothers where they would encourage one another as well as running some small projects where they would raise money that the can use for those children. (P17:72)* *…the other thing is we do not even have follow-ups at home to check on the mother if ever they are doing the home programmes that they have to do. (P19:33). Things like support group should be there things like courses or education where they will all gather as a group in one day should be made available… I think the hospital should have a programme where there would be support group day once a month or after two months (P20:163 & 165)* *…there is a rehab centre at Dzumeri, but we have never featured it anywhere. As health providers, we should at least be visiting them… (P21:25)* *... we do not have a support group programme…(P24:101)* *We used to have a support group where we would meet mothers on these children and involved them in everything, and they would tell us what they expect from us as well as gauging their satisfaction…but now we don't have those meetings anymore…(P28:78 & 80)* *We had a support group every three months just to get them motivated.(P30:71)*
	Infrastructure	No colourful rooms No dedicated therapy room	*…we do not even have a colourful environment for these children. (P18:92)* *…our clinic…is not conducive for therapy because there are so many things inside. When you are busy with the children they quickly get distracted by some of the things that are in the room…(P21:31)* *…now they have given somebody an office which used to be a treatment room, the room that we use for CP is also used for hand injuries…there is no group room as it is now an office, there is no space anymore where we can sit and have meetings with the mothers and talk about issues that concern them. (P28:136 & 143)*
	Equipment and material	No toys No equipment	*…If you can go and check in our clinic, we don't have toys and equipment to work with…(P18:92)* *…some of our equipment get stolen. When you look for the equipment when the patients comes, you'll find that they are missing, meaning that they are lost. (P19:23)*
	Budgetary constraints	No budget Financial challenge	*Again we don't have a budget to buy toys and equipment which we use for these kids. (P17:57)* *The only thing that I can think of that can affect us is financial challenges because we need to buy equipment for the children. When you work with CPs, you tend to think of equipment and financial wise that is a challenge in the hospital. (P19:31)*

Table 3.28 Challenges experienced (5)

Category	**Subcategory**	**Code**	**Quotation**
Community related	Inadequate special schools	Schooling problem Use of normal crèches Few special schools School not appropriate	*…there is a schooling problem for small children with CP...When they send them to normal crèches, they send these children back because they cannot manage them. (P18:114 & 116)* *…I think we should also have a lot of special schools with remedial teachers so that disabled children can go to school closer to their homes. There is a need for remedial teachers because many of the disabled children are taught at school and crèches by ordinary teachers who do not know how to meet the need of children with CP…(P21:29)* *…wanted to go to school but they could not because their children were rejected at crèches…(P28:110)* *…we have a backlog of children who need to be placed at special schools…some of the challenges are beyond us just like the schools…(P31:126 & 133)*
	Recreational facilities	No aftercare centres	*There is a dire need for aftercare centres…others need after care centre that we do not have; this is one of the major challenges that we have…(P31:118 &126)*

3.3.2 4 Question 4: What is your role as a rehabilitation professional during the rehabilitation of CWDs?

Concept: Role of rehabilitation professionals

The role of rehabilitation professionals was derived from 20 codes, nine subcategories and five categories as shown in Tables 3.29 (on page 108) and 3.30 (on page 109). The five categories are examination, support, skills training, rehabilitate and follow-up. Examination category consists of screening and assessment. Support category consists of counselling and support. Skills training category consists of caregiver education. Rehabilitate category comprises hands-on role, issuing of assistive device, referring, and issuing of home programme. The follow up category include conducting home visits.

Table 3.29 Role of rehabilitation professionals (1)

Category	**Subcategory**	**Code**	**Quotation**
Examination	Screen and assess	Screen newborn babies Test babies Assess	*…sister S screen newborn babies from the maternity ward and she identify defects in the children...(P17:21)* *…what we know is that she screens and tests babies for genetic problems immediately after birth at maternity ward… (P21:34)* *…she also checks where the problem comes from, whether it has been inherited or not (P27:23)*
Support	Counsel	Counsel	*…we tell them to accept their condition that it is not a sin to get a disabled child and we counsel them…(P22:58)* *We also counsel…(P27:38)* *…we assist them with counselling…we request those mothers to come back to us for continuous counselling and to meet other mothers where they share their problems and resources…(P31:31 & 37)*
	Support	Encourage Provide support	*…we also encourage them not to stop coming because change takes time. (P22:66)* *…and encourage them to rehabilitate their kids because as mothers; they are the ones who spend most of the time with the kids than us…giving the mother and child emotional support. (P24:67 & 75)* *…encourage, support…(P27:38)* *We also provide them with support. (P31:33)*
Skills training	Education	Teach Educate Explain Train Guide	*…we also teach the mothers how to handle the kids at home as well as exercising them…(P18:62)* *…our other role is to educate the mothers about their children's conditions…(P20:99)* *…we explain to them what their children's or grandchildren's conditions are…(P22:58)* *We try to explain to them and encourage them to rehabilitate their kids…(P24:67)* *…we teach the caregivers…(P26:48)* *…and train the caregivers on how to care for their children…(P27:38)* *…we are just here to guide them with the expertise that we have…(P29:21)*

Table 3.30 Role of rehabilitation professionals (2)

Category	**Subcategory**	**Code**	**Quotation**
Rehabilitate	Hands-on role	Mobilise child Facilitate Stretch Treat Use different techniques	*We are offering rehabilitation services where we mobilise children, and facilitate…..Some children come with contractures, and we stretch those contractures using back slabs…(P18:62)* *…we treat them…(P22:44)'* *…It is rehabilitation, treating the kids…(P24:75)* *…we use different kinds of techniques to treat them for their development…(P26:48)*
	Issue assistive device	Assistive device	*…and issuing assistive devices. (P24:75)*
	Refer	Refer	*…we refer kids to them. (P18:52)* *If we assess the child and find that there is a hearing or eye problem, we refer to the speech-therapist or optometrist. (P20:133)* *…we do refer clients to those other disciplines…(P21:32)…when we identify the social problem, we refer them to social workers or straight to the doctors who will assist them with a disability grant…(P22:46)* *Referring them to relevant health professionals, for example, dieticians, and dental. (P24:79)* *…refer to other health professionals based on the needs that we have identified. (P31:31)*
	Home programme	Home programme	*… we then show them home programmes…(P18:66)* *…ask the caregivers if they are performing the home programme that we gave to them…(P20:85)* *…we teach the mothers of these children to do home programmes such as positioning… (P22:52)* *…we teach the caregivers as well so that they can do the home programme when they are at home…(P26:48)*
Follow-up	Conduct home visits	Home visits Home follow-up	*…we also do home visits where we do follow-ups on what we have showed them in the hospital…(P18:64)* *…after discharging them, we do follow ups at home or refer them to CRWs, who will do home visits. We also do home visits from the hospital… (P22:48)*

3.3.2.5 Question 5: What are the competences of the rehabilitation professionals working in the rehabilitation clinic?

Concept: Rehabilitation professionals' competency

The rehabilitation professionals' competency was derived from 27 codes, nine subcategories and two categories. The two categories include adequate professional competency that rehabilitation professionals have as well as inadequate professional competency that they lack. The adequate professional competency that rehabilitation professionals have includes advocacy, therapeutic, and teamwork and collaboration as summarised in Table 3.31. However through the interviews it was identified that the rehabilitation professionals lacked professional competency such as advocacy, therapeutic, collaboration, communication, management, and professionalism and motivation as summarised in Table 3.32 (on page 112).

Table 3.31 Rehabilitation professionals' competency (1)

Category	Subcategory	Code	Quotation
Adequate professional competency	Advocacy	Home visit in addition to hospital	*…we also do home visits where we do follow-ups on what we have showed them in the hospital…(P18:64)*
		Referral in addition to treatment	*…when the treatment fails we send them for services such as care dependency grants where they get money that will assist in attaining their daily needs. We also assist them in getting disability grants so that they can bring their children for treatment…after discharging them we do follow-ups at home or refer them to CRWs who will do home visits…(P22:44 & 48)*
	Therapeutic	Train caregivers	*…train the caregivers on how they can look after their children…(P27:38)*
		Exercising	*…we also teach the mothers how to handle the kids at home as well as exercising them…(P18:62)*
		Use different techniques	*…we use different kinds of techniques to treat them…(P26:48)*
		Mobilise	*…we mobilise children…(P18:62)*
		Treat Give emotional support Issue assistive device	*…It's rehabilitation, treating the kids, giving the mother and child emotional support and issuing assistive devices.(P24:75)*
		Maximize independence	*…maximise people's independence. (P22:40)*
	Teamwork and collaboration	Teamwork Collaboration	*Two professionals (occupational therapy assistant and a community service physiotherapist) conducted the treatment session for the day (P77:08)*

Table 3.32 Rehabilitation professionals' competency (2)

Category	**Subcategory**	**Code**	**Quotation**
Inadequate professional competency	Advocacy	No additional support groups No additional awareness campaigns No additional home visits	*… we should also have support groups for those mothers where they would encourage one another as well as running some small projects where they would raise money (P17:72)* *We used to go out to the communities to have awareness campaigns and educate people…(P31:96)* *…we do not even have follow-ups at home to check on the mother if ever they are doing the home programmes… (P19:33). Things like support group should be there things like courses or education where they will all gather as a group in one day should be made available… (P20:163)* *…If there were some support groups they could benefit...(P24:101)* *We used to have a support group…However, now we do not have those meetings anymore…(P28:78 & 80)* *…we had a support group every three months just to get them motivated.(P30:71)*
	Therapeutic	Not touch the child Late diagnoses No prevention No promotion	*…you just tell the mother to go and do what they have been taught to do without touching the child you see…(P27:34)* *…we only identify problems when it is too late that is why we need to prevent and promote. (P31:129)*
	Collaboration	No MDT No integration No teamwork	*… it was going to be better if all the other professions were involved because it is a CP clinic of two active departments that is Physio and OT…(P20:151)* *…there is a need for other disciplines to be part of the clinic because it is only Physio and OT…(P21:32)* *…there is not enough of MDT…(P25:51)* *…I think we are not working as a team with colleagues in the CP clinic…(P29:24)* *…we should integrate fully and work in one place.(P31:85)*
	Communication	Discharging patients without MDT Poor communication	*…some of my colleagues are even discharging patients without telling us, and when you happen to meet those discharged patients and ask them why they are not coming they will tell you I have been discharged. We do not even know they were discharged, but there is nothing (P28:76)* *I was equally disappointed as the physiotherapy assistant about the poor communication between the two clinics. (P40:10)*
	Management	Poor human resource management	*…the nurses that we have trained are not being placed and once you are not given a chance to do what you have been trained in; you lose interest and focus…(P31:94)*
	Professionalism and motivation	Not willing to treat Not working	*…you sometimes find that you are not willing to treat a child, and you just tell the mother to go and do what they have been taught to do without touching the child you see… (P27:34)* *…these days they are not telling us to go, so we just sit and not do anything as if we do not know our things…(P28:126)*

3.3.2.6 Question 6: What are the factors that affect or influence your commitment to your work in the clinic?

Concept: Factors affecting the rehabilitation professionals' work ethic

This concept was derived from 23 codes, 13 subcategories, and two categories as shown in Tables 3.33 and 3.34 (on page 115). The two categories include factors that positively and negatively affect the rehabilitation professionals' work ethic. The positive factors consist of the rehabilitation professionals' sense of ownership, results they see on CWDs, availability of facilities in the hospital, working with children, and caregivers' commitment and compliance. The negative factors consists of the commitment of colleagues, managerial support, budgetary constraints, commitment and compliance of caregivers, results that rehabilitation professionals see on CWDs, referral pattern, working far from home and the lack of learning opportunities.

.

Table 3.33 Factors affecting rehabilitation professionals' work ethic (1)

Category	Subcategory	Code	Quotation
Positive factors	Ownership	I started the clinic	*The first thing that gives me the courage is the fact that I started the clinic…(P17:37)*
	Results	Something happens There is a change Discharged children Others walk Functional Improvement of the child	*…the book says you can work with the child for twenty years, and nothing will happen but I have come to realise that something does happen…everything that we do on those children brings about change. Seeing the change on those children's lives and seeing those children progress is one of the things that give me courage… there are many children that we have discharged; some are fine now others can even walk. (P17:37, 39 & 41)* *…When you start seeing the child being independent and walk you get excited and commit yourself to your work… (P21:36)* *…I get some fulfilment when my services help people to get better and be functional…(P25:35)* *…when you see an improvement on the child that you treat, reaching the goals that you have set gives you the energy to continue and to say to yourself that I am actually doing something…(P27:32)* *…when I remember seeing the first child that I started treating to walk, I was so excited and that I did something to that kid…looking at both the mother and the child's face it makes you feel……the feeling is priceless. You feel like I did something, you feel like you have done something even though you are getting paid to do what you do…(P29:36 & 37)*
	Availability of facilities	There are facilities	*…there are facilities even though some of them are damaged, but all in all we do have facilities to use in the hospital. (P20:57)* *…my department has got the facilities that we need. We might be short sometimes but there as an OT we have to improvise on some of the things that we do not have…(P26:29)*
	Children	The love of children	*…I love working with children because when you work with children you never face as many problems as compared to adults. When you treat children, there is not much that they think of, they hardly think of why you are doing what you do…(P22:42)*
	Caregivers' commitment and compliance	Mothers' commitment Mothers' compliance	*I am influenced by the mothers' commitment and their attendance. I get very excited when I see those mothers doing the home programme exactly as I have shown them to do… (P27:31)*

Table 3.34 Factors affecting the rehabilitation professionals' work ethic

Category	Subcategory	Code	Quotation
Negative factors	Commitment of colleagues	Commitment of colleagues	*…what discourages me; the first thing is the commitment of my colleagues…(P17:47)*
	Managerial support	Lack of support of management	*…we do not get support from the management. They never visit us to check what our challenges are. (P17:53)*
	Budgetary constraints	Budgetary constraints	*Again we do not have the budget to buy toys and equipment…(P17:57)* *The only thing that I can think of that can affect us is financial challenges because we need to buy equipment for the children…(P19:31)*
	Commitment and compliance of caregivers	Mothers' commitment Defaulting on appointments Not following programme	*Sometimes it is the mothers' commitment you see…(P29:21)* *…It is frustrating because you never know if they will be coming for their appointments or not. Sometimes they come in larger numbers than expected as they often default on their appointment date and come the following week. (P23:31)* *…it is just that you sometimes find that they are not following the programme…they only treat those children when they are here but at home they do not do anything. (P24:61)*
	Results	Slow progress No improvement	*…progress on the child is very slow. As a therapist, you'll find that you have been seeing this child for a year, and nothing has improved…(P24:85)* *…if nothing happens you will keep on asking yourself whether it is your fault or the mother's fault that there is no improvement. (P27:32)*
	Referral	Fewer referrals No seeing patients	*…we get very few referrals in a week. I can spend a day or two without seeing a single patient, not that I want them to get sick or anything but that lack of work, me not having any work to do is a little demotivating…(P25:40-41)…what I can say I am not comfortable with is the level of…let me say busyness. I am not saying I want the patients to get sick, but I understand it is a new hospital, and it is very small and not too many patients are coming in…(P26:27 & 77)*
	Working far from home	Working far from home	*The place is workable [it is ok] but as a mother I prefer working closer to home. I want to leave it is just that I do not have the transfer as yet but if possible I would like to work closer to home so that I can go home every day after work. (P28:41)*
	Learning opportunities	No opportunities to learn	*…there I had a bigger opportunity to learn, here… I guess the people that I worked with were passionate about work, and they were always motivated. They were also training student, and they involved us. I was also lucky because we had a deputy manager, and I got to learn a lot from different people (P30:47 & 51)*

3.4 INFORMATION OBTAINED FROM COMMUNITY REHABILITATION WORKERS

In this section results obtained during the interviews with CRWs are presented. These results include CRWs demographic information and the emerging concepts. Results on the following emerging concepts are introduced: (1) role of caregivers, (2) role of CRWs, and (3) role of rehabilitation professionals.

3.4.1 Community Rehabilitation Workers' Demographic Information

Two CRWs agreed to participate in the face-to-face interviews. A data sheet (Appendix T) was used to collect the CRWs demographic information such as age, gender, profession, occupation, qualification and experience as summarised in Table 3.35.

Table 3.35 Community rehabilitation workers demographic information

Code	Age	Gender	Profession	Occupation	Qualification	Experience
CRW1	40	Female	OTA	CRW	Diploma OTA	12 years
CRW2	41	Male	OTA	CRW	Diploma OTA	12 years

3.4.2 Development of Concepts from Community Rehabilitation Workers

In this subsection, the results from the face-to-face interviews with CRWs are shown. Results emanate from the perspectives of the CRWs following the face-to-face interviews which were based on three guiding questions (Appendix L). The question, developing concept and the results comprising quotations from participants, codes, subcategories and the categories are presented.

3.4.2.1 Question 1: What is the role of caregivers during the rehabilitation of CWDs?

Concept: Role of caregivers

The role of caregivers was derived from seven codes, four subcategories and one category as shown in Table 3.36. The continuity of care as the only category under this concept is made up of active roles such as to update CRWs on the progress of the child based on what is happening in the hospital, demonstrate their skills to professionals, conducting home programme and to assume the CRWs' role.

Table 3.36 Role of caregivers

Category	Subcategory	Code	Quotation
Continuity of care (Active)	Update CRWs	Give feedback Update CRWs	*…we expect them to give us feedback on our next meeting. They must also update us on what they have been doing in the hospital as we are not the only ones who treat them [children]. (P14:47)*
	Demonstrate	Demonstrate to the professional	*…when these clients get to the CP clinic, they demonstrate to the professional what we have taught them at home…(P15:69)*
	Home programme	Home programme	*…If the caregivers are literate I also give them a home programme to do in the morning, during the day and in the evening… (P15:60)*
	Assume CRWs role	Copy what CRWs do Continue with treatment They should be OTAs	*…the caregivers should copy what we do and keep doing it in our absence… In other words, they should play our role when we are not there; they should be OTAs. (P14:47 & 49)* *…where I am over-committed I just show the family what to do, and they continue designing the corner seat…the main thing that we do is to demonstrate some of our duties to them, and they continue doing it when we are not there because we are not always with them. (P15:54 & 61)*

3.4.2.2 Question 2: What is the role of CRWs during the rehabilitation process of CWDs?

Concept: Role of CRWs

This concept was derived from 12 codes, six subcategory, and four categories as summarised in Table3.37. The four categories are support, skills training, multitask, and rehabilitate.

Table 3.37 Role of CRWs

Category	**Subcategory**	**Code**	**Quotation**
Support	Support	Support Telling them not to be scared	*…ask them how we can help, and they will tell us what they expect…(P14:45)* *…telling them not to be scared, and they understand. (P15:51)*
Skills training	Education	Teach Birth education	*…to have discussions with them so that they can understand that the child is disabled… we will then add on what they have already told us based on the knowledge that we have. (P14:45)* *…we give them birth education about the disability that they are facing in the family…(P15:51)*
Multi-task	Multidisciplinary	Do other professions' duties	*We also do the other professions' duties…Our main function is in OT. The other professions did not require our services as such, but we do take their crutches and POP back slab.(P15:81)*
Rehabilitate	Hands-on role	Use of Physioball Work on parallel bars	*…we know that there are some activities that are only done in the CP clinic because we do not have the equipment in the community, and we can only do some activities at home like the Physioball. (P14:54)* *…If there are parallel bars, we show them what to do on parallel bars…(P15:61)*
	Issue assistive device	Arrange wheelchairs Arrange walking callipers Arrange corner seat Issue crutches	*…We also arrange for wheelchairs and Maclaryn…when there is a need for a corner seat, we design it together with the family… we also issue crutches to clients at home. (P15:54 & 82)*
	Home programme	Home programme	*…we set their programmes…where they struggle with the programme, and we modify it accordingly…(P14:35)* *…we intervene by giving the caregivers home programmes that they should do on a daily basis…(P15:53)*

3.4.2.3 Question 3: What is the role of rehabilitation professionals during the rehabilitation process of CWDs?

Concept: Role of rehabilitation professionals

This concept was derived from four codes, four subcategories, and two categories as summarised in Table 3.38. The two categories are multi-task and rehabilitate. The multi-tasking role consists of complementation of CRWs while the rehabilitating role comprises of issuing of assistive devices, referring, and conducting home programme.

Table 3.38 Role of rehabilitation professionals

Category	Subcategory	Code	Quotation
Multi-task	Complement CRWs' role	No progress when working alone	*…they cannot see progress when working alone because they only see the children once, but we see these children many times at home…(P15:69)*
Rehabilitate	Issue assistive devices	Issue toy	*…they sometimes give children toys to take home with…(P15:69)*
	Refer	Refer	*…when they refer them to us we see them at home…(P15:69)*
	Home programme	Additional activities	*…the professionals in the clinic also give them additional activities to do…(P15:69)*

3.5 INFORMATION OBTAINED FROM THE LAUNCH OF THE GREATER GIYANI DISABILITY FORUM

In this section, results emanating from the launch of the GGDF are presented. Concepts were developed based on the information from the Mayor's prepared speech as well as on the researcher's field notes.

3.5.1 Development of Concepts Based on the Information from the Mayor's Prepared Speech

The Mayor's prepared speech was accessed from the Greater Giyani Municipality's website (www.greatergiyani.go.za). Three concepts were identified from the mayor's prepared statement: (1) role of the municipality towards CWDs, (2) available services for CWDs and (3) challenges experienced by CWDs.

3.5.1.1 Concept: role of the municipality towards PWDs and CWDs

This concept was derived from six codes, four subcategories, and two categories as shown in Table 3.39 (on page 121). The role of the municipality is to commit towards PWDs. However, the mayor has also acknowledged that their current role in meeting the needs of PWDs/CWDs was inadequate.

3.5.1.2 Concept: available services

This concept was derived from five codes, four subcategories and two categories as shown in Table 3.40 (on page 122). The two categories are rehabilitation services and community bases services. Rehabilitation services comprise of physiotherapy and occupational therapy. Community-based services comprise of disability forum and special schools.

3.5.13 Concept: challenges experienced by CWDs

This concept was derived from eight codes, four subcategories, and one category as shown in Table 3.41 (on page 122).

Table 3.39 Role of the municipality toward CWDs

Category	Subcategory	Code	Quotation
Commit toward PWDs	Finance	Increase in financial resources	*…this forum came at a great time just few days after we have passed our IDP [integrated development planning] and budget for the financial year 2010/2011, which saw the municipality increasing the resources towards special programmes, which include PWDs. (P76:11)*
	Address needs of PWDs	Major role to play	*…we must remember that it is us, and only us, who can grasp this chance and make a just and equal society a reality mainly because this is a sphere of government that interacts with PWDs on daily basis. (P76:30)*
	Promote rights and create opportunities for PWDs	Ensure rights of PWDs Provide opportunities to participate in society	*Our task is to explore and improve in working together to harness what we have started and to make equal rights for PWDs a reality…I wish to indicate that PWDs must have their human rights recognised and realised and be given the opportunities like others to participate fully in the communities, and equal rights to pursue their dreams and to develop their talents…as many people here will agree with me out of their own experience that PWDs have equal potential to contribute to the development of society. Given opportunities to participate, receiving vocational training and employment PWDs can change the pace at which we deliver services to our communities. …my own conviction is that children and young PWDs have their own ideas of what they would like to do with their lives, and they are entitled to realise them. (P76:26, 31,33 & 42)*
Inadequate	Acknowledge limitations	Still long walks Still in lower levels	*But we should also acknowledge that there are still long walks together in an effort to see a total emancipation of PWDs…however, it should be noted that PWDs are still in the lower levels [still few]. (P76:25 & 29)*

Table 3.40 Available services

Category	Subcategory	Code	Quotation
Rehabilitation services	Physiotherapy Occupational therapy	Physiotherapy Occupational therapy	*…services provided by the occupational therapy and physiotherapy departments [at Nkhensani] (P75:76)*
Community bases services	Disability forum	Forum for PWDs	*…managed to form a forum inclusive of caregivers of CWDs and PWDs in general. (P75:51)*
	Special school	Pfunanani Special School Nthabiseng Special School	*He is grateful for the local school of intellectually impaired children known as Pfunanani Special School and the newly built Nthabiseng Special School in Phalaborwa. (P75:59)* *…I therefore wish to congratulate the special school at Section A, for their startling work, the last time I was there with MEC for education I saw the enthusiasm and zeal of disabled young people who are full of life and hope. (P76:43)*

Table 3.41 Challenges experienced by PWDs and CWDs

Category	Subcategory	Code	Quotation
Community related challenges	Gender-based discrimination	Discrimination	*…as part of the challenges we should realise that discrimination has its levels, I wish to point out here today that women and girls with disability experience particular problems. They are often confronted with multiple forms of discrimination and tend to be more socially isolated and poorer than their male counterparts. (P76:36-37)*
	Abuse	Living in isolation Risk of violence Abuse	*When women or girls with disability are living in isolation, not only do they not receive services offered by government, they are also at greater risk of violence and abuse. (P76:39)*
	Education	No education Shortage of special schools	*…If a girl with a disability does not receive education, their life prospects are doomed. Their chance of getting any work, let alone meaningful work is diminished…another area of particular concern is the high proportion of children with disability who do not go to school because of various reasons, poverty being one of those shortages of special schools in the nearby areas etc. (P76:38 & 40)*
	Societal perception	Negative attitude Negative beliefs	*…as I conclude I wish to point out that perhaps the first step is changing our attitude and beliefs in relation to PWDs…(P76:44)*

3.5.2 Development of Concepts Based on the Researcher's Field Notes

This subsection is based on the researcher's field notes taken during the launch of the GGDF. The field notes are based on what the researcher observed, heard or saw during the launch. Two concepts were identified: (1) challenges experienced by PWDs/CWDs, (2) societal perception of CWDs and (3) available services for PWDs/CWDs

Concept: available services

The available services concept was derived from four codes and two categories as shown in Table 3.42 (below). There are no subcategories under this concept. The two categories are rehabilitation services and community-based services.

Concept: challenges experienced by PWDs/CWDs

This concept was derived from 12 codes, five subcategories, and one category as shown in Table 3.43 (on page 124). The community challenges identified under this concept include subcategories such as: (1) access to inclusive education, (2) access to water, (3) accessibility of public places, (4) employment opportunities, and (5) abuse.

Concept: societal perception of CWDs

This concept was derived from eight codes, six subcategories, and one category as shown in Table 3.44 (on page 125). The only category under this concept is negative perception which is made up of subcategories such as: (1) intolerance, (2) stare, (3) ridicule, (4) fear of CWDs, (5) witchcraft, and (6) name calling.

Table 3.42 Available services for PWDs/CWDs

Category	Code	Quotation
Rehabilitation services	Physiotherapy Occupational therapy	*…services provided by the occupational therapy and physiotherapy departments [at Nkhensani] (P75:76)*
Community bases services	Disability forum	*…managed to form a forum inclusive of caregivers of CWDs and PWDs in general. (P75:51)*
	Special school	*He is grateful for the local school of intellectually impaired children known as Pfunanani Special School and the newly built Nthabiseng special school in Phalaborwa. (P75:59)*

Table 3.43 Challenges experienced by PWDs/CWDs

Category	Subcategory	Code	Quotation
Community related	Access to inclusive education	No opportunity for school	*…few PWDs have an opportunity to go to school. (P75:57)*
		Tired of special schools	*PWDs are tired of special schools such as Letaba, which is seen as a school for children on wheelchairs and crutches and want an inclusive school. (P75:58) [There are few special schools and the mainstream schools are not admitting CWDs.]*
	Access to water	Village taps	*The plight of disabled people like him on crutches extends to basic things such as drinking water from a tap in the villages (P75:32).*
	Accessibility of public places	More than ten steps Steps throughout Entrance with ramps always locked	*…I then went straight to the entrance where I had to go climb more than ten steps. The disability friendly entrance was locked. People on wheelchairs were assisted by caregivers and members of the public to negotiate the steps. There were many adults in the hall on wheelchairs while others were on crutches… (P75:9-11)* *He said the churches are inaccessible for disabled persons because there are steps throughout [the buildings]. During his presentation, the chairperson dwelled a lot on the issue of accessibility. He started with a stage where he was standing on. He said many PWDs would not be able to speak from that stage where he was speaking due to its inaccessibility. He stated that the community hall was not accessible to the disabled people who were in attendance even though there is an entrance with ramps, but it is always locked. The central business area was also reported to be one of the inaccessible areas in Giyani. (P75:33-37)*
	Employment opportunities	Low employment rate	*There are PWDs working at the municipality even though their numbers is very minimal*. *(P75:52)*
	Abuse	PWD exploited PWDs are passports Wheelchairs used as wheelbarrows Abuse of caregivers Self-abuse	*…many disabled people [are] exploited by their families when applying for RDP houses, he said disabled persons are used as 'passport" to get an RDP house and yet not allowed to stay in it. He suggested that the government must verify all RDP housing applications that are done on behalf of PWDs (P75:38). Some of the PWDs are abused by their own families who use their wheelchairs as wheel barrows (P75:72).The other problems that PWDs face include…abuse of caregivers of CWDs… (P75:42 & 44).He said self-abuse is when PWDs abuse alcohol in bottle stores and using their crutches as weapons to assault others causing the crutches to break. In addition, he said there were those who were renting the wheelchairs to others to be used as wheel barrows. (P75:67).*

Table 3.44 Societal perception of CWDs

Category	**Subcategory**	**Code**	**Quotation**
Negative perception	Intolerance Stare Ridicule Fear of CWDs Witchcraft Name calling	Intolerant Starring	*The programme director started by asking the audience to be tolerant of all the people with disabilities. I think he was mainly referring to a young man with intellectual impairment who was sitting next to me who kept on talking to his mom and making noise. Some of the people without disabilities who were also sitting next to me kept on staring at the young man and his mother. I supported the programme director's remarks. (P75:15)*
		Mockery Frightened	*…as part of his speech, the speaker highlighted how persons with disabilities were treated in the past. He reminded the older persons with disabilities how they used to be locked indoors, hiding them so as to ensure that their families were not mocked by the society at large. (P75:19)* *…able-bodied persons would faint after seeing a person with disabilities as they were frightened. (P75:26)*
		Hide CWDs	*…he praised the mothers for their courage in looking after their disabled children even though they would hide the disabled child in big clay pots. He described those pots as a living area and a toilet at the same time. (P75:27)*
		Accused of witchcraft	*He also reminded the audience that the in-laws did not allow cripples in their families and would blame the mother and accuse her of witchcraft, and she would usually be sent back home to her family as a result. (P75:27)*
		Unwanted	*…he said that the forum was formed in order to fight for the recognition of persons with disabilities because they were unwanted and called cripples who deserved to be hidden…(P75:25)*
		Cripple	*"Disabled people do not want to be called cripples" (P75:28)*

3.5.3.1 Question directed to the mayor by the researcher

The researcher had an opportunity to ask the municipal mayor whether the Greater Giyani Municipality has any plans to: (1) address the accessibility of PWDs, (2) have parks and recreational facilities for PWDs, and (3) impose penalties on poorly designed buildings that lack accessibility for PWDs.

The mayor's response

The mayor said there would be ramps in all taxi-ranks by the end of the year (2010) even though she did not specify whether she meant calendar year or the municipality's financial year end. The mayor also said that they did not have a specific budget for PWDs in the municipality but will do their best to address some of the challenges of this marginalised group (P75:89).

3.5 INFORMATION OBTAINED FROM PFUNANANI SPECIAL SCHOOL

Information that was obtained from Pfunanani Special School was presented in Section 2.4 under study location in Chapter 2 (on page 49).

3.6 SUMMARY OF CHAPTER 3

Results presented in Chapter 3 emanate from the face-to-face interviews with caregivers, rehabilitation professionals and CRWs. Additional information and results were obtained during the launch of the GGDF. The results as presented in this chapter are summarised in Table 3.45 (on page 127).

Table 3.45 Summary of Chapter 3

Caregivers	**Rehabilitation professionals**	**CRWs**	**Launch of GGDF**
The following concepts were identified • Cause of childhood disability • Role of caregivers • Available services • Challenges experienced • Role of CRWs • Caregivers’ level of satisfaction • Caregivers’ expectations • Caregivers’ coping strategy • Caregivers’ source of support • Societal perception of CWDs	The following concepts were identified • Role of caregivers • Available services • Challenges experienced • Role of rehabilitation professionals • Rehabilitation professionals’ competency • Factors affecting rehabilitation professionals’ work ethic	The following concepts were identified • Role of caregivers • Role of CRWs • Role of rehabilitation professionals	The following concepts were identified • Role of the municipality towards PWDs and CWDs • Available services for PWD’s • Challenges experienced by PWD’s • Societal perception of PWDs/CWDs

In Chapter 4, results emanating from the FGDs with caregivers and rehabilitation professionals are presented.

CHAPTER 4

RESULTS OF PHASE 2

4.1 INTRODUCTION

In Chapter 4, the results of Phase 2 of the study are presented. Chapter 4 is divided into subsections in which information obtained through FGDs with caregivers and rehabilitation professionals are presented.
The objectives of Phase 2 of the study were to gather more data from caregivers and rehabilitation professionals through FGD in order to develop concepts on: (1) the role of caregivers, rehabilitation professionals and CRWs in the rehabilitation of CWDs, (2) challenges that CWDs and their caregivers encounter, (3) other specialised services for CWDs, (4) support structure for CWDs and caregivers, and (5) caregivers' satisfaction and expectations of services.

4.2 INFORMATION OBTAINED FROM CAREGIVERS

In this section, results emanating from the FGDs with caregivers are presented. The results include caregivers' demographic information, demographic information of children whose caregivers participated in the study and the developing concepts.

Results on the following emerging concepts are presented: (1) cause of childhood disability, (2) the role of caregivers, (3) available services for CWDs, (4) challenges experienced by CWDs, (5) role of CRWs, (6) caregivers' level of satisfaction, (7) caregiver's expectation, (8) caregivers' coping strategy, (9) caregivers' source of support, and (10) societal perception of CWDs.

4.2.1 Caregivers' Demographic Information

A data sheet (Appendix S) was used to collect the caregivers' demographic data. A summary of the caregivers' age, gender, marital status, relation to the child, number of dependent children, highest educational level, employment status, source of income, estimated family income, living arrangement, availability of electricity and access to water is presented in Table 4.1.

Table 4.1 Caregivers' demographic information

Code	Group	Age	Gender	Marital status	Relation to the child	Dep[3]	Education	Employment status	Source of income	Family income	Living arrangement	Electricity	Water
CG11	FGD1	49	Female	Single	Mother	4	Grade 7	Unemployed	Social grants	R250	Self	Yes	No
CG12		23	Female	Single	Mother	2	Grade 10	Unemployed	Social grants	R500	Parents	No	No
CG13	FGD2	20	Female	Single	Mother	1	Grade 12	Unemployed	Social grants + Miner	-	Parents	Yes	No
CG14		34	Female	Single	Mother	2	Grade 12	Unemployed	Social grants + old age pension	R3150	Parents	Yes	Yes
CG15		24	Female	Single	Mother	1	Grade 11	Unemployed	Social grants + farm labourer	R1250	Parents	Yes	No
CG16	FGD3	43	Female	Married	Mother	4	Grade 11	Unemployed	Social grants	R500	Partner	Yes	No
CG17		53	Female	Single	G/mother	-	Nil	Unemployed	Social grants	R1100	Self	Yes	No
CG18		18	Female	Single	Mother	1	Grade 10	Unemployed	Social grants	R500	Parents	Yes	Yes
CG19		28	Female	Single	Mother	1	Grade 11	Unemployed	Social grants	R500	Sister	No	No
CG20		26	Female	Single	Mother	2	Grade 11	Unemployed	Social grants	R500	Parents	Yes	Yes

---

[3] The number of dependent children

4.2.2 Demographic Information of Children whose Caregivers Participated in the Study

The data sheet (Appendix S) was used to collect the age, gender and the diagnoses of the CWDs whose caregivers participated in the FGDs. The age of the children ranged from one to nine years. There were five females and five males. Eight of the children had a cerebral palsy diagnosis. A summary of the demographic information of all the CWDs whose caregivers participated in the study is shown in Table 4.2.

Table 4.2 Demographic information of children with disability

Code	Group	Age	Gender	Diagnosis
CG11	FGD1	1	Female	Down syndrome
CG12		1	Female	Cerebral palsy
CG13	FGD2	2	Male	Cerebral palsy + epilepsy
CG14		9	Male	Cerebral palsy
CG15		1	Male	Cerebral palsy
CG16	FGD3	1	Female	Microcephalus
CG17		1	Male	Cerebral palsy
CG18		2	Female	Cerebral palsy
CG19		2	Female	Cerebral palsy
CG20		2	Male	Cerebral palsy

4.2.3 Development of Concepts from Caregivers of Children with Disabilities

In this subsection, the results from the FGDs with caregivers are presented. The developing concepts, question asked and the results consisting of quotations from participants, codes, subcategories and the categories are presented.

4.2.3.1 Question 1: What can you tell me about this child?

Concept: Cause of childhood disability

This concept was derived from 14 codes, nine subcategories and four categories as shown in Table 4.3. The four categories comprise of religious belief, other belief, biomedical reason, and lifestyle and habits.

Table 4.3 Cause of childhood disability

Category	Subcategory	Code	Quotation
Religious belief	Curse	Cursed	*They say it started because my child's family was provocative…her family was very provocative and talked a lot while I was pregnant, that is why I am having a disabled child. It all started there while I was pregnant or maybe I have been cursed. (P33:35 & 37:R1)*
	Witchcraft	People are responsible	*When I first identified the problem I started by going to the church where I was told that God has brought the child being normal, but there are people who are responsible for causing the disability. (P32:19: R2)*
	God's decision	It is from God Gift from God	*It is from God, and I cannot say another human being has caused it. It is from God…I do not have a problem for having a child with disabilities I have accepted it as a gift from God. (P32:17 & 61:R1)*
		It was caused by God.	*The reason I came to the hospital was that I thought people [church] were testing me, thinking that I will say whom I suspected to have caused this while it was caused by God. So I wanted to get the doctors' opinion. (P32:21: R2)*
Other belief	Misconception	Lack of stepping reflex	*It happens when a child is born without being able to stand on their feet [stepping reflex]…(P34:27: R4)*
		Not crying	*…some say the child will be disabled if she does not cry during birth. (P33:27: R3)*
Biomedical	Poor immunisation	Default on immunization	*….it is caused by defaulting on the immunisation programme. (P34:23:R5)*
	Oxygen deprivation	Oxygen deprived	*…she looked tired at birth and did not cry. She was put on oxygen for some time after birth. So they though the oxygen could have cause some damages. (P33:42: R3)*
	Stress in pregnancy	Stress	*They said stress caused this. I was thinking a lot while pregnant. (P33:40: R2)*
		Thinking a lot	*It is caused by the mothers who think a lot during pregnancy.(P34:25: R2)*
Lifestyle and habits	Smoking & drinking	Drinking Smoking	*Yes, you will find that some mothers drink or smoke whilst they are pregnant. (P34:21: R3)*
	Spicy food	Atchar Chilly food	*Based on what I have seen and what I know; this child's mother ate many foods that she was not supposed to eat during pregnancy. I think the child got this from the mother as a result of the food that the mother used to eat…she used to eat atchar and a lot of chilly foods during pregnancy. (P34:23:R5)*

4.2.3.2 Question 2: What is the role of caregivers during the rehabilitation of CWD?

Concept: Role of caregivers

This concept was derived from ten codes, four subcategories, and one category. Caregivers who participated in the FGDs were of the opinion that their role was to ensure that there is continuing of care of the CWD. The four subcategories includes learning new skills, perform hands-on role, demonstrate their newly acquired skills to rehabilitation professionals, and to perform home programmes as indicated in Table 4.4.

Table 4.4 Role of caregivers

Category	Subcategory	Code	Quotation
Continuity of care (Active)	Learn	We watch I see what they do I look	*We watch what they do…after the session, they expect me to show them how they have been stretching the child so that they can be sure that I understand and have been watching what they did. (P34:76 & 80:R4)* *They tell me to hold her if she cries while they stretch her but if she does not cry I just sit down and not do anything. (P34:78: R2)* *…I can see what they do during treatment. (P34:81: R3)* *I look at what they do during treatment…(P34:82: R1)*
	Hand-on-therapy	Position her We combine treatments We assist with treatment	*I will give you an example with my child who can sit. When they are busy training the child they normally tell me to position her…(P32:31: R1)* *…they then do what they do, and I combine what they do with what I do and I continue with the programme. (P32:33: R2)* *We assist them as they treat our children by doing what they tell us to do. (P33:85: R3)* *we assist them by holding the children's arms, and they hold the legs when they teach the children to stand…(P33:83: R2)*
	Demonstrate	We show them Demonstrate	*…we also show them what we do at home…(P33:83: R2)* *After the session, they expect me to show them how they have been stretching the child so that they can be sure that I understand and have been watching what they did. (P34:80: R4)*
	Home Programme	Do at home Continue with programme	*They also encourage me to continue doing what they do at home. (P32:31: R1)* *…and I continue with the programme. (P32:33: R2)* *…I cannot do what they tell me to do at home when they only treat her for three minutes and tell me to go…(P34:34: R5)* *…they showed me how I should stretch her at home…they expect us to continue doing what they just did at home. (P34:54 & 76:R4)* *every morning when I wake up at home, I continue with what they have been doing [in the hospital]. (P34:82: R1)*

4.2.3.3 Question 3: What are the available services for CWDs and their caregivers in Giyani?

Concept: Available services

This concept was derived from three codes, three subcategories, and three categories as shown in Table 4.5. The three categories are rehabilitation services, community-based services, and social services.

Table 4.5 Available services

Category	Subcategory	Code	Quotation
Rehabilitation services	Physiotherapy	Physio	*…what I can say is that I know Physio works, and you can get the results that you least expect. (P34:127:R5)*
Community-based services	Special schools	Letaba Special School	*…I will take her to Letaba [special school] when she turn five as we stay closer to the school. (P33:77: R1)* *I will also take my child to a school for the disabled when she is discharged. (P33:79: R2)*
Social service	Social grants	Grant Money we get	*The R 250 grant that they are giving us is too little…(P32:35: R1)* *…the money that we are getting is very little and does not meet all of the child's basic needs such as clothes and food… (P32:37: R2)* *…I only get the R 250 grant…(P33:65: R1)*

4.2.3.4 Question 4: What are the challenges that you experience as you to seek rehabilitation for the child?

Concept: Challenges experienced

This concept was derived from 25 codes, 11 subcategories, and four categories. The four categories are child related, caregiver-family related, health-care related, and community related as shown in Tables 4.6, 4.7 (on page 136), 4.8 (on page 137), and 4.9 (on page 137).

The child related category consists of clothing and nutrition subcategory. The family-caregiver related category consists of the following subcategories: information, social grants access, affordability, and appropriate transport.

The health-care related category consists of hands-on roles, allocated treatment time, uniformity, and equipment and material. The community related category consists of inadequate special school subcategory.

Table 4.6 Challenges experienced (1)

Category	**Subcategory**	**Code**	**Quotation**
Child related	Clothing	Clothes Diapers	*I think the main problem is what she has said as well as clothes and pampers…(P32:58: R2)*
	Nutrition	Dietary problems	*…Its mainly dietary problems. The food that the child is supposed to eat is not available due to the monetary problem...(P32:55: R1)*
		Cannot afford food	*…they prescribe food, milk and medication for these children, and it is very expensive. We just cannot afford. You need peanut butter to mix with soft porridge, you need fruits, and we cannot afford. (P32:58: R2)*
		Struggle to swallow	*…the other day I came to see a doctor where I explained to him that my child struggled to swallow…(P33:54: R3)*
		Feeding problem	*…I can see that there are some changes as she could not eat soft porridge from a spoon. I had to put it into a feeding bottle where she had to suck…(P34:72: R1)*

Table 4.7 Challenges experienced (2)

Category	**Subcategory**	**Code**	**Quotation**
Family-caregiver related	Information	I did not know She had stroke	*…This has helped, and I did not know about it…I did not have the opportunity to use that channel due to lack of information. (P32:23 & 45:R1)* *I came to Nkhensani because I want my child to be helped as she had a stroke…(P34:18: R2)* *…at first this baby had foam in the mouth, and we did not know what she ate immediately after birth…(P34:19: R1)*
	Social grants access	Unclear grant application (bureaucracy)	*…I started coming to sister S in march and she is the one who makes the decision. Sometimes you find that the doctor who has to assess the child is not around. We are not sure whether sister S or a doctor takes the decision. When we get to sister S, she tells us whether to see a doctor…(P32:41: R1)* *…to apply, you need a doctor's letter that will recommend whether a child qualifies or not. They tell us that it is a slow process, but there are not giving us the doctors' letters in order to apply. (P32:42: R2)* *Last month I came to sister S where I explained to her that I need a grant, and she referred me to a doctor at OPD. When I gave the doctor the file and explained to him my problems he said have you ever seen a small child like this get old age pension but the people that I am coming here with are getting it. (P33:145: R1)*
		Insufficient grant	*The R 250 grant that they are giving us is too little…(P32:35: R1)* *I support the fact that the money that we are getting is very little and does not meet all of the child's basic needs such as clothes and food… (P32:37: R2)* *What I want is a grant that is equal to old age pension. I would take her to different treatment areas as I am only bringing her to the hospital. I only get the R 250 grant, and I have to buy pampers and powdered milk. The grant is not enough...(P33:65 &149: R1)*
		Inconsiderate staff	*…I think they have to take the child's condition into consideration because children like these struggles to live…(P32:35: R1)*
	Affordability	Grant too little Lots of expenses Cannot afford basics	*The R250 grant that they are giving us is too little. Every time I come to the hospital to get her food parcel I use money for transport, when I bring the child for training I use money, when the child is sick I need money to go the doctor or the hospital…(P32:35:R1)* *…the money that we are getting is very little and does not meet all of the child's basic needs such as clothes and food….(P32:37: R2)*
	Appropriate transport	Transport problem	*We used to struggle in the past with these children carrying them on our backs not knowing how to transport them, but they are now giving us these buggies [Madiba buggy]. I can now position and transport my child using this bike…she is getting big and too heavy for me to carry. (P33:53 & 139:R3)*

Table 4.8 Challenges experienced (3)

Category	**Subcategory**	**Code**	**Quotation**
Health-care related	Hands-on-therapy	They do not check the child	*When I come here they [professionals] only give my child toy cars to play with and they tell me to buy him toys saying that I will be fine.(P34:50: R2)*
	Allocated treatment time	3 minute's treatment Should spend more time	*As I come for Physio, I am not happy with the service that I receive because they only treat her for three minutes and stretch his arm…they should be spending more time with the child. You would find that every month I would be coming here for a three to five minute's session… (P34:34: R5)* *…I wish they can spend more time with the children may be my child can gain the use of her hand.(P34:97: R4)* *I wish they can spend more time with the children…I think they should spend more time with each and every child. They must not spend less time with one child but spend more time with another.(P34:101 & 106: R4)*
	Uniformity	Equal treatment	*…they must not spend less time with one child but spend more time with another. We should be equal treated. (P34:106: R4)* *...they must treat people equally. (P34:128:R5)* *They have to treat us equally. (P34:130: R1)* *I think they should treat us equally. (P34:132: R3)* *…they should not give others special treatment because they know them; they should treat us all equally regardless of whether they know you or not. (P34:134: R2)*
	Equipment and material	They only use hands No assistive devices No machines No standing frame No walking frame	*At the moment, they only train our children with the use of their hands. When a child cannot walk, there is something that they can give a child that can be pushed, and the child will walk. My concern is on training our children without the use of assistive devices. (P32:27: R1)* *…why is the doctor not taking the child to the machine where he will check whether the problem is on the muscles or bones? I wish they could have these machines to verify where the problem is. (P32:29: R2)* *… I also hope they can use a machine to straighten lower back maybe she could sit. (P33:141: R1)* *I wish they could give these children something so that they can stand and walk. (P33:143: R2)*

Table 4.9 Challenges experienced (4)

Category	**Subcategory**	**Code**	**Quotation**
Community related	Inadequate special schools	Build appropriate crèches	*They can build crèches where these children can have access to people [teachers] who can train them... (P34:66: R4)* *I support what number 4 has said. (P34:70: R2)* *I will say what number 4 has said…(P34:72: R1)*

4.2.3.5 Question 5: What can you tell me about the role of community rehabilitation workers?

Concept: Role of CRWs

This concept was derived from four codes, three subcategories, and two categories as shown in Table 4.10. The two categories are the adequate and absent roles. The adequate role that CRWs play include to counsel, hands-on role, and assistive devices.

Table 4.10 Role of CRWs

Category	Subcategory	Code	Quotation
Adequate roles	Counsel	Counsel	*Ei! Hmm…actually they also counsel us to accept our children's conditions. (P33:110: R3)*
	Hands-on role	Stretch children	*They assist us to stretch the children, and they also talk to the children. (P33:91: R3)*
	Assistive device	They bring buggies	*Sometimes when the buggy is broken we report to them, and they bring new ones…(P33:105: R3)*
Absent roles		Not known	*I do not know them. (P33:87: R1)* *I do not know them. (P33:88: R2)*

4.2.3.6 Question 6: How is your general satisfaction with the health-care services you have received?

Concept: Caregivers' level of satisfaction

This concept was derived from ten codes, five subcategories, and two categories. The two categories include services that caregivers felt were adequate, and those that they felt were inadequate. The services that caregivers were satisfied with are summarised in Table 4.11. Services that caregivers were not satisfied with are summarised in Table 4.12 (on page 140).

Table 4.11 Caregiver's level of satisfaction (1)

Category	Subcategory	Code	Quotation
Adequate service	Compassionate	Caring	*I am also satisfied with the service that I get from Physio because they are not afraid of our children, and they play with them as they treat. (P33:50: R2)*
	Effective service	Good service	*…the service is good because when I started coming here my child could only sit at the age of one year three months but now she can crawl. When I come here, they treat the child and tell me what to do at home, something that I did not know because I thought as God created her; she will automatically sit and crawl. P32:23: R1)*
		Happy with results Good job	*I am happy because ever since I started coming here I can see that there is a change. I can see that she is now active, even at home when I play with her I can see that there is a change. (P32:25: R2)*
		Happy with their work	*The people [professionals] I find here are good to me unlike what my fellow caregivers have experienced. When I get here, they stretch her and do all the things that I see she could not do. When I started coming here, this child was just a thing that I could not even manage. However, now when I lift her you can see that I have lifted a person because she can even do this [stretch] to her arms. Even when I put her to bed she can turn and lift her head up its only that she cannot crawl. Now there are changes as she used to be a useless cabbage and I can say that they [professionals] are doing a good job…she can now stretch her arms as her arms used to…. [Have contractures]. There are changes in her condition. Even her face has changed as you could not believe that she was a human being (P34:58 & 61: R1)* *I am happy with how they work because as I come here they show me how and what to do at home. They showed me how I should stretch her at home. When I first came here, she could not stand but now she can stand when assisted. (P34:56: R4)*

Table 4.12 Caregivers' level of satisfaction

Category	Subcategory	Code	Quotation
Inadequate service	Quality of service	Hospital filling system Slow	*…I am not happy with the service I get from the hospital filling section… you will find that I get there at seven but only get the file at nine. The people there are so slow as if they are not at work. (P33:44 & 46:R1)*
	Staff attitude	Poor work ethic	*I think the Physio staff need to change the way they work. They have to acknowledge that they have come to work in order to help our children like their own. You sometimes find that the little time that they dedicate to us is also wasted on something else. They sometimes leave us in the treatment areas to go and do their own things. I think, they have to do what they have been employed to do. (P34:140:R5)*
	Hands-on-therapy	Limited time Limited hands-on-therapy	*As I come for Physio, I am not happy with the service that I receive because they only treat her for three minutes and stretch his arm. I believe that I cannot do what they tell me to do at home when they only treat her for three minutes and tell me to go… I do not feel good at all, but I have not told them how I feel about their treatment… It is just that when I come here there are two people [professionals] who seem to be in a hurry to go somewhere when they treat my child. (P34:34, 36 & 40:R5)* *I do not feel good because toy cars will not make my child stand and walk. (P34:52: R2)*

4.2.3.7 Question 7: What are your expectations from the available services?

Concept: Caregivers' expectations

This concept was derived from eight codes, and three categories as shown in Table 4.13. Subcategories were not identified for this concept. The caregivers had different expectations from different services such as health-care services, social services, and community services.

Table 4.13 Caregivers' service expectation

Category	**Code**	**Quotation**
Health-care services	Access to village services	*I think it would help if there were nominated people from the hospital who would come where we stay to check on the progress of our children. (P34:64:R5)*
	Hands-on therapy	*I came to Nkhensani because I want my child to be helped as she had a stroke. I expect them to stretch her arm and leg. (P34:18: R2)*
	Improve treatment time	*…they should be spending more time with the child. You would find that every month I would be coming here for a three to five minute's session. (P34:34: R5)*
	Assistive devices	*I wish they can give my child a walking frame from Physio so that she can stand and walk…I wish they could give these children something so that they can stand and walk. (P33:68 & 143:R2)* *…I wish they could give her something to support her neck…(P33:141: R1)*
	Improvement of condition	*I wish they could give these children something so that they can stand and walk. (P33:143: R2)* *…I wish she can regain the use of her hands…(P33:141: R1)* *We brought them here so that they can get help and exercises in order for them to live like any other children. (P34:13: R3)* *…I want my child to get help and be able to walk. (P34:15: R4)* *I came to Nkhensani because I know what Physio is all about. I know that that deal with bones and they can help fix my child's bones. (P34:17:R5)*
	Others specialised services	*…I also wish they can use a machine to straighten lower back maybe she could sit. (P33:141: R1)*
Social services	Social grants	*What I want is a grant that is equal to old age pension… (P33:65: R1)*
Education services	Appropriate schools	*I wish she can sit by herself and gain the use of her hands so that she can go to school because her mindset is ok. She cannot go to school because she is still on pampers, cannot sit, cannot use her hand and cannot turn by herself when sleeping. (P33:75:R5)* *I heard the children gets discharged at the age of five so I will take her to Letaba [special school] when she turn five as we stay closer to the school. (P33:77: R1)* *I will also take my child to a school for the disabled when she is discharged. (P33:79: R2)*

4.2.3.8 Question 8: How do you cope with the pressures of having a child with disabilities?

Concept: Caregivers' coping strategy

This concept was derived from four codes and two categories as displayed in Table 4.14. Subcategories were not identified for this concept. Caregivers used acceptance of their children's condition and religious beliefs as their coping strategy.

Table 4.14 Caregivers' coping strategy

Category	Code	Quotation
Acceptance	Accept	*…I have accepted it as a gift from God. Even when people talk I accept it as I am not the first one to have a disabled child, there are many out there…they play with her, and they have accepted that its' a God given gift. (P32:61 & 122:R1)* *I just have to accept because I cannot change the situation. I just let them talk; I know they will get tired. (P33:127: R2)* *However, I remember there was a certain man who used to sell bread and my sister bought bread for us from this man and asked him to pass by and dropped they bread. When I saw him standing next to our yard, I asked him whom he was looking for, and he said he had been asked to drop bread at a crippled child's family.I accepted it, and I corrected him that we did not say crippled but disabled. He later apologised, and I accepted his apology as he did not know. (P33:130: R3)*
Religious belief	I believe	*I also do not have a problem because I believe my child will walk one day. (P32:62: R2)*
	Trust in God	*…I only trusted in God that what they [professionals] are doing to her would help, and I believe that it is helping…(P34:61: R1)*
	God's help	*God should help us to change our children's conditions. (P34:103: R2)* *I will be happy if God helps us. (P34:104: R3)*

4.2.3.9 Question 9: What are your sources of support?

Concept: Caregivers' source of support

This concept was derived from 12 codes, four subcategories and two categories as shown in Table 4.15. The two categories include those caregivers who receive adequate support and those without support. The adequate support category comprises of the following subcategories: religion, family, friends and neighbours, crèche, and community-based services.

Table 4.15 Caregivers' source of support

Category	**Subcategory**	**Code**	**Quotation**
Adequate support	Religion	Belief in God	*…I only trusted in God that what they [professionals] are doing to her would help, and I believe that it is helping. (P34:61: R1)*
		Church	*I get support from the people I stay with at home as well as the people I go to church with…(P33:121: R3)* *I get support from the people I go to church with. They tell me that it is crucial for me to come to the hospital…(P34:125: R1)*
	Family, friends and neighbours	My mother At home Relatives Friends Neighbours	*My mother takes care of my child when I am not around. (P32:66: R1)* *My mother supports me…there is nobody other than her…when I wake up in the morning she bath, feed and carries the child on her back, and I do all the household activities. (P33:113, 115 & 117:R1)* *I also get support from home. My mother stays with my child even when she goes to Johannesburg…(P33:119: R2)* *I get support from the people I stay with at home (P33:121: R3)* *I normally get support from the people I stay with at home, parents, friends and relatives. (P34:121: R4)* *I get support from my entire family...(P34:123:R5)* *It is the people I stay with, friends…(P34:119: R2)* *I normally get support from the people I stay with at home, parents, friends...(P34:121: R4)* *…neighbours (P34:119: R2)*
	Crèche	Crèche	*…I take her to crèche when I go to school. (P34:68: R4)* *I will say what number 4 has said. If you want a child to be helped you must take her to crèche. I also take this one to crèche…(P34:72: R1)*
	Community-based services	Support group Other caregivers	*I am involved in a group where we sew using our hands and generate some money by selling the end products…there is a group. We just have to tell ourselves that we can raise our children.(P34:116: R4)* *I am involved in a group. We sew using our hands. I just forgot to bring the end product which I generally show and sell to other people in the hospital generating some money for the child. (P34:112: R1)*
Absent support		No support My sister refuses	*I do not have support. I always take my child with where ever I go. Even if I get a job, I will take her to crèche because my mother is also working, and she stays at her place of work. (P32:67: R2)* *… I stay with my sister, but she refuses to babysit my child…I always take my child with me. (P32:69 & 71:R2)*

4.2.3.10 Question 10: How are you and the child perceived in the community?

Concept: Societal perception of CWDs

This concept was derived from six codes, five subcategories, and two categories as summarised in Table 4.16. The two categories comprise of positive perception and negative perception.

Table 4.16 Societal perception of CWDs

Category	**Subcategory**	**Code**	**Quotation**
Positive perception	Care	Play with her	*They play with her, and they have accepted that it is a God-given gift. (P33:123: R1)*
	Support	They accept its God's gift	*…others support you, greet and play with the child. (P33:125: R2)*
		They support you	
Negative perception	Name calling	Cripple	*There are those who laugh at you saying that you have a crippled child…(P33:125: R2)* *However, I remember there was a certain man who used to sell bread and my sister bought bread for us from this man and asked him to pass by and dropped they bread. When I saw him standing next to our yard, I asked him whom he was looking for, and he said he had been asked to drop bread at a crippled child's family.I accepted it, and I corrected him that we did not say crippled but disabled. He later apologised, and I accepted his apology as he did not know. (P33:130: R3)*
	Ridiculed	Laugh	*There are those who laugh at you…(P33:125: R2)*
	Gossip	People talk	*…even when people talk I accept it as I am not the first one to have a disabled child…(P32:61: R1)*

4.2 SECTION B: INFORMATION OBTAINED FROM REHABILITATION PROFESSIONALS

In this section, results emanating from the FGDs with rehabilitation professionals are presented. These results include rehabilitation professionals' demographic information and the developing concepts.

Results on the following developing concepts are presented: (1) genetic clinic, (2) challenges experienced by CWDs, and (3) rehabilitation professionals' plan of action to correct the challenges that they have identified.

4.3.1 Rehabilitation Professionals' Demographic Information

A total of six out of the eight rehabilitation professionals who participated in Phase 1 of the study agreed to participate in the FGD. A summary of the rehabilitation professionals' demographic information is presented in Table 4.17.

Table 4.17 Rehabilitation professionals' demographic information

Code	Age	Gender	Profession	Occupation	Qualification	Experience
Prof 1	46	Male	Occupational therapy technician	Occupational therapy assistant	Diploma in Occupational Therapy Assistant (Community)	10 years
Prof 2	26	Female	Occupational therapist	Occupational therapist	Bachelor of Occupational Therapy	3 years
Prof 3	47	Male	Physiotherapy assistant	Principal Physiotherapy assistant	Registered with HPCSA (No formal qualification	25 years
Prof 4	23	Female	Occupational therapist	Occupational therapist (community-service)	Bachelor of Occupational Therapy	5 months
Prof 5	30	Male	Physiotherapist	Physiotherapist (community-service)	Bachelor of Science in Physiotherapy	5 months
Prof 6	43	Female	Occupational therapy assistant	Occupational therapy assistant	Diploma in Occupational Therapy Assistant (Community)	10 years

4.3.2 Developing Concepts from Rehabilitation Professionals

In this subsection, the results from the FGDs with rehabilitation professionals are presented. The developing concepts, question asked, and results consisting of quotations from participants, codes, subcategories and the categories are shown.

4.3.2.1 Question 1: What do you know about the genetic clinic?

Concept: Genetic clinic

This concept was derived from 13 codes, nine subcategories, and four categories as summarised in Tables 4.18, 4.19, 4.20 (on page 148), and 4.21 (on page 149). The four categories include the history of the clinic, knowledge about the clinic, opinion of the clinic, and the role of the clinic.

Table 4.18 Genetic clinic (1)

Category	Subcategory	Code	Quotation
History of the clinic	Established	Around for long	*…genetic clinic has been in our hospital for a long time now…(P35:23: R3)*
		Had specialist visits	*…Previously there was a specialist who used to come and visit our hospital. They were specialising with kids who had cleft palates. When they [specialist] came and assess them [children] they would make some arrangement and book them [children] for operations in Pretoria or book them [children] at the provincial hospital for correction of those defects. (P35:18: R2)*

Table 4.19 Genetic clinic (2)

Category	Subcategory	Code	Quotation
Knowledge the clinic	Known	I know	*…I know that the genetic nurse is based at maternity ward where she screens newborn babies…(P35:18: R2)* *…I also know genetic to counsel. They get children from maternity and also counsel their mothers. They also teach the mothers about their children's condition as well as the causes of such conditions…(P35:24: R4)*
	Unknown	I do not know	*I did not know much about the genetic clinic before but since number 2, 3 and 4 have mentioned it, it makes much sense…(P35:25:R5)* *…I think it is the first time for me to hear about that [genetic clinic]… since number 1, 2, 3 and 4 explained, it does make sense to me because I did not know there is a genetic clinic in the hospital. So now, it makes sense. (P35:26: R6)* *Personally I do not know much about it, I only know a bit about it…(P35:16: R1)*

Table 4.20 Genetic clinic (3)

Category	Subcategory	Code	Quotation
Opinion about the clinic	Not organised	No collaboration between genetics and CP Criteria for clinic not clear	*It would be better if we had a place where we discuss and explain to these caregivers that it is important that they attend both the clinics. I think that would strengthen our relationship because sometimes only 2, 3 or 5 people attend the genetic clinic. They [genetic staff] do not even have uniform on whom to see because they just grab whomever they find on that particular day. If there were good communication, we could even ask the caregivers to wait for one another [after treatment] so that they go [to the genetic clinic] together. The way it is run at the moment is not right but it is good that we have time to come with a new approach…. we can see that as time goes on this can cause confusion and we might end up fighting as health providers because we do not have that [how genetic clinic works] in our programmes on how it will be run. That is what we see as a problem but because we are working together and for the sake of these people [children and caregivers] we have accepted the way it is done even though it is not right for these people. (P35:31 & 32:R3)* *I want to agree with the point that number 3 made, it's the point that I wanted to raise because a problem that we had before was the structuring of the whole treatment from OT to genetic because sometimes it's a problem for them [caregivers] to come to OT and Physio treatment and then go back to the genetic clinic. So what he is saying is right, I think it is better that we have one venue where we can all attend the caregivers and the children together in one place so that they do not get confused. (P35:33: R5)*

Table 4.21 Genetic clinic (4)

Category	**Subcategory**	**Code**	**Quotation**
Role of the clinic	First point of contact	Early intervention	*...I feel good because the kids were managed and fixed at an early stage (P35:22: R2).*
		Screen babies	*…....they also assist by referring such children to specialists where they insert shunts. …by the time they [caregivers] came to us we can see that they have already been counselled, and they understand they children’s condition…(P35:23: R3)*
		Early referral	*…from the birth of the children, the mothers get to know how to manage the children, and they get insight into their children’s condition…(P35:25:R5)*
	Screen	Screen babies	*…they screen babies before and after they are born to check whether they are at risk of developing certain diseases when they grow. When they detect chromosomal problem, they can tell that the child will have a problem later on…(P35:23: R3)* *…genetic nurse is based at maternity ward where she screens newborn babies…(P35:18: R2)*
	Counsel	Counselling	*…they also assist caregivers of CWDs by counselling them, by the time they came to us we can see that they have already been counseled and they understand they children’s condition…(P35:23:R3)* *…I also know genetic to counsel. They get children from maternity and also counsel their mothers… (P35:24: R4)* *…all I know is that they only do counselling and further than that I do not know much about it. (P35:16: R1)*
	Education	Teach mothers	*…they also teach the mothers about their children’s condition as well as the causes of such conditions because some mothers think they are being punished by God while others think they have been bewitched…(P35:24:R4)* *…so I think it’s a very good idea because uhm from the birth of the children, the mothers get to know how to manage the children and they get insight into their children’s condition so that they don’t be so much scared or detached from their children…(P35:25:R5)*
	Support	She supports them	*…she also supports them in many different ways…(P35:25: R4)* *…she does activities with the caregivers of the children where she does beads work with them and then she gives it to them, and they can sell them and a make profit…(P35:25:R5)*
		Support group	*…I just heard last of last week that she [genetic nurse] has started a support group…(P35:30: R2)* *…I think it is a good idea because it support the caregivers…(P35:26: R6)*
	Refer	She refers	*…she refers the child; she refers the babies to relevant disciplines…(P35:18: R2)* *…they refer to the appropriate discipline…(P35:23: R3)* *...I just saw referrals but since number 1, 2, 3 and 4 explained, it does make sense to me because I didn’t know there is a genetic clinic in the hospital…(P35:26:R6)*

4.3.2.2 Question 2: What are the challenges that caregivers and CWDs experience?

Concept: Challenges experienced

This concept was derived from 13 codes, seven subcategories, and two categories. The two categories are family-caregiver related (Table 4.22) and health-care related (Tables 4.23, on page 151 and 4.24, on page 152). The family-caregiver related comprise of information subcategory. Health related category comprises of the following subcategories: (1) communication, (2) teamwork/ collaboration, (3) staff burnout, (4) uniformity, (5) caregiver support, and (6) infrastructure.

Table 4.22 Challenges experienced (1)

Category	Subcategory	Code	Quotation
Family-caregiver related	Information	Lack of information	*…I think it is a lack of information [on the caregivers]…(P35:49: R3)* *There are some caregivers who need a time frame as to how long will it take to stimulate a child to sit even though it depends on the severity of the child's condition and the way the mother stimulate the child at home…(P35:53:R4)*

Table 4.23 Challenges experienced (2)

Category	Subcategory	Code	Quotation
Health-care related	Communication	Poor communication	*….What I find to be lacking is communication… I just heard last of last week that she [genetic nurse] has started a support group but when I checked with my supervisor, I found that she [genetic nurse] did not even communicate with my supervisor. I think that is what is lacking. (P35:30: R2)* *…If there was good communication we could even ask the caregivers to wait for one another [after treatment] so that they go [to the genetic clinic] together…(P35:31: R3)* *…I want to agree with the point that number 3 made, it's the point that I wanted to raise because a problem that we had before was the structuring of the whole treatment from OT to genetic because sometimes it's a problem for them [caregivers] to come to OT and Physio treatment and then go back to the genetic clinic…(P35:33:R5)*
	Teamwork/ collaboration	No teamwork No collaboration No MDT discussions	*…no teamwork…the main problem is that other disciplines are not involved in the CP clinic… (P35:88: R2)* *…we can see that as time goes on this can cause confusion and we might end up fighting as health providers because we do not have that [how genetic clinic works] in our programmes on how it will be run…(P35:32:R3)* *…as professionals I think we also have to gather the files of all the children we have seen in the CP clinic and discuss them…We have to discuss the children's conditions because we do not see the same child every time the clinic is run. If we do not discuss then the caregivers will be surprised and confused by how we work. (P35:54: R4)*
	Staff burnout	Used to have support groups Used to have meetings	*We used to have a support group for caregivers…We used to have meetings with them, we contributed as a support group toward the formation of Pfunanani Special School, and we used to have Christmas parties as a support group. It is only that the support group has not been revived, but it is there. (P35:56: R3)* *…we used to have meetings every second month where we would all [professionals and caregivers] meet and discuss issues. The speech-therapist, dietician and social workers would tell us what their role is and how they could assist those children…(P35:86: R2)*

Table 4.24 Challenges experienced (3)

Category	**Subcategory**	**Code**	**Quotation**
Health-care related	Uniformity	Treatment methods not the same No standardised treatment	*…obviously our treatment methods cannot be the same as we did not go to the same training institution. However, that does not mean that our different treatment methods do not lead to the same goal. We end up achieving the same goal…(P35:39: R1)* *…sometimes we use the child's condition or functional status to determine what will be done. When the child improves and can do what she could not do last month; then we have to change the treatment to suit the child's condition… (P35:45: R2)* *…at school we were taught to utilise any available resources. Therefore of all the activities we do, any [professional] can think as to which technique can they use to prevent disability? What they [professional] choose at a giving time might be different to what others choose and the caregivers can understand that the treatment is different but they [professionals] will be preventing disability and maximising health…children's milestones are tricky more especially the CP's. As they grow, you'll find that they always get sick. When you focus on crawling, and the child gets sick, the next time you see the same child, the child cannot do what she used to do before. Then you will have to go back… (P35:40 & 48:R3)* *…some of the things that confuse caregivers are the way in which we treat these children; for an example, the child is at a stage where she cannot sit but you will find that the child was previously taught to walk. Maybe it confuses them when they are shown different techniques…what do you expect when you teach a child who cannot even sit to walk (P35:43: R4)*
	Caregiver support	No support groups No meeting	*We used to have a support group for caregivers of CWDs. We used to have meetings with them…(P35:56: R3)* *On those support groups we use to give caregivers certificate of appreciation at the end of the year where we were encouraging them to bring their children for further treatment…as number 3 said, we just need to revive it. (P35:58: R2)*
	Infrastructure	Space problem Space not enough	*…the issue of space is a problem. I can see that every Tuesday when we treat there is no enough space…Just imagine if all professionals are there inside. (P35:74: R6)* *…the point of asking management for more space will not work as they are failing as of now (laugh). (P35:78: R4)*

4.3.2.3 Question 3: What is your plan of action to correct the challenges that you have identified?

Concept: Rehabilitation professionals' plan of action

This concept was derived from 13 codes, seven subcategories, and two categories as shown in Tables 4.25, 4.26 (on page 155), 4.27 (on page 155), 4.28 (on page 156), 4.29 (on page 157), and 4.30 (on page 158). Rehabilitation professionals' plan of action aims at correcting challenges that are family-caregiver related, as well as health-care related.

Table 4.25 Rehabilitation professionals' plan of action (1)

Category	Subcategory	Code	Quotation
Family-caregiver related	Information	Educate caregivers	*…we have to tell these caregivers that no medication or pill will fix the child's brain because you may find that they end up spending a lot of money by going to different places where they are told they will get miraculous cure. They spend money that they can be spending on important things such as buying special chair for the child…the other day somebody came to me to ask for a report that she has to take with to Pastor Chris. You can easily see that this caregiver lacks knowledge and information. It is important that we do this. (P35:120 & 121:R2)* *…caregivers should be educated before treatment that different professional can use different treatment techniques to achieve the same goal. We [professionals] also need to review how we do our work. (P35:40: R3)* *…I support what number 1, 2 and 3 has said. I want to emphasise on the issue raised by number 3 of educating the caregivers...to avoid that confusion, they [caregivers] have to be educated that 1, 2, 3 is happening so that they understand. …through health talks we can educate caregivers about their children's conditions and it will be easy for them to do their home programmes. (P35:42 & 117:R6)*
		Revive caregiver meetings Conduct health talks	*…It would be better if we had a place where we discuss and explain to these caregivers that it is important that they attend both the clinics. I think that would strengthen our relationship because sometimes only 2, 3 or 5 people attend the genetic clinic…that is why we are talking about revival. Revival means bringing back something that was there…we have to give them a platform to voice their concerns, and that will assist us in improving the quality of our services. (P35:31, 92 & 109:R3)* *…I think we need to revive those meeting. When we draw up our programmes we need to know that there would be a mass meeting every second month where we all meet and discuss our different roles…(P35:87: R2)* *I think all we need is to have a meeting with the caregivers as we cannot address all the problems and challenges that we have here. (P35:101: R1)* *Health talk is crucial for caregivers…(P35:114: R1)* *…I think the issue of health talks is crucial. Through health talks, we can educate caregivers about their children's conditions, and it will be easy for them to do their home programmes. (P35:117: R6)*

Table 4.26 Rehabilitation professionals' plan of action (2)

Category	**Subcategory**	**Code**	**Quotation**
Health-care related	Communication	Improve communication with colleagues	*…we also need to sit down and discuss what to do. As number 2 said, It seems that the caregivers get confused not knowing why they go to genetic [clinic]. They might question why they have to come to the [CP] clinic and genetic clinic while they do not communicate with one another… (P35:31: R3)* *…we have to discuss the children's conditions because we do not see the same child every time the clinic is run. If we do not discuss then the caregivers will be surprised and confused by how we work. (P35:54: R4)*

Table 4.27 Rehabilitation professionals' plan of action (3)

Category	**Subcategory**	**Code**	**Quotation**
Health-care related	Teamwork/ Collaboration	Include other disciplines Include other professionals Include speech-therapist Include dieticians Include optometrist	*…I think it will be better if we include other disciplines in there…(P35:64: R5)* *…I also think it would be better to include other professionals because it will make the teamwork, to work in one place...(P35:67: R6)* *I understand what number 1 has said but in the past we used to meet as MDT and briefed those people [caregivers] whilst we all listened. It used to help because we used to say whatever mattered whilst everybody else listened…By doing that we were alerting them about the different disciples available…(P35:71: R3)* *...as we draw the programme for CP clinic, we do it as Physio and OT. Even though we might have space problems it is expected of the speech, diet and eye to be available…We expect the dietician to avail themselves on the days that the clinic is run in order to render services to CP children…I think we have to involve these people [other professionals] in order to address this challenge…(P35:75: R2)* *I think number 1 was not saying all disciplines will be seeing the children at once but was saying that on the day of the treatment, the child [and caregivers] will not move from one department to another as these disciplines are housed in one clinical block. (P35:78: R4)* *…exactly what I said...What should happen is for dieticians and speech [therapist] to have awareness campaigns where they will be explain to people what they do as professionals. Children who require dietitian and speech [therapist] services will be referred (P35: 80-82: R1).*

Table 4.28 Rehabilitation professionals' plan of action (4)

Category	**Subcategory**	**Code**	**Quotation**
Health-care related	Collaboration	I am against working together It will not function OT and Physio methods are similar Unaware of the role of speech-therapist Unaware of the role of dieticians CP clinic is the responsibility of OT and Physio Never worked with speech-therapist and dieticians Speech-therapist and dieticians should only screen CWDs	*I am against the issue of working together in one room; I do not think it will be functional…OT and Physio's treatment methods and techniques are more or less the same that is why it is easier for us to work in one place. So I do not know dietician and a speech [therapist] in the same room because they also do counselling, and they need a quiet place…The problem that I see is that the space will not be enough also to accommodate the dietician and speech in that room [treatment room]. While I was doing my practical in Mankweng, we would see the CP kids being OT's and Physios and afterwards send them to dietician, speech and other disciplines…OT and Physio render rehabilitation as an ongoing process whilst their [speech-therapist and dietician] rehabilitation stops. We have to rehabilitate the child from the first milestone until… that is why they are not that involved in the CP clinic. In other ways, CP clinic is our responsibility as OT and Physio. (P35:69 & 84:R1)* *…sometimes you find that you have seen or treated the child at 08:30 am only to find that by 11:00 am or 12:00 pm the child and the caregiver are sitting waiting to be seen by the dietician you understand? They know that we are running the clinic every Tuesday. However, if we try to involve them I think they will cooperate…(P35:85: R2)* *…They do not have to be actively involved in the [CP] clinic but they can come once a month and screen. (P35:90: R6)*

Table 4.29 Rehabilitation professionals' plan of action (5)

Category	Subcategory	Code	Quotation
Health-care related	Uniformity	Query previous treatment	*If these different methods are severe case scenarios to the caregivers, what we can do is first find out what they had learnt already when they came for their home programme you see…practically read the notes in the files what they have learnt already and then from there we can continue either to teach them a new method and say that they can use this one as well or we can just tell them to carry on from that one.(P35:41:R5)* *…she [R5] also mentioned the issue of finding out what the caregivers have learned from the treatments as well as the home programmes that they are doing. It is crucial to ask… that is why most of the time it seems like they [caregivers] are confused because we utilise different methods of treatment to achieve the same goal…I think one thing that I have picked up is that it is crucial to look at the last notes where the other professionals wrote. It gives us the direction of where to go and where to start with the treatment (P35:42 & 47: R6)* *…It is better to ask them what they have been shown to do as their home programme…(P35:43: R4)* *…whenever I see those people[child and caregiver] I start by asking what they have observed, trying to find out if they have notice any changes and they will tell you; yes now the child is better, last time the child could not sit without support but now she can…(P35:49:R3)*

Table 4.30 Rehabilitation professionals' plan of action (6)

Category	Subcategory	Code	Quotation
Health-care related	Caregiver support	Compassion Sensitive communication	*Those people [caregivers] have got their own problems; let us not put more problems on their problems because most of the times we hurt those people by the way we talk to them as health providers. Some caregivers end up getting to the point where they cry ...I think we should be sensitive and not hurt them in the process of communicating with them. They should laugh instead of crying. (P35:107 & 108:R3)* *I once asked a certain caregiver where the mother of the child was only to find that she was the mother. My questioning hurt her, but I thought she was the child's granny...(P35:114: R4)*
		Conduct Home visit	*…I don't know how efficient it will be but I think it will be nice to do home visits to these mothers to monitor and follow up on the child's progress…(P35:97:R5)* *I'm just supporting number 5 (P35:99:R6)*
		Revive support group Give emotional and physical support	*…we just need to revive it. (P35:59: R2).* *I support the issue of the support group, If ever the support is dead; it is better that we revive it. It is important that we give the caregivers both emotional and physical support. One day I had a group with all the parents, I think I called them five, five and I realised that it helped a lot. (P35:61: R1)*
		Revive CRWs	*I am burning because our CRWs need to be revived as well because they are no longer seeing these children at home. When you ask them [caregivers] they will tell you that they do not know who those people [CRWs] are. (P35:119: R3)*

4.4 SUMMARY OF CHAPTER 4

Results presented in Chapter 4 emanate from the FGDs with caregivers, and rehabilitation professionals. A summary of results as presented in this chapter are summarised in Table 4.31.

Table 4.31 Summary of Chapter 4

Caregivers	**Rehabilitation professionals**
The following concepts were identified • Cause of childhood disability • Role of caregivers • Available services • Challenges experienced • Role of CRWs • Caregivers' level of satisfaction • Caregivers' expectations • Caregivers' coping strategy • Caregivers' source of support • Societal perception of CWDs	The following concepts were identified • Genetic clinic • Challenges experienced • Rehabilitation professionals' plan of action

In the next chapter, discussion of the results emanating from Chapter 3 and Chapter 4 are presented. The discussions are followed by the development of non-relational statement

CHAPTER 5

DISCUSSION OF RESULTS AND DEVELOPMENT OF NON-RELATIONAL STATEMENTS

5.1 INTRODUCTION

In Chapter 5, the results of Phase 1 and Phase 2 of the study are combined and jointly presented. This chapter is divided into five sections made up of: (1) introduction, (2) discussion of caregivers and CWDs, (3) discussion of rehabilitation professionals and CRWs, (4) clarification, refinement and sharpening of concepts, and (5) summary of the chapter.

5.2 CAREGIVERS AND CHILDREN WITH DISABILITIES

In this section, the demographic information of all caregivers who participated in the face-to-face interviews and the FGDs is discussed, followed by the discussion of the demographic data of children whose caregivers participated in the study.

5.2.1 Caregivers' Age Groups

The majority of caregivers (75%) who participated in Phase 1 and Phase 2 of the study are younger and below the age of 34 years as shown in Table 5.1 (on page 161). This finding is similar to that of study conducted in poorly resourced areas of Limpopo and Gauteng Provinces of South Africa by Saloojee *et al* (2009) in whose study caregivers below the age of 34 years were at 68 per cent. Another South African study by Kropiwnick, Elphick, and Elphick (2014) which was conducted in a poorly resourced Gauteng area found that only 14 per cent of caregivers in their study were below the age of 34 years. However, participating caregivers in the study by Kropiwnick, Elphick, and Elphick (2014), were mainly mothers of older children between the age of five and 15. The age group of the majority of caregivers who participated in the current study falls within the economically active and productive population, but their participation in the economy are inhibited because of the demands of caring for a CWD.

Table 5.1 Caregivers' age

Age range	Frequency	Percentage
18-23	6	30%
24-29	7	35%
30-34	2	10%
35-39	1	5%
40-44	1	5%
45>	3	15%
Total	**20**	**100%**

5.2.2 Caregivers' Gender

The fact that only one out of the 20 caregivers who participated in the present study is male shows that the majority of the primary caregivers of CWDs are females and young mothers. According to the South African Census 2011, there are 51.3 per cent of females in the country as compared to 48.7 per cent of males. In addition, Limpopo Province was reported to have the highest number of females at 53.3 per cent (STATSSA, 2012).

Regardless of the geographic location, the gender compilation among the caregivers who participated in the present study is similar to that of western countries. Miles, Steiner, Luken, Sanderson, Coyne-Beasley, Herrick, Mizelle and Ford (2011), also found that the majority (79%) of the primary caregivers of CWDs were females.

5.2.3 Caregivers' Marital Status

Thirteen (65%) of the caregivers who participated in the present study, were single, and seven (35%) were married. These findings are similar to that of Kropiwnick, Elphick, and Elphick (2014) who reported that 59 per cent of caregivers who participated in their study were single with 36 per cent being married. However, these findings of marital status are in contrast to those of Miles *et al* (2011) who found that 75.6 per cent of caregivers who participated in their study were married. The differences between the findings are understandable considering that Miles *et al* 's (2011) study was conducted in a western society.

Nonetheless, several studies suggested that caregivers of CWDs in western societies tend to have marital problems and are more likely to be single parents compared to caregivers of typically developing children who are primarily single (Marshall, Olsen, Mandleco, Dyches, Allred, & Sansom, 2003; Rivers & Stoneman, 2003; Brobst, Clopton, & Hendrick, 2009; Parker, Mandleco, Roper, Freeborn, & Dyches, 2011; Walsh & O'Leary, 2013).

5.2.4 Relationship of the Caregiver to the Child

About 18 (90%) of the caregivers who participated in the current study were mothers, one (5%) was a grandmother, and one (5%) was the father. The implication of this finding is that mothers are the primary caregivers of CWDs in Giyani. The study by Kropiwnick, Elphick, and Elphick, (2014) reported that 91 per cent of caregivers in their study are mothers while nine per cent are grandmothers.

5.2.5 Caregivers' Number of Dependent Children

Caregivers who had more than one child were 68 per cent of the total sample of caregivers, which is similar to the result of Miles *et al* (2011). About six (32%) caregivers only have one child; eight (42%) caregivers have two dependent children and five (26%) caregivers have over three dependent children. These findings suggest that 68 per cent of the caregivers who participated in the study had two or more children to care for. According to Crnic, Gaze, and Hoffman (2005), raising a child has some level of parental stress even if the child is developing without any disabilities. It is also known that raising a CWD is associated with high levels of parental stress (Neece, Shulamite, & Baker, 2012; Algood, Harris, & Hong, 2013; Estes *et al*, 2013). Therefore, a caregiver who has more than two dependent children is more likely to have higher levels of parental stress.

5.2.6 Caregivers' Educational Background

About 18 (90%) caregivers had a secondary level education ranging from grade 8 to grade 12. One (5%) caregiver attended school up to higher primary level, and another (5%) caregiver's level of education is unknown.

These findings are in line with the results of the South African Census 2011 where 81.2 per cent of black South Africans over the age of 20 years had only primary- and secondary-level education (STATSSA, 2012). In addition, the findings of the current study are similar to those of the study in Limpopo and Gauteng Provinces by Saloojee *et al* (2009) where 85.5 per cent of caregivers had primary- and secondary-level education. However, these findings do not necessarily imply that caregivers of

CWDs are poorly educated; it is therefore clear that poorly educated caregivers of CWDs probably don’t have the financial resources to seek rehabilitation services in private health-care sector and are making use of public health-care facilities. This fact is closely associated with caregiver's employment status (Section 5.2.7), family income (Section 5.2.8) and their sources of income (Section 5.2.9).

5.2.7 Employment Status

All of the caregivers who participated in this study were unemployed. These findings of employment status are in contrast with the findings of Miles *et al* (2011), who found that over 70 per cent of the caregivers in a HIC who participated in their study were employed. A local South African study by Saloojee *et al* (2009) found that the number of unemployed caregivers who participated in their study was 78.3 per cent of the total number of participants. The educational qualification that a person has, is closely associated with the skills that he/she has. These skills in turn are closely associated with one’s employability (Allais, 2012). Considering that the caregivers of CWDs who participated in the present study had poor educational backgrounds and skills, it is not surprising that all of them were unemployed. According to the Census 2011, the unemployment rate in South Africa is at 24.7 per cent (STATSSA, 2012).

5.2.8 Estimated Family Income

In Table 5.2 (on page 164), the CWDs and their caregivers’ estimated family income are presented. According to South African Census 2011, Limpopo Province had an average monthly income of R4 737 (STATSSA, 2012).These findings on the estimated family income suggest that the caregivers who participated in the study are among the poorest in the country as the average income is far below R4 737. Limpopo Province was considered to be the province in which people with the lowest average monthly income South Africa lives (STATSSA, 2012).

Table 5.2 Family's estimated income

Income range (R)	Frequency	Percentage
< 500	1	5%
500-1000	7	37%
1001-1500	8	42%
1501+	3	16%
Total	**19**	**100%**

5.2.9 Caregivers' Sources of Income

In Table 5.3, the caregivers' sources of income are presented. About 13 (65%) of the caregiver's households relied exclusively on social grants as their source of income. The other seven (35%) relied on a combination of social grants and other 'odd jobs' as their source of income. According to the General Household Survey of 2011 by Statistics South Africa, Limpopo Province had the highest level of reliance on social grants as the primary source of income. It was reported that 58.2 per cent of the general population of Limpopo Province relied on social grants (STATSSA, 2011). Even though the provincial rate (58.2%) is less than the rate of the caregivers who participated in the current study (100%), the fact remains that the population of Limpopo in general relies heavily on social grants as the primary source of income.

Table 5.3 Caregivers' sources of income

Source of income	Frequency	Percentage
Social grants only	13	65%
Social grants + artisan jobs	2	10%
Social grants + farm labourer	2	10%
Social grants + miner	1	5%
Social grants + domestic work	1	5%
Social grants + guard	1	5%
Total	**20**	**100%**

5.2.10 Caregivers' Living Arrangements

About 12 (60%) caregivers stay with their parents, four (20%) with their partners, two (10%) alone, one (5%) alternate between parents and partners, and there is one (5%) who stay with relatives. This result is not surprising because 13 (65%) caregivers are single. The result may also indicate that the family model of support is high in the area in which the study was conducted. Several studies in the literature focused on the living arrangement of CWDs themselves during the transition of being a dependent child into an adult (Glew & Bennett, 2011; Maggs, Palisano, Chiarello, Orlin, Chang, & Polansky, 2011; Alriksson-Schmidt, Hägglund, Rodby-Bousquet, & Westbom, 2014).

5.2.11 Availability of Electricity

About 18 (90%) caregivers have access to electricity. Only two (10%) caregivers did not have access to electricity. These results confirm the findings of the South African Census 2011 where it was reported that 87.1 per cent of the residents of Limpopo Province had access to electricity (STATSSA, 2012). What can be inferred is that the local government is trying to ensure that all citizens including CWDs are being provided with basic services in the form of electricity.

5.2.12 Availability of Water

Ten (50%) caregivers had access to piped water either in their yard or outside their yard. The remaining ten (50%) had no access to piped water, and they depended on getting water from the rivers or buying from those who have boreholes in their yards. This finding is contrary to the findings of the South African Census 2011, where 52.3 per cent of the population in Limpopo Province had access to piped water in their yard, 33.7 per cent had access to piped water outside their yard and only 14 per cent had no access to piped water (STATSSA, 2012). Without access to piped water, female CWDs would struggle fetching water from other sources such as rivers when they reach adolescence and will only be able to do so if their functional ability permits them to do household functions. It is culturally expected of an adolescent to do household activities like fetching water and cooking.

5.2.13 Children's Age

Sixteen (80%) children whose caregivers participated in the current study are between the ages of one to three years, three (15%) are between the ages of four to six years, and one (5%) is between the ages of seven to nine years. This means that these children's conditions had been identified and diagnosed early, which is contrary to the findings of Scherzer *et al* (2012) who reported that professionals in LMIC such as South Africa have limited formal or informal education or sensitisation, interest or the ability to recognise early developmental delays in children. Early detection of childhood disability is necessary because children who receive early intervention have a very functional outcome compared to those who are only diagnosed at a later age (Meisels & Atkins-Burnett, 2000)

5.2.14 Children's Gender

There were 12 (60%) female children as compared to eight (40%) male children whose caregivers participated in the present study. This finding is in contrast to the reported findings from other studies. In a study by Raina, Razdan, and Nanda (2011) and Ibrahim and Bhutta (2013), more male CWDs participated in their study than female CWDs. Although the South African Census 2011 reported that the number of male children born in South Africa is greater than the number of females (STATSSA, 2012), the conclusion cannot be made that more female children have disabilities than male children because the sample of CWDs whose caregivers participated in the present study, was not a representative sample of the total population.The higher number of female CWDs could mean that the larger number of caregivers with female children were recruited.

5.2.15 Children's Diagnoses

Cerebral palsy is the most common diagnosis (80%) of children whose caregivers participated in Phase 1 and Phase 2 of the study, as shown in Table 5.4. These findings confirm the assertion that cerebral palsy is the most common childhood disability in LMIC (Raina, Razdan, & Nanda, 2011; Ibrahim & Bhutta, 2013).

Table 5.4 Diagnoses of children

Diagnosis	**Frequency**	**%**
Cerebral palsy	16	80%
Microcephalus	2	10%
Down Syndrome	1	5%
Achondroplasia	1	5%
Total	**20**	**100%**

5.3 REHABILITATION PROFESSIONALS' AND COMMUNITY REHABILITATION WORKERS

In this section, the demographic data of rehabilitation professionals and of the CRWs who participated in the study is presented. When rehabilitation professionals and CRWs are discussed together, they are categorised under the group referred to as "health professionals".

5.3.1 Age of Health Professionals

The health professionals' ages ranged between 23 to 56 years with the median age of 37.8 years as shown in Table 5.5. The age range of health professionals who participated in the current study is similar to those of their counterparts in the study by Braga and Rochette (2013). In this latter study, the health professionals' ages ranged between 31 to 44 years with a median age of 37.5 years. The age of health professionals suggests that CWDs are mainly managed by health professionals in their middle ages and who will be soon approaching their possible retiring age of 55 years. It is also likely that younger health professionals are not interested in the field of paediatric rehabilitation in rural communities.

Table 5.5 Health professionals' age

Age range	Frequency	Percentage
20-25	1	10%
26-31	3	30%
32-37	0	
38-43	3	30%
44-49	2	20%
>50	1	10%
Total	**10**	**100%**

5.3.2 Gender of Health Professionals

Six (60%) female health professionals participated in the present study compared to four (40%) males. Even though the sample size of health professionals who participated in the present study is lower than the sample size in other studies, Braga and Rochette (2013) found that the rehabilitation professionals in their study were mostly female. The finding of the present study is in line with the South African Society of Physiotherapy's (SASP) membership in terms of gender because in South Africa rehabilitation is mainly a profession conducted by females.

5.3.3 Occupation of Health Professionals

The health professionals in the current study had training in physiotherapy, occupational therapy and nursing, as shown in Table 5.6. Similarly, rehabilitation professionals who participated in a study conducted by Bunning, Gona, Odera-Mung'ala, Newton, Geere, Hong, and Hartley (2014) had training in physiotherapy and occupational therapy. However, in a study conducted by Braga and Rochette (2013) rehabilitation professionals had training in a variety of fields – such as physiotherapy, occupational therapy, speech language therapy, social work, neuropsychology, and guidence counselling. The provision of services for CWDs at Nkhensani Hospital is mainly performed by the physiotherapy, occupational therapy and nursing personnel. Speech-therapists, social workers and psychologists are available in the hospital but are not part of the rehabilitation clinic. Nonetheless, they do accept referrals from the rehabilitation clinic to assess and treat CWDs should their services be required.

Table 5.6 Occupations of health professionals

Occupation	**Frequency**	**Percentage**
Occupational therapy assistant	3	30%
Occupational therapist	2	20%
CRWs	2	20%
Physiotherapy assistant	1	10%
Physiotherapist	1	10%
Professional Nurse	1	10%
Total	**10**	**100%**

5.3.4 Qualifications of Health Professionals

Six (60%) out of ten health professionals who participated in the present study had a diploma or equivalent qualification, these six health professionals had 'professional' training for a duration of two years or less. As a result of this fact, it is likely that the quality of rehabilitation service rendered can be questionable when taking into considering the duration of the training of the of service providers. The qualification levels of health professionals who participated in the present study were different from those of the participants of a similar study carried out in the rural areas of Kenya. Out the ten "rehabilitation professionals" who participated in the Kenyan study, two had a certificate qualification while eight had a diploma qualification (Bunning *et al*, 2014). It seems that the rehabilitation services in rural parts of Africa tend to be serviced mainly by rehabilitation professionals with non-degree qualifications. In Europe, the health professionals and the rehabilitation professionals in particular are adequately trained in their professional field. Countries such as Slovenia, Croatia and Hungary train rehabilitation professionals for a period of between three to five years where the outcome of the training is a bachelor’s degree (Eldar, Marincek, & Kullmann, 2008).

5.3.5 Experience of Health Professionals

The experience of health professionals who participated in the current study ranged from zero to 35 years with an average of 11 years (Table 5.7). These findings are similar to those from Bunning *et al* (2014), where the rehabilitation professionals’ experience ranged from zero to 29 years, with an average experience of 13 years.

Table 5.7 Experience of health professionals

Experience in years	Frequency	Percentage
< 1	2	20%
1-3	1	10%
4-6	1	10%
7-9	0	
10+	6	60%
Total	**10**	**100%**

Although the health professionals who participated in the current study had varying levels of training and qualification as discussed in Section 5.3.4, the majority of them have over ten years of working experience.

It is, therefore, not all categories of health professionals in Giyani who stays for a short period during their careers as rehabilitation professionals.

5.4 CLARIFICATION, REFINEMENT AND SHARPENING OF CONCEPTS

In this section, the existing body of literature was used to clarify, refine and sharpen concepts in a process that (Walker & Avant, 2005) refers to as concept analysis. Non-relational statements were developed after the clarification, refinement and sharpening of concepts. The purpose of the non-relational statements is to define the concept, even though the definition is abstract and unmeasurable (Walker & Avant, 2005). A total of 16 concepts were clarified, refined and sharpened.

5.4.1 Concept: Cause of Childhood Disability

The development of this concept was based on the perspectives of caregivers during the face-to-face interviews and FGDs as shown in Table 5.8. Caregivers' perspectives on the cause of their children's disabilities were based on: (1) their religious beliefs, (2) their other beliefs, (3) biomedical reasons, and (4) their lifestyle and habits.

Religious and other beliefs

Caregivers in the present study thought that their religious beliefs and other beliefs are a possible cause of childhood disabilities. This finding as reported in the current study has also been found in other studies. According to Hebert and Koulougliotí (2010) caregivers of CWDs hold a wide variety of beliefs about the cause of their children's disabilities such as genetic factors, events surrounding the child's birth, and environmental influences in the early childhood period. In addition, some caregivers attribute their children's disability to immunisations.
Two studies have found that caregivers of CWDs think that theological- or religious-based beliefs are responsible for causing childhood disabilities (Croot *et al*, 2008; Daudji, Eby, Foo, Ladak, Sinclair, Laundry, Moody, & Gibson, 2011).

Some of the caregivers who participated in the current study believed that the lack of a child's stepping reflex or not crying directly after birth was also responsible for causing childhood disability. This belief is a misconception because the lack of a stepping reflex or not crying at birth which is associated with low Apgar score may be an indication or a sign that the child may have a neurological or developmental problem (Lie, Grøholt, & Eskild, 2010).

Biomedical reasons

In modern medicine, belief-based reasons are not considered to be a possible cause of childhood disabilities as there is no evidence to support it. Instead, biomedical reasons are considered to be the primary cause of childhood disabilities (Jauhari *et al*, 2011; Karthikeyan & Ramalingam, 2012; Mcintyre, Taitz, Keogh, Goldsmith, Badawi & Blair, 2013).

Several studies have suggested that infectious diseases are a leading cause of childhood disability (Rivara, Koepsell, Wang, Temkin, Dorsch, Vavilala, Durbin, & Jaffe, 2011; Kristina, Kate, Gudrun, Marian, Teresa, Ulla-Britt, & Bo, 2013; Khandaker, Muhit, Rashid, Khan, Islam, Jones, & Booy, 2014). The infectious diseases that lead to childhood disabilities include amongst others congenital rubella syndrome, pneumococcal, meningococcal and *Haemophilus influenzae* type b meningitis are all preventable by using vaccines (Maulik & Darmstadt, 2007). The lack of vaccination or immunisation was also suggested by caregivers who participated in the face-to-face interviews and FGDs as a possible cause of disability. In order to reduce the likelihood of disability due to preventable infectious disease, Ibrahim and Bhutta (2013) has highly recommended that children should be immunised.

As alluded by the caregivers who participated in the present study, hypoxia has been reported in the literature as a possible cause of disabilities in children (Nielsen, Schendel, Grove, Hvidtjørn, Jacobsson, Josiassen, Vestergaard, Uldall, & Thorsen, 2008; Fatemi & Folsom, 2009; Natarajan, Shankaran, Pappas, Bann, Tyson, McDonald, Das, Hintz, Vohr, & Higgins, 2014). However, a review of the literature by Ellenberg and Nelson (2013) has suggested that the current available data does not support the belief that birth asphyxia can be recognised as a reliable cause of disability.

Some caregivers in the present study have reported that head injury to the child during birth is a possible cause of disability. These caregivers' suggestions may be considered to be true considering that there is sufficient evidence in the literature to support the suggestion that head injuries are responsible for causing childhood disabilities. According to Bax, Flodmark, and Tydeman (2007) an insult or injury to the brain before birth or in early childhood may result in childhood disability.

Stress during pregnancy, as suggested by some caregivers who participated in the present study, has also been thought to be the cause of childhood disabilities. According to Loomans, Van Dijk, Vrijkotte, Van Eijsden, Stronks, Gemke, and Van Den Bergh (2013) pregnant mothers who experience psychosocial stress are at risk of delivering babies with an adverse birth outcome such as disability. According to Schetter and Tanner (2012) anxiety, depression, and stress in pregnancy are risk factors for adverse outcomes for mothers and children. Anxiety in pregnancy is associated with shorter gestation and has adverse implications for foetal neurodevelopment and the child outcomes.

Lifestyle and habits

The idea that a pregnant woman's lifestyle and habits may result in disability of the unborn child has also been reported in other studies. Croot *et al* (2008) as well as Underberg, Kesmodel, Landrø, Bakketeig, Grove, Wimberley, Kilburn, Sværke, Thorsen and Mortensen (2012) has suggested that the use of alcohol and tobacco in pregnancy can result in some degree of developmental delay or disability in the child. According to Peadon, Payne, Henley, D'Antoine, Bartu, O'Leary, Bower and Elliott (2011) alcohol is teratogenic and alcohol consumption during pregnancy may lead to growth restriction, birth defects, and structural and/or functional problems of the central nervous system in the exposed foetus. A study conducted in Denmark has shown a significant association between heavy maternal smoking (more than ten cigarettes per day) during pregnancy and risk of childhood disability, but no significant association was found for moderate smoking (Streja, Miller, Bech, Greene, Pedersen, Yeargin-Allsopp, Braun, Schendel, Christensen, Uldall, & Olsen, 2013).

Some caregivers in the current study indicated that consumption of the wrong food during pregnancy such as spicy food may cause childhood disabilities. However, Gao *et al* (2013) suggested that avoidance of certain foods during pregnancy is associated with mother's cultural beliefs and does not necessarily mean that there would be an adverse impact on the child. Instead *capsicum annuum L* which is a chemical found in pepper contains vitamin A and C as well as having antioxidant properties which is good for both the pregnant mother and the child (Mateos, Jiménez, Román, Romojaro, Bacarizo, Leterrier, Gómez, Sevilla, del Río, Corpas, Palma, 2013). This example indicates how important it is for pregnant mothers to receive appropriate nutritional education. A summary of the causes of childhood disability is shown in Table 5.8.

Table 5.8 Cause of childhood disability

Category	**Phase 1 Caregivers**	**Phase 2 Caregivers**
Religious Belief	Witchcraft	Curse Witchcraft
	God’s decision	God’s decision
Other belief	Misconception	Misconception
Biomedical	Head injuries	Poor immunisation Hypoxia Stress in pregnancy
	Hypoxia	Poor immunisation
Lifestyle and habits		Smoking and drinking Spicy food

Summary

The caregivers who participated in the current study attributed the cause of their children’s disability on their religious and other beliefs. However, beliefs cannot be scientifically tested or proven as a possible cause of disability and there is no evidence in the literature that it is a cause of childhood disability although some authors have indicated that caregivers in their studies share the same/similar beliefs. Caregivers have also attributed biomedical reasons and their own lifestyles and habits as possible causes of childhood disability. Sufficient evidence in the literature suggests that biomedical reasons and the caregivers own lifestyles and habits have the potential to cause disabilities in children. Shonkoff and Marshall (2000) have suggested that childhood disabilities are caused by: (1) genetic disorders such as chromosomal abnormalities, single-gene defects, mitochondrial disorders, and multifactorial disorders, (2) early brain malformations such as myelodysplasia, hydrocephalus, microcephaly, megalencephaly, and agenesis of the corpus collusum, (3) infections such as cytomegalovirus, congenital rubella, toxoplasmosis, and HIV, (4) toxic insults such as fetal alcohol syndrome, cocaine, and smoking of tobacco, (5) malnutrition, and (6) prenatal and perinatal brain injury.

Non-relational statement

Childhood disability is caused by biomedical factors before, during or after the birth of a child as well as the mothers’ lifestyle and habits during pregnancy (Shonkoff & Marshall, 2000; Bax, Flodmark, & Tydeman, 2007; Maulik & Darmstadt, 2007; Croot *et al*, 2008; Nielsen *et al*, 2008; Fatemi & Folsom, 2009; Jauhari *et al*, 2011; Peadon *et al*, 2011; Rivara *et al*, 2011; Karthikeyan & Ramalingam, 2012; Schetter & Tanner, 2012; Underberg *et al*, 2012; Ellenberg & Nelson, 2013; Kristina *et al*, 2013; Loomans *et al*, 2013; Mcintyre *et al*, 2013; Streja *et al*, 2013; Khandaker *et al*, 2014; Natarajan *et al*, 2014). Caregivers have also suggested that childhood disability occurs as a result of religious and other belief based reasons. However, there is no scientific evidence in the literature to suggest that belief based factors could lead to childhood disability. Even though belief based factors cannot be scientifically proven as a possible cause of childhood disability, relevant information has to be provided to caregivers of CWDs.

5.4.2 Concept: Available Services

The development of this concept was based on the perspectives of caregivers and rehabilitation professionals during the face-to-face interviews, FGDs with caregivers, and the launch of the GGDF.

The available services as reported by caregivers, rehabilitation professionals and during the launch of the GGDF are shown in Table 5.9 (on page 175). The available services in Giyani are: (1) health-care services, (2) rehabilitation services, (3) community services, and (4) social services.

Health-care and rehabilitation services

One of the rehabilitation professionals in the current study has expressed that one of the available services in Giyani include health-care services in the form of hospitals. Rehabilitation service in Giyani is mainly located within the hospital setting. Physiotherapy, occupational therapy, speech therapy, and orthotics and prosthetics services were mentioned as some of the available rehabilitation services. The findings of the present study are similar to those that were reported in the rural parts of Kenya where Bunning *et al* (2014) found that the rehabilitation services that caregivers and their CWDs accessed, comprised hospital-based occupational therapy, physiotherapy and orthopaedic technology (i.e. orthotics and assistive devices).

Community-based services

The community-based services in Giyani comprise disability forum, special schools, CRWs, and home-based carers. The office of the disability forum was not in the public domain. Neither the caregivers nor rehabilitation professionals made any mention of where the offices of the GGDF were located nor did the researcher establish it. Pfunanani is the only special school in the Greater Giyani Municipality. Five CRWs served the whole of the Greater Giyani.

Bunning *et al* (2014) stated that there were community based services such as special education establishments, education assessment resource centre, and community-based organisation relevant to CWDs in their study as it was the case in the current study.

Social services

Caregivers and the rehabilitation professionals alike reported about the availability of social services in the form of social grants.

Table 5.9 Available services

Category	**Phase 1 Caregivers**	**Phase 1 GGDF**	**Phase 1 Rehabilitation professionals**	**Phase 2 Caregivers**
Health-care services			Hospitals	
Rehabilitation services	Physiotherapy Occupational therapy Speech therapy Orthotics and prosthetics	Physiotherapy Occupational therapy		Physiotherapy
Community-bases services	Special schools CRWs Home-based carers	Disability forum Special school	Disability group Special school CRWs	Special schools
Social services	Social grants		Social grants	Social grants

Summary

Caregivers, rehabilitation professionals and the people attending the launch of the GGDF have indicated that the services which are available for CWDs in Giyani include: (1) health-care and rehabilitation services, (2) community-based services, and (3) social services. The findings of the current study are similar to what was found in others studies. For an example, Saloojee *et al* (2007) found that education, rehabilitative, social grants and supportive services were available for CWDs in under-resourced areas in South Africa.

Non-relational statement

Services that are available for caregivers and CWDs include general health-care and rehabilitation services, community-based services, and social services. However, the health-care, rehabilitation and social services are mainly available in the town of Giyani and not in the communities where caregivers and CWDs reside. Therefore, the accessibility of those services by caregivers and CWDs is questionable more especially when taking into consideration the: (1) distance between the villages and the town of Giyani, and (2) the accessibility, availability and affordability of the modes of transport to the town of Giyani.

5.4.3 Concept: Role of caregivers

The development of this concept was based on the perspectives of caregivers during the face-to-face interviews and FGDs, as well as rehabilitation professionals and CRWs during the face-to-face interviews as shown in Table 5.10 (on page 179). The role of caregivers from the perspectives of caregivers, rehabilitation professionals and CRWs is to ensure that caregivers support the child and to ensure that there is continuity of care for the CWD.

Support the child (Passive care)

The caregivers and health professionals who participated in the present study have suggested that the role of caregivers during the rehabilitation of CWDs is to support the child. Just like any other typical developing children, CWDs are children who need love, nurturing and care. CWDs have been reported to require more attention and care compared to typically developing counterparts (Nelson, 2002; Crowe & Florez, 2006; Raghavendra, Virgo, Olsson, Connell, & Lane, 2011), CWD as such are therefore likely to require more attention than anticipated by their caregivers. According to Mondal, Ferdous, Islam, Hossain, Shahiduzzaman, and Choudhary (2014) CWDs are at a higher risk of being victims of abuse, exploitation, and maltreatment at home, schools, play areas, and society in general. This vulnerability of CWDs to be victims of abuse and exploitation requires that the role of caregivers should be to take extreme precautions to protect CWDs through comprehensive support and care (Mondal *et al*, 2014). In another study, caregivers of CWDshave indicated that what is critical to the quality of life of CWDs is their role, as well as the support network that they have (Mayes, Llewellyn, & McConnell, 2008).

The majority of caregivers (90%) who participated in the present study were mothers of CWDs, and it is expected of them to play a motherhood role. According to Harkness and Super (1995), motherhood role includes nurturing, socialising, educating and caring for children. In addition, another study has also indicated that the role of caregivers of CWDs is to care for the CWDs (Sawyer, Bittman, Greca, Crettenden, Borojevic, Raghavendra, & Russo, 2011).

Continuity of care (Active care)

Some caregivers who participated in the present study have suggested that caregivers play an active role in the form of continuity of care during the rehabilitation process of their children. Caregivers ensured that CWDs received rehabilitation services in the hospital and continued implementing the rehabilitation activities suggested by the rehabilitation professionals at home. According to Cowie, Morgan, White, and Gulliford (2009) continuity of care is defined: (1) as an aspect of care experienced by persons receiving care, and services over time, (2) it entails the clients' experience of consistent, and coordinated care, (3) it relates to how clients experience integration of services and coordination by providers.

The findings of the present study are in line with an earlier finding by Egilson (2011) that caregivers of CWDs prefer to play an active role in their children's rehabilitation. Caregivers' relationship with health professionals is characterised by mutual respect between the caregivers and health professionals, joint decision making and collaboration with health professionals. Similarly Dirks and Hadders-Algra (2011) have also found that caregivers play an active role during the rehabilitation process of their children within the health-care facility as well as at home.

Caregivers and rehabilitation professionals in the current study have suggested that the role of caregivers include: (1) to learn hands-on skills, (2) to perform hands-on skills, (3) to demonstrate their skills, and (4) perform home programmes. The rehabilitation professionals and CRWs suggested additional functions that caregivers did not mention, such as playing the role of rehabilitation professionals and CRWs respectively. Unlike the caregivers and rehabilitation professionals, CRWs in the present study did not include the learning of hands-on skills and the performance of hands-on skills as some of the roles that caregivers play. The possible explanation of the omission of the learning of hands-on skills and performance of hands-on skills is that CRWs do not show caregivers what to do but instead they expect caregivers to demonstrate to them what they have been taught by the rehabilitation professionals in the hospital.

The results of the present study confirm the findings of Dirks and Hadders-Algra (2011) who reported that caregivers play the role of a therapist which include the planning of the rehabilitation process, performing hands-on therapy and carrying out a home programme.

Furthermore, rehabilitation professionals in the present study have also suggested that caregivers are the main role players in the rehabilitation of CWDs. The finding implies that caregivers have a significant role to play in the rehabilitation of CWDs more than any other role players such as the rehabilitation professionals and CRWs. The importance of the caregivers in the rehabilitation of their CWDs was also reported in another study where caregivers indicated that they were “more than just a mom.” Caregivers’ role was not just parenting, but multidimensional. Each caregiver used the term “24/7” to indicate the level of intense, nonstop involvement they had with their children (Anderson, 2009). Similarly other researchers have reported that caregivers are experts when it comes to meeting the needs of their children (Garwick, Patterson, Bennett, & Blum, 1998; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005).

Table 5.10 Role of caregivers

Categories	Phase 1 Caregivers	Phase 2 Caregivers	Phase 1 Rehabilitation professionals	Phase 1 CRWs
Support the child (Passive care)	Love		Love	Update CRWs
			Care	
Continuity of care (Active care)	Learn	Learn	Learn	
	Hands-on	Hands-on	Hands-on	
	Demonstrate	Demonstrate	Demonstrate	Demonstrate
	Home programme	Home programme	Home programme	Home programme
			Assume professionals' role	Assume CRWs role
			Main role player	

Summary

The Information that was obtained from the caregivers, rehabilitation professionals, CRWs, and the literature indicated that the role of caregivers in the rehabilitation of CWDs is to support the child and to sure that there is continuity of care for the child.

Non-relational statement

Caregivers have two main roles to play. These roles are: (1) to support, nurture, and love the child, and (2) to ensure that there is continuity of care by learning hands-on skills and performing them at home in the form of home programme. Caregivers should be the primary rehabilitators of CWDs at home as they spend more time with the child than rehabilitation professionals. Caregivers and rehabilitation professionals alike accept that caregivers should be the primary rehabilitators of CWDs at home where their role should be similar to that of health professionals such as performing hands-on role. The expectation from rehabilitation professionals is that caregivers should learn how to conduct hands-on skills in the hospital so that they can conduct it at home in the form of a home programme.

5.4.4 Concept: Caregivers’ Source of Support

The development of this concept was based on the perspectives of the caregivers during the face-to-face interviews and FGDs as shown in Table 5.11. The caregivers have indicated in the present study that their source of support includes: (1) religion, (2) family, friends, and neighbours, (3) health-care services, and (4) community-based services. However, there are caregivers who reported not to have received any form of support from anybody.

Caregivers’ sources of support as reported in the current study are similar to the formal and informal support structures as reported by Kenny and McGilloway (2007). The formal support structures include the hospital services provided by hospital staff whereas informal support structures include family, friends, church, neighbours, home-based carers, schools and other caregivers (Kenny & McGilloway, 2007). Another study has also confirmed that caregivers of children with a brain tumour were reported to receive support from the extended family, siblings, the health-care worker, rehabilitation workers and workers in educational services (Shortman, Beringer, Penn, Malson, Lowis, & Sharples, 2013).

Religion

Religion as a source of support when caring for a CWD as reported in the current study has also been reported in other studies. Several studies have reported that religion and spirituality was the primary source of support for families or caregivers of CWDs (Rogers-Dulan, 1998; Skinner, Correa, Skinner, & Bailey, 2001; Tarakeshwar & Pargament, 2001; Duvdevany & Vudinsky, 2005; Khamis, 2007; Pillay, Girdler, Collins, & Leonard, 2012; Gallagher, Phillips, Lee, & Carroll, 2014).

Family, friends and neighbours

As in the current study, other authors have also found that family, friends, and neighbours were the number one providers of support for caregivers of CWDs (Pillay *et al*, 2012; Pfeifer, Silva, Lopes, Matsukura, Santos, & Pinto, 2014).

Health-care services

As in the current study, other studies have also found health professionals were the main providers of support for caregivers of CWDs (Summers, Marquis, Mannan, Turnbull, Fleming, Poston, Wang, & Kupzyk, 2007).

Community-based services

Caregivers in the present study have reported that they also get support from community-based services such crèche, home-based carers, and support groups. Similar findings were also reported by Kenny and McGilloway (2007) and Pillay *et al* (2012). However, there were caregivers in the present study who reported not to have received any form of support from anyone not even from their family, hospital or the rehabilitation professionals in the rehabilitation clinic. Shortman *et al* (2013) found the same source of support for caregivers that what was found in the present study.

Table 5.11 Caregivers' source of support

Category	Phase 1 Caregivers	Phase 2 Caregivers
Adequate support	Religion	Religion
	Family and neighbours	Family, friends and neighbours
	Health-care services	
		Crèche
	Community-based services	Community-based services
Absent support		

Summary

Sufficient evidence in the literature suggests that caregivers' informal sources of support are religion and family, friends and neighbours. Formal sources of support are health-care services, and community-based services (Kenny & McGilloway, 2007; Tadema & Vlaskamp, 2010). Terminology that is also used in the literature to describe formal and informal sources of support to caregivers include: (1) immediate family, (2) kinship network, (3) informal networks, and (4) professional service providers (Correa, Bonilla, & Reyes-MacPherson, 2011).

Non-relational statement

Caregivers have multiple sources of support. These sources of support include: (1) religion where caregivers uses their religious beliefs, church mates, and the church as a source of support, (2) Family, friends and neighbours, (3) health-care/rehabilitation services, and (4) community-based services. However, some caregivers felt that they had not received any form of support from anyone. The implication of the reported lack of support is that rehabilitation professionals should ensure that they facilitate the formation of support groups and facilitate other social interactions group that may contribute to the social/emotional support of the caregivers and CWDs.

5.4.5 Concept: Caregivers' Coping Strategy

The development of this concept was based on the perspectives of caregivers during the face-to-face interviews and FGDs as shown in Table 5.12. Caregivers in the current study have suggested that their coping strategies are based on: (1) acceptance of the CWD, (2) patience, (3) fait accompli, and (4) religious belief.

Acceptance

The finding of the current study that acceptance of the CWD is a coping strategy has also been reported in other studies as one of the leading coping strategies of caregivers of CWDs (MacDonald, Fitzsimons & Walsh, 2006; Wang, Michaels, & Day 2011). Even though the study by MacDonald *et al* (2006) differentiated between the coping strategies used by male and female caregivers, they also reported coping strategies such as beliefs, looking for positives in all situations and finding additional information about the child's condition.

Patience and fait accompli

Learning to be patient and the assertion that it was not the caregivers' choice to have a CWD, were also reported in other studies as means of coping with the pressure of having a CWD. Shortman *et al* (2013) reported that a female caregiver looking after a child with a brain tumour managed to cope because of the feelings she had towards the child; being driven by the responsibility of being a mother and her free choice regarding her own personal attitude.

Religious beliefs

The use of religion as a coping strategy when caring for a CWD was reported in the current study as well as in other studies. Several studies have reported that religious belief and spirituality was the main coping strategy for families or caregivers of CWDs (Rogers-Dulan, 1998; Skinner, Correa, Skinner, & Bailey, 2001; Tarakeshwar & Pargament, 2001; Duvdevany & Vudinsky, 2005; Khamis, 2007; Pillay *et al*, 2012; Gallagher *et al*, 2014).

Table 5.12 Caregivers' coping strategies

Category	**Phase 1 Caregivers**	**Phase 2 Caregivers**
Acceptance	Accept	Accept
Patience	Be patient	
Fait accompli	Did not choose	
	Did not request	
Religious belief	I thank God	I believe
	Gift from God	Trust in God
	I was given	
	God’s decision	God’s help

Summary

The concept was based on the perspectives of caregivers. Caregivers have indicated that they mainly used four coping strategies which include: (1) the acceptance of the CWD, (2) exercising patience, (3) fait accompli, and (4) religious belief.

Non-relational statement

To be able to cope with the pressure of having a CWD, caregivers used different strategies. By: (1) accepting the condition of the child, (2) exercising patience, (3) accepting the fact that it was not their choice to have a CWD (fait accompli), and (4) practicing their religious beliefs; caregivers were able to cope with the stress of raising a CWD.

5.4.6 Concept: Caregivers’ Level of Satisfaction

The development of this concept was based on the perspectives of caregivers during the face-to-face interviews and FGDs as shown in Table 5.13. Caregivers in the current study were either satisfied with the adequate service that they received or not satisfied with the service that they received. The latter group viewed the service as inadequate.

Adequate service

Caregivers in the current study reported that they were satisfied by the compassionate nature of rehabilitation professionals as well as the effectiveness of the service that they received. According to Schreiber, Benger, Salls, Marchetti, and Reed (2011) caregiver/parent satisfaction is defined as a judgement of the quality of the structure, process, and outcomes of care. The findings of the present study were also reported in other studies. King, Cathers, King, and Rosenbaum, (2001) found in their study that caregivers who were satisfied with the service delivery process were also happy with the service-delivery process. Caregivers were particularly happy if they were treated respectfully and in a supportive way–for instance if they felt that they were listened to and had some rapport with rehabilitation professionals. Similarly, Schreiber *et al* (2011) found that caregivers were more likely to be satisfied with ‘strengthened’ personal relationship between themselves or their child and the rehabilitation professionals. Hasnat and Graves (2000) focused on caregivers’ satisfaction about how the information regarding the CWD was disclosed to the caregivers. Caregivers in the current study reported that they were satisfied with the way in which the information about the CWD was disclosed to them.

In the present study, the effectiveness of treatment/service rendered to the CWDs and their caregivers that has been said to contribute towards caregivers’ satisfaction with the service is also reflected in the outcome of other studies as a factor that lead to caregiver satisfaction (Gohar, Comito, Price, & Marchese, 2011).

Inadequate service

Some caregivers reported that they were not satisfied with the quality of service they and their children received, the bureaucracy they were subjected to, staff attitude and the lack of hands-on therapy by the rehabilitation professionals. A study by

Morgan, Pogrebnoy, and McDonald (2014) also suggest that adults with cerebral palsy are dissatisfied with the perceived inadequate expertise and knowledge of the rehabilitation professionals. Furthermore, the skills of rehabilitation professionals and the lack of continuity were of concern in the study by Morgan *et al* (2014) similar to what was found in the current study.

Table 5.13 Caregivers' level of satisfaction

Category	**Phase 1 Caregivers**	**Phase 2 Caregivers**
Adequate service	Compassionate	Compassionate
	Effective service	Effective service
Inadequate service	Quality of service Bureaucracy	Quality of service
	Staff attitude	Staff attitude Hands-on-role

Summary

Caregivers in the current study were either satisfied or not satisfied with the rehabilitation service that they received. Caregivers were satisfied by the compassionate nature of rehabilitation professionals and the effectiveness of the service that they received because they believed that it was adequate. However, there are caregivers who felt that some services were inadequate and this lead to their dissatisfaction. Some caregivers were not satisfied with the quality of service they received, bureaucracy they were subjected to, bad staff attitude and the lack of hands-on-role by rehabilitation professionals, which all contribute toward the overall quality of service received.

Non-relational statement

Caregivers are satisfied by the compassionate nature of rehabilitation professionals as well as the effectiveness of services. The effectiveness of services is related to the outcome/result of the CWDs. However, some caregivers are not satisfied with the quality of services they received ranging from bad staff attitude, being sent from one department to another (bureaucracy), and the lack of hands-role by the rehabilitation professionals. It is, therefore, important that the factors that caregivers are not satisfied with should be addressed.

5.4.7 Concept: Caregivers' Expectations

The development of this concept was based on the perspectives of caregivers during the face-to-face interviews and FGDs as shown in Table 5.14. Caregivers in the current study had different expectations from the services that were available to them and their children in Giyani such as: (1) health-care services, (2) social services, (3) educational services, and (4) community-municipal services.

Health-care services

From the health-care services, caregivers expected to be provided with food and clothes. The provision of food and clothes for CWDs is the responsibility of the welfare services (Loman & Siegel, 2012) or the Department of Social Development in the South African context (Mogotlane, Chauke, Van Rensburg, Human, & Kganakga, 2010). It is not surprising that caregivers expected food and clothes from the health-care services because, in Limpopo Province, the Departments of Health and Social Development used to be one (the same) department in the past.

Caregivers have also indicated that they expect rehabilitation services in their respective villages instead of accessing these services in town. By decentralising the rehabilitation services into the villages/communities, the barriers associated with access to those services will be reduced (WHO, 2011). Some of the caregivers expressed the expectation that they would like to receive quality services from the rehabilitation professionals which include hands-on role, issuing of assistive devices and efficient service/results. Participants in a study by Morgan *et al* (2014) also expected quality service associated with adequate expertise, skills, and knowledge of the rehabilitation professionals in order to bring about change in the condition of the recipient of service. For changes in condition to happen, CWDs required assistive devices and walking aids which caregivers expected health-care professionals to issue. The caregivers' expectation to be issued with assistive devices as expressed in this study was also reported in other studies (Saloojee *et al*, 2007; WHO, 2011).

Some of the caregivers in the present study expected CWDs to be transformed from a state of 'being unable to perform certain functions' to a state of 'performing'. This expectation is similar to the findings of Daudji *et al* (2011), where immigrant caregivers in a HIC expected their children to be transformed within the health-care setting from a state of being unable to walk into a state where they could walk.

Social services

Caregivers expected CWDs to receive care dependency grants from the Department of Social Development. The South African Social Assistance Act of 2010, states that a person is, subject to section 5, eligible for a care dependency grant if he or she is a parent, primary caregiver or foster parent of a child who requires and receives permanent care or support services due to his or her physical or mental disability (RSA, 2010). In a way, this Act confirms that caregivers of CWDs in South Africa are indeed entitled to receive a care dependency grant for their children. Some caregivers have also indicated that they expect the government to appoint appropriately qualified personnel to assess children who are eligible for a care dependency grant as stipulated in Chapter 5 of the South African Social Assistance Act of 2010 (RSA, 2010).

Educational services

Some caregivers in the current study indicated that they expected their children to attend appropriate schools in their own villages. However, some of the caregivers prefer inclusive schools (mainstream education) as opposed to special schools for CWDs. The caregivers' expectations that are associated with access to schools or educational facilities were also reported in other studies (Saloojee *et al*, 2007; Resch *et al*, 2010). Having proper schools or educational facilities in the villages will go a long way in addressing the barriers associated with access to education by CWDs.

Community-municipal services

Caregivers in the current study expected CWDs to be provided with houses and recreational facilities. In addition, they expected the society to accept CWDs as well as the local government structures to promote the rights of CWDs. The expectation of free houses may sound strange in other parts of the world, but it is a common phenomenon in South Africa. The South African government post-apartheid started a programme of building low cost houses commonly known as RDP houses to poor people as a way of redressing some of the housing injustices of the past (Goebel, 2007; Lizarralde & Massyn, 2008; Shackleton, Hebinck, Kaoma, Chishaleshale, Chinyimba, Shackleton, Gambiza, & Gumbo, 2014).

Caregivers also expected the municipality to provide recreational facilities for CWDs. The availability of recreational facilities or similar facilities for children has been found to contribute towards the development of the child as well as improving the child's quality of life and promoting their health (Larson & Verma, 1999; Mahoney, Schweder, & Stattin, 2002). Despite the reported benefits of having recreation facilities or similar resources, CWDs do not have access to available recreational facilities due to the lack of such facilities in the community or as a result of environmental barriers (Engel-Yeger, Jarus, Anaby, & Law, 2009; King, Law, Hurley, Petrenchik, & Schwellnus, 2010; Law, Anaby, Dematteo, & Hanna, 2011). It is, therefore, reasonable for caregivers to expect the local municipality to provide or create recreational facilities for CWDs.

Furthermore, caregivers also expect the municipality to promote the rights of CWDs. Human rights are fundamental principles for people to maintain their dignity and freedom (Ruck, Keating, Abramovitch, & Koegl, 1998) and often protect a country's most vulnerable citizens such as CWDs (Donohue, Bornman, & Granlund, 2014). The South African Bill of Right as enshrined in the constitution states that every person including CWDs, has a right to live in adequate housing, and receive health-care, water, food, and social security (RSA, 1996). According to article 26 of the bill of rights, the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of these rights (RSA, 1996). These rights in the South African constitution make it reasonable and justifiable for caregivers of CWDs to expect the municipality to provide the recreational facilities, housing and other resources to their CWDs.

Just like rehabilitation professionals, caregivers of CWDs should always act in the best interest of CWDs. Caregivers should do anything legally possible to ensure that CWDs participate in societal activities. Negative societal attitude/perception of CWDs has been reported in the literature as a barrier to societal participation (Durkin & Maenrer, 2014; Margareta, 2014; Shields & Synnot, 2014). It is also within the rights of caregivers to expect a society to have positive attitudes towards CWDs in an effort to promote participation in society.

Table 5.14 Caregivers' expectations

Category	Phase 1 Caregivers	Phase 2 Caregivers
Health-care services	Food Clothes	
	Access to village services Hands-on role Quality of service	Access to village services Hands-on role Improve treatment time
	Toys Improvement of condition Other specialised services	Assistive devices Improvement of condition Other specialised services
Social services	Social grants Relevant appointments	Social grants
Education services	Attend school Village schools Inclusivity	
	Appropriate schools	Appropriate schools
Community-municipal services	Housing Recreational facilities Societal acceptance Promotion of human rights	

Summary

Caregivers of CWDs expected children to be provided with food, clothes, quality and efficient village-based rehabilitation service provided by the health-care services. Caregivers also expected hassle free social assistance grants application process as well as being provided with social grants from social services. From the education sector, caregivers expected their children to have access to education at appropriate schools or special schools in their communities. However, some caregivers were against the use of special schools and instead preferred inclusive education in mainstream schools. As a way of removing barriers to societal participation, caregivers expected the society to have a positive attitude towards CWDs. Lastly, as enshrined in the constitution of the Republic of South Africa, caregivers expected their CWDs to be provided with houses, and recreational facilities, as well as having equal rights with non-disabled children (RSA, 1996).

Non-relational statement

Caregivers have different expectations from the different sectors that they received services from. They have expectations from the health-care services, social services, education services, and community-municipal services.

5.4.8 Concept: Role of Rehabilitation Professionals

The development of this concept was based on the perspectives of rehabilitation professionals and CRWs during the face-to-face interviews as well as the FGD with rehabilitation professionals as shown in Table 5.15 (on page 192).

According to the rehabilitation professionals who participated in the current study, the role of health professionals in the rehabilitation of CWDs include: (1) examination of CWDs, (2) support for the CWD and the caregiver, and (3) skills training for caregivers of CWDs. The CRWs together with rehabilitation professionals have agreed that the role of health professional is to rehabilitate CWDs. Furthermore, CRWs suggested that health professionals should multi-task and perform roles that are not traditionally theirs.

Examination of CWDs

The examination of CWDs in the context of the current study includes screening and assessment of children. The focus of the examination is on identifying biological characteristics of the child. The application of the ICF model guides the health professionals in the examination or assessment and planning the treatment/management of CWDs. The model cautions against focusing only on biological characteristics of the child. Instead the ICF guides health professionals towards a comprehensive examination of health, including biological, individual and social perspective of the child should be conducted (WHO, 2001; Stucki, 2005).

Support

Rehabilitation professionals have expressed that they view their role to include amongst other things the support of caregivers of CWDs as well as to counsel them. It has been widely reported in the literature that caregivers of CWDs are subjected to high levels of stress (Dabrowska & Pisula, 2010; Parkes, Caravale, Marcelli, Franco, & Colver, 2011; Hayes & Watson, 2013) and they require some form of support and counselling in order to reduce it (Raina *et al*, 2005).

Skills training

Rehabilitation professionals in the current study have also indicated that their role include skills training for caregivers through health education. The need for health professionals in providing skills training to caregivers of CWDs was also reported by Einfeld, Stancliffe, Gray, Sonfronoff, Rice, Emerson, and Yasamy (2012). Considering that the rehabilitation of CWDs is not a once off event, but a lengthy process that happens both in the hospital and at home. It is, therefore, essential to equip caregivers with the necessary skills to enable them to continue with the rehabilitation at home. Skills training is cost-effective in the long run while taking into consideration the shortage of health professionals in LMIC (Einfeld *et al*, 2012), and in particular rural areas.

Rehabilitate

Rehabilitation professionals and CRWs have stated that the role of health professionals is to rehabilitate CWDs. According to the ICF, the aim of rehabilitation of CWDs should be to maximise function, minimise incapacity, and modify the environment in order to promote participation (WHO, 2001). Rehabilitation professionals in the current study reported that rehabilitation of CWDs is achieved through: (1) the use of their hands-on role such stretching, exercise, and positioning as well as, (2) issuing of assistive devices. Another role that has been mentioned by both the rehabilitation professionals and CRWs is to refer CWDs to other health professionals when there is a need to do so. Furthermore, CRWs have suggested that the role of rehabilitation professionals should include the prescription of home programme for caregivers. However, the prescription of home programme is seen as part of skills training that health professionals impart to caregivers.

The role of health professionals such as screening and assessment, hands-on role, issuing of assistive devices and initiating home programmes was also reported in other literature (WHO, 2011; Bunning *et al*, 2014).

Table 5.15 Role of rehabilitation professionals

Category	**Phase 1 Rehab professionals**	**Phase 1 CRWs**	**Phase 2 Rehab professionals**
Examination	Screen and assess		Screen
Support	Counsel		Counsel
	Support		Support
Skills training	Education		Education
Rehabilitate	Hands-on role		
	Issue assistive device	Issue assistive devices	
	Refer	Refer	Refer
		Home programme	
Multi-task		Complement CRWs' role	

Summary

From the results of the present study, it can be deduced that rehabilitation professionals play multiple roles during the rehabilitation of CWDs. The various roles that rehabilitation professionals play are not only focused on the child but the family as well.

Even though it has not been mentioned as such, rehabilitation professionals in the current study used an approach that focused on both the child and the caregiver/family. This approach is similar to the family-centred approach (King, Teplicky, King, & Rosenbaum, 2004). The use of a family-centred approach together with a combination of physiotherapy and occupational therapy improves the functional status of a disabled child, as well as the satisfaction level of the caregiver (Baker, Haines, Yost, DiClaudio, Braum & Holt, 2012). This means that health professionals should ensure that the family member(s) are active participants in the rehabilitation process in the sense that they must be given the opportunity to participate in the decision making and goal formulation and integrate the CWD's management to be part of their daily routine.

Non-relational statement

Rehabilitation professionals have multiple roles to play during the rehabilitation of CWDs such as: (1) the examination of CWDs, (2) to support the caregivers and CWDs, (3) to provide rehabilitation skills training to caregivers, and (4) to rehabilitate the CWD.

5.4.9 Concept: Rehabilitation professionals' competency

The development of this concept was based on the researcher's deduction based on the information obtained from the rehabilitation professionals as shown in Table 5.16 (on page 194). It was established that there were certain competencies that rehabilitation professionals had (adequate professional competency) while there were other competencies that they lacked (inadequate professional competency).

Adequate professional competency

Some of the rehabilitation professionals in the present study demonstrated some advocacy skills by acting in the best interest of both the caregivers and the CWDs. According to Milteer and Ginsburg (2012), advocacy skills include the health professionals' ability to educate and support the caregivers/families of the CWDs. Furthermore a study by Kelland, Hoe, McGuire, Yu, Andreoli, & Nixon (2014) suggest that rehabilitation professionals such as physiotherapists should be able to play the following advocacy roles: (1) collaboration, (2) communication, (3) scholarly practice, (4) management, (5) professionalism, (6) passion, (7) perseverance, and (8) humility. Even though the rehabilitation professionals failed to play all the advocacy roles as suggested by Kelland *et al* (2014), they managed to play some of the roles.

Rehabilitation professionals in this study have also demonstrated competency in performing therapeutic skills. The performance of therapeutic skill is one of the essential skills that any rehabilitation professional need to have in order to practice their profession (Chen, Kang, Hong, Chen, Chen, & Wu, 2013).

The rehabilitation clinic at Nkhensani Hospital was managed by staff members of the physiotherapy and occupational therapy departments. These staff members typically address CWDs in the same room even though each rehabilitation professional is allocated his or her own child to treat. Treatment in a common room is a sign that rehabilitation professionals had the opportunity to work as a team. It is said that rehabilitation professionals working with CWDs must at least have team collaboration skills to effectively and efficiently conduct the rehabilitation of children (Effgen, Chiarello, & Milbourne, 2007).

Inadequate professional competency

As suggested by Kelland *et al* (2014), rehabilitation professionals should display or acquire the following skills: (1) collaboration, (2) communication, (3) scholarly practice, (4) management, (5) professionalism, (6) passion, (7) perseverance, and (8) humility. However, some rehabilitation professionals in the current study lacked advocacy, therapeutic, collaboration, communication, management, and professionalism and motivation skills.

Table 5.16 Rehabilitation professionals' competency

Category	Phase 1 Rehabilitation professional
Adequate professional competency	Advocacy Therapeutic Teamwork and collaboration
Inadequate professional competency	Advocacy Therapeutic Collaboration Communication Management Professionalism and motivation

Summary

Some rehabilitation professionals in the current study had adequate professional competencies, but there are some who had inadequate professional competencies. Based on the information obtained from the rehabilitation professionals, the adequate professional competencies include advocacy, therapeutic, and teamwork and collaboration. The inadequate professional competencies include advocacy, therapeutic, collaboration, communication, management, and professionalism and motivation. However Kelland *et al* (2014), suggests that all of the adequate and inadequate professional competencies as discussed in this subsection are components of advocacy skill.

Non-relational statement

Rehabilitation professionals demonstrated adequate professional competencies in some areas but also lacked certain competencies in other areas. According to Kelland *et al* (2014), all the skills/competencies as reported in the current study can be classified as advocacy skills. Therefore, rehabilitation professionals showed fewer advocacy skills.

5.4.10 Concept: Factors that affects the rehabilitation professionals' work ethic

Rehabilitation professionals who participated in the current study expressed both positive and negative factors that influenced their work ethic as shown in Table 5.17 (on page 197). The positive factors include: (1) the rehabilitation worker's sense of ownership of the clinic, (2) result/progress that is seen in CWDs, (3) the availability of facilities/physical resources in the workplace, (4) working with children, and (5) caregivers' commitment and compliance to the given and suggested intervention.

On the other hand the factors that negatively affect rehabilitation professionals' work ethic include: (1) the lack of commitment by colleagues, (2) lack of managerial support, (3) budgetary constraints, (4) lack of commitment and compliance of caregivers, (5) poor results/progress that are seen in CWDs, (6) fewer referrals in the hospital, (7) working far from home, and (8) lack of learning opportunities and growth in the workplace.

Positive factors

It is known that a happy worker is a productive and committed worker. According to Nel, Werner, Haasbroek, Poisat, Sono, and Schultz (2008), a worker or rehabilitation professionals' commitment is a state where individuals feel strongly drawn to the objectives, values and goals of their employer. Rehabilitation professionals who have a sense of ownership in the rehabilitation clinic are likely to have a high level of commitment to their work (Nel *et al*, 2008). According to Maslow's hierarchy of needs (Huitt, 2007), all workers including rehabilitation professionals have needs within the workplace, such as: (1) physiological needs, (2) safety needs, (3) social needs, (4) ego needs, and (5) self-actualisation needs.

In contrast to what was found in the present study, Braga and Rochette (2013) found that financial reward, family/spousal support, free time, and flexible work schedule were some of the factors that influenced rehabilitation professionals' commitment in a HIC. However, rehabilitation professionals who participated in the present study may not have been concerned about these factors as they did not mention them as factors that influence their commitment in treating the CWDs.

Negative factors

Some of the findings of this current study with regards to the negative factors that affect rehabilitation professionals' work ethic have been reported in other studies. For an example, Skirrow and Hatton (2007) reported that client behavioural problems (such as the lack of commitment and compliance of caregivers), client health problems (such as the lack of results on CWDs), and limited job autonomy are some of the potential stressors which could result in staff burnout. If such stressors are not appropriately managed, they will diminish the effectiveness of care. A study by Gosseries, Demertzi, Ledoux, Bruno, Vanhaudenhuyse, Thibaut, Laureys, and Schnakers (2012) has highlighted that health professionals working with PWDs/CWDs tend to have higher levels of burnout because their patients might show slow progress. Caregivers in the present study considered the lack of patient referrals or shortage of work as a negative factor. This finding is contrary to an earlier finding by Skirrow and Hatton (2007) who found that heavy workload as opposed to a shortage of work negatively affected the health professionals' work ethic.

It also seems that when the Maslow's hierarchy of needs is not met, rehabilitation professionals become unhappy. An example of the Maslow hierarchy of need include working closer to home and getting support from the employer and colleagues (Huitt, 2007). In addition, several studies have indicated that the lack of social resources, such as support from supervisors or colleagues is associated with high levels of burnout among health professionals (Skirrow & Hatton, 2007; Devereux, Hastings, Noone, Firth, Totsika, 2009; Thomas & Rose, 2010).

Table 5.17 Factors affecting rehabilitation professionals' work ethic

Category	Phase 1 Rehabilitation professional
Positive factors	Ownership
	Results
	Availability of facilities
	Children
	Caregivers’ commitment and compliance
Negative factors	Commitment of colleagues
	Managerial support
	Budgetary constraints
	Commitment and compliance of caregivers
	Results
	Referral
	Working far from home
	Learning opportunities

Summary

The positive factors that influenced rehabilitation professionals’ work ethic include: sense of ownership of the rehabilitation clinic, good results/outcome of CWDs, availability of facilities in the rehabilitation clinic or hospital, the love of working with children, and the caregivers’ commitment and compliance to the given intervention. The negative factors which discourage rehabilitation professionals include: lack of commitment of colleagues, lack of managerial support, budgetary constraints in the rehabilitation clinic and or hospital, lack of commitment and compliance of caregivers, poor results/outcome on the CWD, fewer referrals, working far from home, and lack of learning opportunities and growth.

Non-relational statement

Rehabilitation professionals’ work ethic is influenced by the following positive factors: (1) sense of ownership in the rehabilitation clinic, (2) positive results/outcome that they see on CWDs, (3) availability of facilities in the workplace, (4) enjoying to work with children, and (5) caregivers’ commitment and compliance. However, rehabilitation professionals were discouraged by the following negative factors: (1) lack of commitment of colleagues, (2) lack of managerial support, (3) budgetary constraints in the rehabilitation clinic and or hospital, (4) lack of commitment and compliance of caregivers, (5) poor results/outcome on the CWD, (6) fewer referral, (7) working far from home, and (8) lack of learning opportunities and growth.

5.4.11 Concept: Rehabilitation Professionals' Plan of Action

The development of this concept was based on the perspectives of rehabilitation professionals during the FGDs as shown in Table 5.18 (on page 200). Rehabilitation professionals had plans of actions in order to address or rectify the challenges that they identified. The plans were formulated to address family-caregiver related and health-care related challenges. Despite having a plan of action, rehabilitation professionals did not mention how they would go about achieving their objectives. In addition, there was no time frame set on achieving any of the objectives.

Family-caregiver related (plan of action)

Rehabilitation professionals in the current study have indicated that the caregivers' need of information could be addressed by educating caregivers, reviving caregiver meetings and conducting health talks. The main focus of the rehabilitation professionals is on providing the relevant and appropriate information to the caregivers. The findings of the present study confirm what was found in another study by Gona, Mung'ala-Odera, Newton and Hartley (2011). Gona *et al* (2011) stated that caregivers in a LMIC expect health-care providers to give them information about the child's condition that they could readily understand. Caregivers expected to be addressed in layman's language and not medical jargon. It is also important that health-care providers provide anticipatory guidance and communicate with other team members to provide accessible, holistic and co-ordinated services in an effort to reduce family needs pertaining to the child's health condition. Similarly, other studies have also reported on the need of providing information about the condition of the CWDs to the caregivers (Almasri, Palisano, Dunst, Chiarello, O'Neil, Polansky, 2012; Chadwick, Mannan, Iriarte, McConkey, O'Brien, Finlay, Lawlor, & Harrington, 2013; Uccelli, Traversa, Trojano, Viterbo, Ghezzi, & Signori, 2013).

Health-care related (plan of action)

The rehabilitation professionals reported on a plan to improve communication with colleagues, improve teamwork/ collaboration, address the issue of treatment uniformity and ensure that there is caregiver support. The plan to improve communication with colleagues as reported by rehabilitation professionals in the current study was also reported in the literature. For an example, Arnold and Boggs (2011) emphasised the importance of improving communication between rehabilitation professionals. Effective communication between rehabilitation professionals is said to improve the quality of service offered, as well as ensuring that there is continuity of care for CWDs (Arnold & Boggs, 2011). Good communication amongst rehabilitation professionals is a prerequisite for teamwork and collaboration. Without proper and effective communication between the rehabilitation professionals teamwork/collaboration would not be possible (Brooks, Rhodes, & Tefft, 2014). It has been reported in the literature that family-centred service for CWDs is one of the most effective approaches to use in the rehabilitation of CWDs (King *et al*, 2004; Eason, Connell, & Barry, 2014). However, family-centred approach requires collaboration between professionals and professionals as well as between professionals and the family/caregiver.

The rehabilitation professionals' proposed a plan of addressing uniformity which to check the previously written records of other rehabilitation professionals in the child's file. This strategy of checking previous records was also reported by Pollack (2011) who suggested that health/rehabilitation professionals should compare notes regarding specific therapies and medical providers in order to improve the quality of service being offered to CWDs.

The need of supporting caregivers as proposed in the current study was also reported by Sandy, Kgole and Mavundla (2013) who found in their case study in Limpopo Province, that caregivers were in need of emotional support, practical support, training about the child's condition, respite care, training on coping with affiliated stigma of having a CWD and partnership with professionals.

Table 5.18 Rehabilitation professionals' plan of action

Category	**Phase 1 Rehabilitation professionals**	
Family-caregiver related	Information	Educate caregivers Revive caregiver meetings Conduct health talks
Health-care related	Communication	Improve communication with colleagues
	Teamwork/ Collaboration	Include other disciplines Include other professionals Include speech-therapist Include dieticians Include optometrist
	Uniformity	Query previous treatment
	Caregiver support	Compassion Sensitive communication Conduct Home visit Revive support group Give emotional and physical support Revive CRWs

Summary

The rehabilitation professionals’ plan action was to address family-caregiver related challenge by providing caregivers with information by the caregivers. The plan for the health-care related challenges include: (1) improving communication amongst rehabilitation professionals, (2) working as a team/collaborating, and (3) supporting caregivers. If the communication between rehabilitation professionals improves the uniformity that rehabilitation professionals expressed as their concern will be rectified.

Non-relational statement

The rehabilitation professional’s plan of action to address identified challenges include: (1) educating caregivers as a way of providing information about the condition of the child, (2) improving communication amongst rehabilitation professionals, (3) working as a team/collaborating, and (4) supporting caregivers.

5.4.12 Concept: Role of Community Rehabilitation Workers

The development of this concept was based on the perspectives of caregivers and CRWs during the face-to-face interviews as well as the FGDs with caregivers as shown in Table 5.19 (on page 202).

Caregivers and CRWs reported on a number of adequate roles that they perceived CRWs to play during the rehabilitation process of CWDs. The roles include: (1) continuous evaluation of CWDs, (2) supporting, counselling, and being a link between family and the hospital, (3) education, (4) hands-on role, issuing of assistive devices, and revision of their home programme, and (5) a multidisciplinary role/multi-tasking role. However, some of the caregivers felt that the hands-on role of CRWs was inadequate while others felt that CRWs were not playing any meaningful role in the lives of CWDs. The adequate roles that CRWs were said to play are similar to that of rehabilitation professionals. The main difference between the role of CRWs and rehabilitation professionals is the location in which the services are conducted. CRWs mainly provide services to CWDs in the community whilst rehabilitation professionals provide services to CWDs in the hospital.

The results of this current study on the role of CRWs confirm earlier findings of two South African studies that reported that the role of CRWs include identification of clients (PWDs which include CWDs) in the community who are not making use of the services at the hospital/health-care services; conduct follow-up treatment with clients; conduct home visits in the communities where clients reside; counsel clients and family; make assistive devices; help/rehabilitate/ treat/give therapy; and health education to caregivers of CWDs. CRWs also act as a link between hospital and community (Petrick, Sichangwa, Pickford, & Collinson, 2002; Chappel & Johannsmeier, 2009). Nonetheless, there is insufficient evidence in the literature to prove the efficacy of CRWs in LMIC (Robertson *et al*, 2012).

Table 5.19 Role of CRWs

Category	Phase 1 Caregivers	Phase 1 CRWs	Phase 2 Caregivers
Adequate roles	Continuous evaluation		
			Counsel
	Family-hospital link	Support	
	Education	Education	
		Hands-on role	Hands-on role
	Assistive device	Issue assistive device	Assistive device
		Home programme	
		Multidisciplinary	
Inadequate roles	Hands-on role		
Absent roles			

Summary

Caregivers and CRWs have expressed their views on the role of CRWs. The roles that CRWs play are similar to the roles of rehabilitation professionals. These roles include the examination of CWDs, supporting the caregivers and CWDs, educating or providing skills training to the caregivers of CWDs, and to rehabilitate CWDs.

Non-relational statement

The role of CRWs is similar to that of rehabilitation professionals. The only difference is that CRWs provide service to CWDs in the communities while rehabilitation professionals mainly provide services in a hospital setting.

5.4.13 Concept: Role of the Municipality towards People with Disabilities

The mayor of the greater Giyani has expressed how the municipality is committed toward improving the quality of life of PWDs and, in particular, children as summarised in Table 5.20 (on page 203). It has been reported in the current study that the Greater Giyani Municipality is committed on: (1) ensuring that there are financial resources and other resources to improve the quality of life for PWDs/CWDs, (2) addressing the needs of PWDs/CWDs, and (3) promoting the rights and creating opportunities for PWDs/CWDs. However, the mayor of the Greater Giyani Municipality has acknowledged that not much has been done with regards to meeting the needs of PWDs/CWDs.

According to Erbaydar, Caman, and Cilingiroglu (2013), municipalities have a crucial role in the adaptation of urban/rural spaces, buildings, and public service to provide PWDs/CWDs full accessibility to the public buildings and services. Even though the role of the municipality in the current study is not the same as that of Erbaydar et al (2013), the adaptation of open spaces, buildings, and public services would not be possible without financial commitment of the municipality. Considering that there are a growing number of children with developmental delays and disabilities in LMIC, Scherzer *et al* (2012) recommend that local governments should prioritise regular childhood developmental surveillance and to pursue early referral for CWDs or those who are at risk of disability for intervention. Furthermore, Scherzer *et al* (2012) has also suggested that local governments have to commit resources towards the rehabilitation of CWDs to optimise their participation in community activities.

Table 5.20 Role of the municipality

Category	**Phase 1 Launch of GGDF**
Commit toward PWDs	Finance Address needs of PWDs Promote rights and create opportunities for PWDs
Inadequate	Acknowledge limitations

Summary

Based on the information obtained from the mayor and the literature, the role of the municipality towards PWDs/CWDs is to commit resources towards PWDs/CWDs, and ensure that barrier that limits the participation of PWDs/CWDs are removed in society.

Non-relational statement

The role of the municipality toward CWDs is to provide financial and other resources so as to ensure that the barriers that limit the participation of CWDs in society are eliminated.

5.4.14 Concept: Role of Pfunanani Special School

The caregivers and the rehabilitation professionals alike have indicated that they have Pfunanani Special School in Giyani. Pfunanani is a school for moderate-to-severe intellectually impaired children. Only eight out of 35 teaching staff at Pfunanani Special School had specialised training in teaching children with special needs. These findings are in contrast to what was found by Bunning *et al* (2014), where 34 out of 40 teaching staff had training in special-needs education in the form of additional diplomas and degree(s).

The curriculum offered at the school is different from that offered in the mainstream schools. A special “vocational curriculum” is offered. The aim of such curriculum is to deal with ‘familiar’ or ‘everyday’ knowledge rather than with ‘non-knowledge’ as cited by Todd (2009). For example, the beadwork class and gardening class at Pfunanani Special School do not suggest that the aim of the classes are to transmit or develop competencies in those areas. Rather, the apparent value of the classes is to provide a means for pupils’ ‘outside’ or community experiences to be brought into the classroom and rendered visible (Todd, 2009). With this kind of curriculum being offered, learners or pupils are not guaranteed to develop literacy and numeracy skills. The employability of CWDs when they become adults will not be easy without literacy and numeracy skills, limiting them to unskilled and often manual labour.

Non-relational statement

Pfunanani Special School is a school for children of all ages with mild-to-moderate intellectual disability. Educators who have been trained in the mainstream curriculum are responsible for teaching children with intellectual disability vocational skills.

5.4.15 Concept: Challenges Experienced

The development of this concept was based on the perspectives of caregivers and rehabilitation professionals during the face-to-face interviews, FGDs with caregivers and rehabilitation professionals, information from the launch of the GGDF and the researcher’s field notes based on his observation of the launch of the GGDF as shown in Table 5.21 (on page 209).

Multiple challenges in the assistance/education of caregivers in the rehabilitation of CWDs were identified from different sources in the current study. These challenges were categorised into: (1) child-related, (2) family-caregiver related, (3) health-care related, and (4) community-related.

Child related

The child related challenges as reported by caregivers and rehabilitation professionals had to do with clothes and nutrition for the CWDs. Caregivers found it difficult to obtain appropriately sized diapers for the growing child. However, studies in the literature have reported clothing as a challenge but with regard to constant soiling and wetting of clothes because of drooling that is sometimes associated with CWDs (Hussein, Kerrshaw, Tahmasebi, & Fayle, 1998; Meningaud, Pitak-Arnnop, Chikhani, & Bertrand, 2006; Walshe, Smith, & Pennington, 2012).

Furthermore, caregivers and rehabilitation professionals alike expressed how difficult it was to feed the CWD due to several reasons and thus resulting in poor nutrition. The finding of the study confirms that CWDs often have feeding difficulties which is also reported in other studies (Ledford & Gast, 2006; Adams, Khan, Begum, Wirz, Hesketh &Pring, 2012; Reading, 2012; Dahlseng, Finbråten, Júlíusson, Skranes, Andersen & Vik, 2012; Sharp, Berry, McCracken, Nuhu, Marvel, Saulnier, Klin, Jones & Jaquess, 2013).

Family-caregiver related

The family-caregiver related challenges comprises: (1) information, (2) social grant access, (3) affordability, (4) family support, (5) motivation and commitment, and (6) appropriate transport.

Resch, Mireles, Benz, Grenwelge and Peterson (2010) found that access to information, access to services, financial barriers, and lack of family support were some of the main challenges that caregivers of CWDs experienced in an HIC. Similarly in a LMIC it was reported that: caregivers of CWDs were in need of information about the child’s condition, social assistance grants and could not afford to buy a wheelchair, food or even pay for the treatment bills (Saloojee *et al*, 2007; Gona *et al*, 2011). Furthermore, a study by Pollack (2011) also reported that caregivers of CWDs encountered challenges such as the provision of social and emotional support. Lastly, the transportation problems as reported in the current study are not unique as they have been widely reported in the literature (Haveman, Tillmann, Stöppler, Kvas & Monninger, 2013; Bunning *et al*, 2014; Donald *et al*, 2014; Graham, Keys, McMahon & Brubacher, 2014).

Health-care related

Health-care related challenges comprises: (1) accessibility of health-care services, (2) allocated treatment time, (3) staff attitude, (4) caregiver support, (5) communication, (6) teamwork and collaboration, (7) staff burnout, (8) hands-on role, (9) uniformity, (10) staff continuity, (11) leadership and management, (12) infrastructure, (13) budgetary constraints, and (14) equipment and material.

Accessibility of health-care facilities by CWDs is of concern in the current student as it was in other studies. A study in Kenya has suggested that CWDs have limited access to health-care facilities and specialists, as well as a lack of adaptive equipment such as wheelchairs and other ambulation aids, which contributes to the treatment gap for children with CWDs (Njambi, Kariuki & Masinde, 2009). Accessibility of health-care facilities may also be limited by the unavailability of appropriate modes of transport for children on wheelchairs and other mobility assistive devices (Hartley, Ojwang, Baguwemu, Ddamulira & Chavuta, 2005). Furthermore many of the poorest people in the world live in rural areas which are less likely to have health facilities, and where health facilities do exist, caregivers may have to travel long distances with the CWD in order to obtain rehabilitation service (UNICEF, 2013).

Caregivers go through a lot to be able to access rehabilitation services. In the current study, caregivers have reported not being impressed by the duration of treatment as well as the type of treatment that CWDs receive at the rehabilitation clinic. Similar findings were reported in a study which was conducted in multiple countries where caregivers were not happy about the “30 minutes per week” treatment that their CWDs received (Mackintosh, Goin-Kochel & Myers, 2012).

Staff members at the hospital where rehabilitation services were provided were said to have an ‘attitude’. Staff members were slow when providing service or were reluctant to help. Although one might hope and expect that health-care professionals and students entering the health professions should have a more positive attitude towards CWDs than those who are not treating these individuals, research has shown this is not the case (Goreczny, Bender, Caruso & Feinstein, 2011). Some studies have found that health-care professionals also have negative attitudes toward CWDs (Carter & Markham, 2001; Tervo, Palmer & Redinius, 2004; Bunning *et al*, 2014).

Morgan and Tan (2011) reported that caregivers encountered challenges with regard to collaborative-partnership with professionals, information exchange/communication with professionals who render rehabilitation services as was the case with the current study.

Continuity of staff members was reported as a problem in the current study. The introduction of community service for all health professionals in South Africa was meant to address the inequitable distribution of health-care workers in the country (Ataguba & McIntyre, 2013). However at the end of compulsory community service year, health professionals placed in the rural and poor communities tend to move into urban settings or go into private sector (Hatcher, Onah, Kornik, Peacocke & Reid, 2014). The movement of health professionals after completion of their community service year, often affect how the rehabilitation is conducted (uniformity of service) as well as who conduct the rehabilitation (continuity).

Budgetary constraint as reported in the current study is a serious concern because the hospital is not in a position to provide the basic infrastructure or to procure the necessary equipment and material to ensure that adequate rehabilitation of CWDs can take place. The finding on budgetary constraint has also been highlighted in other studies (Gilson & McIntyre, 2007; Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009; Harris, Goudge, Ataguba, McIntyre, Nxumalo, Jikwana & Chersich, 2011).

Community related

Community related challenge comprises: (1) education such as inadequate special schools and lack of inclusive education, (2) access to water, (3) access to houses such as the government built low cost houses, (4) accessibility of public infrastructure, (5) recreational facilities, (6) abuse, (7) gender based-violence, (8) societal perception, and (9) employment opportunities for CWDs.

With regards to the findings of the current study in terms of education for CWDs, other researchers have also reported in their studies that there was a need of educational facilities for CWDs (Saloojee *et al*, 2007; Gona *et al*, 2011). The problem associated with access to water by CWDs is not unique to the context of the study but was also highlighted by Noga and Wolbring (2012) who stated that access to clean water and sanitation was one of the major challenges that CWDs encountered. Lack of access to clean water and sanitation by CWDs is often associated with poor health outcomes such as child mortality, higher risk of diarrhoea, and developmental delays (Fink, Gunther & Hill, 2011).

Caregivers also reported not to have access to public infrastructure such as buildings. This challenge was further worsened by the inaccessibility of public mode of transportation. This finding is in line with that of Anaby, Hand, Bradley, DiRezze, Forhan, DiGiacomo and Law (2013) who reported that poor accessibility to buildings, poor access to public transportation and a lack of ramps were some of the challenges that CWDs encounter in society. Barriers associated with poor accessibility of public areas and public transportation was also highlighted in the *World Report on Disability* (WHO, 2011).

Abuse and gender based-violence was reported in the current study as one of the challenges that CWDs and female children endured in Giyani. All children are vulnerable to abuse but CWDs are at a higher risk of being abused, neglected, and sexually violated compared to their peers (Briggs, 2006; Reiter, Bryen & Shachar, 2007; Jemta, Fugl-Meyer & Oberg, 2008; Kvam & Braathen, 2008).

Caregivers in the present study were subjected to the negative perceptions of the society. This finding was not unique to the current study but was also reported by Anaby *et al* (2013).

In the present study, PWDs have been reported not to have equal employment opportunities as their counterparts. This is despite the fact that PWDs can be productive in appropriate jobs as long as they are provided with the right environment and support (WHO, 2011).

Table 5.21 Challenges experienced (1)

Category	**Phase 1 Caregivers**	**Phase 2 Caregivers**	**Phase 1 Rehabilitation professionals**	**Phase 2 Rehabilitation professionals**
Child-related	Clothes	Clothing		
	Nutrition	Nutrition	Nutrition	
Family-caregiver related	Information	Information	Information	Information
	Social grants access	Social grants access		
	Affordability	Affordability		
			Family support	
			Motivation and commitment	
	Appropriate transport	Appropriate transport	Transport	
Health-care related	Accessibility of health facility			
		Allocated treatment time		
				Caregiver support
			Staff attitude	
			Communication	Communication
			Teamwork and collaboration	Teamwork and collaboration
			Staff burnout	Staff burnout
	Hands-on role	Hands-on-role	Hands-on role	
	Uniformity	Uniformity	Uniformity	Uniformity
			Staff continuity	
			Leadership and management	
			Therapist-assistants infighting	
			Human resource planning	
			Awareness campaigns	
			Duration of treatment	
			Caregiver support	
			Infrastructure	Infrastructure
			Budgetary constraints	
	Equipment and material	Equipment and material	Equipment and material	

Table 5.22 Challenges experienced (2)

Category	Phase 1 Caregivers	Phase 2 Caregivers	Phase 1 Rehabilitation professionals	Launch of GGDF	Researcher’s field notes on launch
Community related	Inadequate special schools	Inadequate special schools	Inadequate special schools	Education	Access to inclusive education
	Access to water				Access to water
	Access to houses				
	Accessibility of infrastructure				Accessibility of public places
	Recreational facilities		Recreational facilities		
				Abuse	Abuse
				Gender-based discrimination	
				Societal perception	
					Employment opportunities

Summary

The concept on challenges experienced by caregivers and CWDs was based on caregivers, rehabilitation professionals, launch of the GGDF, and the researcher's field notes based on his observation at the launch of the GGDF. The challenges were categorised in Table 5.21 and 5.22 as child-related, family-caregiver related, health- care related, and community related.

Non-relational statement

Challenges that caregivers and CWDs experience are categorised into child-related, family/caregiver related, health- care related, and community related. The child-related challenges comprise clothes and proper nutrition for the child. The family-caregiver related challenges include: (1) lack of information, (2) poor social grant access, (3) affordability/poverty, (4) lack of family support, (5) lack of motivation and commitment of the caregiver/family, and (6) lack of appropriate transport for the caregiver and CWDs.

Health-care related challenges includes: (1) accessibility of health-care facilities, (2) allocated treatment time, (3) staff attitude, (4) caregiver support, (5) communication, (6) teamwork and collaboration, (7) staff burnout, (8) hands-on role, (9) uniformity, (10) staff continuity, (11) leadership and management, (12) infrastructure, (13) budgetary constraints, and (14) equipment and material

Community related challenge consists of: (1) education such as inadequate special schools and lack of inclusive education, (2) access to water, (3) access to houses such as the government built low cost houses, (4) accessibility of public infrastructure, (5) recreational facilities, (6) abuse, (7) gender based-violence, (8) societal perception, and (9) employment opportunities for CWDs.

5.4.16 Concept: Societal Perception of Children with Disabilities

This concept is based on the perspectives of caregivers during the face-to-face interviews and FGDs as well as the researcher's perspectives based on his observation during the launch of the GGDF. The societal perception towards CWDs was reported to be both positive and negative as summarised in Table 5.22 (on page 210).

Positive perception

Caregivers have expressed that the society had a positive perception toward CWDs because members of the community loved, cared and supported CWDs. A review of the literature by Anaby *et al* (2013) has suggested that a positive perception/attitude towards CWDs enables them to participate fully in society. Caregivers in the present study have also reported that children in their neighbourhood are playing with their disabled children. The positive perception towards CWDs as reflected in the current study is contrary to an earlier finding by Rosenbaum, Armstrong, and King (1988), which stated that the attitudes of typically developing children were generally more negative toward peers with disabilities than toward non-disabled peers.

Negative perception

The caregivers and the researcher have reported that the society had negative attitudes towards CWDs because of: (1) name calling, (2) ridiculing, (3) gossiping, (4) hating, (5) staring, (6) being fear of CWDs, (7) intolerance, and (8) associating disability with witchcraft. The negative perception/attitude toward CWDs (Anaby *et al*, 2013) and young adults (Rao, 2004; Zascavage & Keefe, 2004) is associated with poor participation of CWDs/PWDs in society. In addition, negative perception/attitude has the potential to prevent individuals with disabilities from finding employment, developing social relationships, and utilizing health-care services (Carter & Markham, 2001; Tervo, Palmer & Redinius, 2004; Hergenrather, Rhodes & McDaniel, 2005).

The negative perception/attitude as reported in the current study is likely to be caused by cultural beliefs (Tervo, Azuma, Palmer & Redinius, 2002) and superstition among African people (Gona *et al*, 2011). According to Gona *et al* (2011), community members tend to speculate about the cause of a child's disability and even engage in rumour mongering where the caregiver ends up being associated with evil spirits, punishment from God, or witchcraft.

Table 5.23 Societal perception of CWDs

Category	Phase 1 Caregivers	Phase 2 Caregivers	Researcher's field note based on the launch of GGDF
Positive perception	Love		
	Care	Care	
	Support	Support	
Negative perception	Name calling	Name calling	Name calling
	Ridicule	Ridicule	Ridicule
	Gossip	Gossip	
			Intolerance
	Hatred		
	Stare		Stare
	Fear of CWDs		Fear of CWDs Witchcraft

Summary

The caregivers who participated in the face-to-face interviews and the FGDs together with the researcher have expressed how CWDs are perceived in the society. What was reported to societal perception in the present study is mainly referred to as societal attitude in the literature (Eagly & Chaiken, 2007; Vignes, Godeau, Sentenac, Coley, Navarro, Grandjean & Arnaud, 2009; Bossaert, Colpin, Pijl & Petry, 2011; De Laata, Freriksen & Vervloed, 2013). As a result of the difference in the terminology used between the present study and the literature, the formulation of the concept is changed from the 'societal perception' of CWDs to 'societal attitude' of CWDs. Based on the information obtained from the research participants and the literature; the community has both a positive and negative societal attitude towards CWDs.

Non-relational statement

The society has both positive and negative attitudes towards CWDs and their caregivers. Community members displayed a positive attitude towards CWDs by showing love, caring and by supporting the caregiver and CWD. However, other members of the community displayed a negative attitude towards CWDs which is displayed by: (1) name calling, (2) ridiculing, (3) gossiping, (4) hating, (5) staring, (6) being fear of CWDs, (7) intolerance, and (8) associating disability with witchcraft.

5.5 SUMMARY OF CHAPTER 5

In Chapter 5, the demographic information of caregivers and CWDs as well as the demographic information of rehabilitation professionals and CRWs were presented. The existing body of literature was used for clarification, refinement and sharpening of 16 concepts, followed by the presentation of a non-relational statement. The 16 concepts are:

- Cause of childhood disability
- Available services
- Role of caregivers
- Caregivers' source of support
- Caregivers' coping strategy
- Caregivers' level of satisfaction
- Caregivers' expectations
- Role of rehabilitation professionals
- Rehabilitation professionals' competency
- Factors that affects the rehabilitation professionals' work ethic
- Rehabilitation professionals' plan of action
- Role of community rehabilitation workers
- Role of the municipality towards people with disabilities
- Role of Pfunanani Special School
- Challenges experienced
- Societal perception of children with disabilities

In the next chapter, the development of relational statements is presented

.

CHAPTER 6

DEVELOPMENT OF RELATIONAL STATEMENTS

6.1 INTRODUCTION

In Chapter 6, relational statements are developed based on the concepts developed in Chapter 5. According to Walker and Avant (2005, p. 120), relational statements describe some type of relationship among or between the concepts. It is also said that relational statements should include a type (e.g causal, probabilistic, concurrent, conditional, and time-ordered amongst others), sign (e.g positive, negative, or unknown), and symmetry (e.g whether the direction is from one concept to the next but never reciprocated) (Walker & Avant, 2005, pp. 124-27). The various types of relational statements are briefly explained in the following paragraphs.

A causal statement is one that is said to be the “cause” of the other, and it is often deduced from laws (Walker & Avant, 2005, p. 124). Even though causal statements are said to be difficult to find in social and health research, they were used in this chapter to show some of the relationships between concepts. Probabilistic statements are usually derived from statistical data and are used if the events occurs some of the time or most of the time, but not all the time (Walker & Avant, 2005, p. 125). Concurrent statements assert that if event A occurs, event B also occurs. The events simply exist together as there may or may not be any causation between the two events (Walker & Avant, 2005, p. 125). Conditional statements are developed when two concepts occurs only in the presence of a third concept (Walker & Avant, 2005). Time-ordered statements are those statements that indicate that some amount of time intervenes between the first concept or event and the second concept or event (Walker & Avant, 2005).

As reported earlier in this chapter, signs and symmetries are used to show relationships between concepts or events. According to Walker and Avant (2005), signs that are used to show relationships between concepts or events follow a positive, negative, or any other symbols or format. The signs are typically shown next to an arrow that shows the symmetry or direction of the relationship. The relationship between concepts or events can either be symmetrical or asymmetrical where the former implies that the relationship is bi-directional.

Several signs, symbols, and acronyms as highlighted below were used in this chapter to show the relationship between concepts. The meaning of the sign, symbol, or acronym as presented below on the left, is shown on the right (e.g. “ CG” means caregiver whereas + means increase).

“CG”: Caregiver

“CG expct”: Caregiver expectation

“G”: Is part of

#: Is not cause of

+: Increase

-: Decrease

? +: May increase

? –: May decrease

“R”: Is associated with

“Role”: Role of

⟶ : Asymmetrical relationship

⟷ : Symmetrical relationship

Each of the text boxes in the Figures that follow has a number such as {0-3} that shows the number of links between the different text boxes. {0-3} means that there are three links of that particular text box and others.

6.2 DEVELOPMENT OF RELATIONAL STATEMENTS

In Chapter 5, non-relational statements were developed on the following concepts:

- Cause of childhood disability (Section 5.4.1)
- Available services (Section 5.4.2)
- Role of caregivers (Section 5.4.3)
- Caregivers' sources of support (Section 5.4.4)
- Caregivers' coping strategy (Section 5.4.5)
- Caregivers' level of satisfaction (Section 5.4.6)
- Caregivers' expectations (Section 5.4.7)
- Role of rehabilitation professionals (Section 5.4.8)
- Rehabilitation professionals' competency (Section 5.4.9)
- Factors that affects the rehabilitation professionals' work ethic (Section 5.4.10)
- Rehabilitation professionals' plan of action (Section 5.4.11)
- Role of community rehabilitation workers (Section 5.4.12)
- Role of the municipality towards people with disabilities (Section 5.4.13)
- Role of Pfunanani Special School (Section 5.4.14)
- Challenges experienced (Section 5.4.15)
- Societal perception of CWDs (Section 5.4.16)

The 16 concepts developed in Chapter 5 (Section 5.4) were merged with one another in Chapter 6 in order to develop or formulate relational statements so as to examine relationships among the concepts (Walker & Avant, 2005). A total of seven relational statements were formulated in sections 6.2.1 to 6.2.7 and presented in the following sub-sections.

6.2.1 Relational Statement on the Cause of Childhood Disability

A causal relational statement was developed based on the findings of the present study and the existing body of literature. The causes of childhood disability as perceived by the caregivers (Section 5.4.1) was reported to be a direct result of belief based factors such as religious and other beliefs, biomedical factors, and the pregnant mothers' lifestyle and habits. However, there is insufficient evidence in the literature to suggest that belief based factors can result in childhood disability. Religious and other beliefs have however been reported as a source of support to caregivers and families of CWDs (Edwardraj, Mumtaj, Prasad, Kuruvilla & Jacob, 2010). Other studies have also showed that caregivers or parents of CWDs used their religious beliefs and or praying as an alternative therapy in addition to being a source of support (McLean & Kemper, 2006; Gözüm & Büyükavcı, 2007; Tokem, Yıldırım & Fadiloglu, 2012). In other words, the caregivers in this community have non-scientific beliefs about the cause of disability which is important to remember during intervention.

Figure 6.1shows that religious and other beliefs do not cause childhood disability. The suggestion by caregivers that belief based factors may be responsible for causing disability indicates that they lack information about the cause of childhood disabilities. There is sufficient evidence in the literature to suggest that the cause of childhood disability has a biomedical origin (Banskota, Foltz, Gosselin & Spiegel, 2014). Furthermore, Figure 6.1 also shows that lifestyle factors such as excessive smoking of tobacco and drinking of alcohol during pregnancy increases a pregnant woman's likelihood of having a CWD. However, the consumption of spicy food as suggested by caregivers in the current study does not cause childhood disability but may decrease/reduce the chances of giving birth to a CWD. For an example, *capsicum annuum* which is a scientific name for chilli pepper is said to be high in antioxidants (Grieger, Wood & Clifton, 2013), essential nutrients, and Vitamin C which is six times that of an orange (Brito-Argáez, Moguel-Salazar, Zamudio, González-Estrada & Islas-Flores, 2009), as well as having antimicrobial properties (Omolo, Wong, Mergen, Hastings, Le, Reiland, Case & Baumler, 2014).

In conclusion, there is sufficient evidence in the literature to suggest that biomedical reasons and some of the pregnant mothers' lifestyles and habits are responsibility for increasing the chances of having a CWD. Mateos *et al* (2013) suggested that the consumption of spicy food during pregnancy does not cause childhood disability as indicated by the caregivers but may decrease/reduce the chances of childhood disability because of it richness in antioxidants, and Vitamins A and C respectively. Religious and other beliefs does not cause childhood disability, instead these practices are implemented as a source of support or alternative form of therapy for caregivers (; McLean & Kemper, 2006: Gözüm & Büyükavcı, 2007; Tokem, Yıldırım & Fadiloglu, 2012). The perception by caregivers that belief based and religious practises could be responsible for childhood disability may indicate a lack of information about the condition of the child by the caregivers and or family.

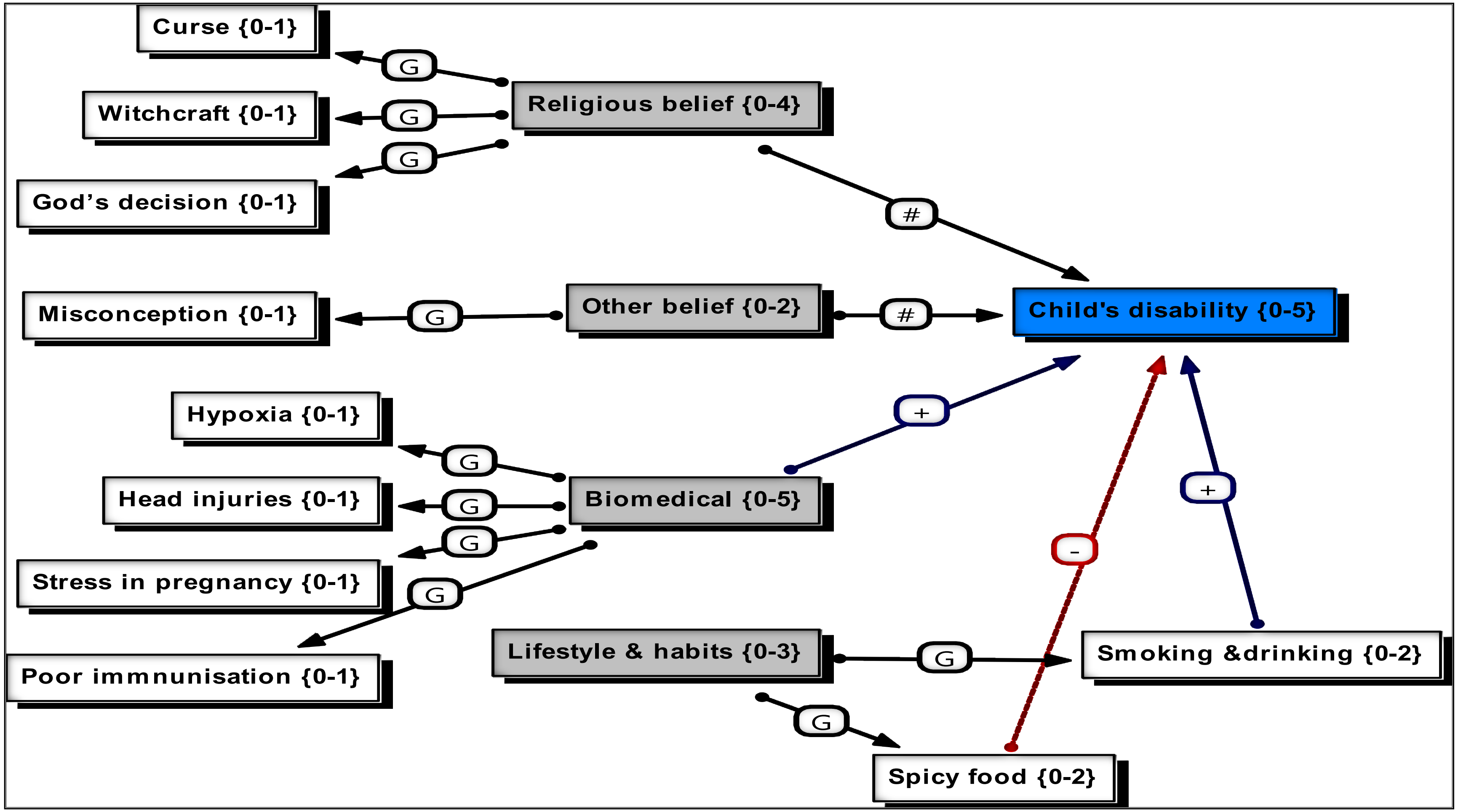


Figure 6.1 Cause(s) of childhood disability

(Refer to page 216 for figure legends)

6.2.2 Relational Statement on Available Services and Roles

The relational statements in this subsection are based on the following concepts: available services for CWDs (Section 5.4.2), the role of rehabilitation professionals (Section 5.4.8), the role of CRWs (Section 5.4.12), he role of the municipality (Section 5.4.13), and the role of the Pfunanani Special School (Section 5.4.14). Figure 6.2 shows the relationships between these five concepts that can be described as being an example of concurrent statements because it does not show causality, but just exist together.

The available services for CWDs and their caregivers have been reported to include amongst others the general health-care and rehabilitation services which are provided by the rehabilitation professionals and CRWs. The CRWs are part of the health-care and rehabilitation services as well as part of the community-based services. The roles of rehabilitation professionals (physiotherapy, occupational therapy and genetic nurse) as suggested in the present study are related or similar to those of CRWs, and they include: multitasking, examining CWDs (Andrade *et al*, 2012), supporting CWDs and caregivers, skills training for caregivers, and rehabilitating CWDs (Egilson, 2011) as shown in Figure 6.2 (on page 222).

Pfunanani Special School as part of community-based services has a role in vocational skills training for CWDs whilst the municipality (local government) which is also part of community-based services has a role of providing financial resources for CWDs, creating opportunities for CWDs to participate in society, promoting the rights of CWDs, and addressing the needs of CWDs such as the educational needs (Saloojee *et al*, 2007) and recreational needs (Rimmer, Rowland & Yamaki, 2007).

In conclusion, Figure 6.2 shows the available services for CWDs and their caregivers in Giyani together with the respective roles of the physiotherapy staff, occupational therapy staff, the genetic nurse, and the CRWs; municipal services or the Greater Giyani Municipality; and Pfunanani Special School. The relational statement in this subsection does not show any causation but only show the co-existence/concurrence of the available services, role of rehabilitation professionals, role of CRWs, role of Pfunanani Special School and the role of the municipality towards CWDs.

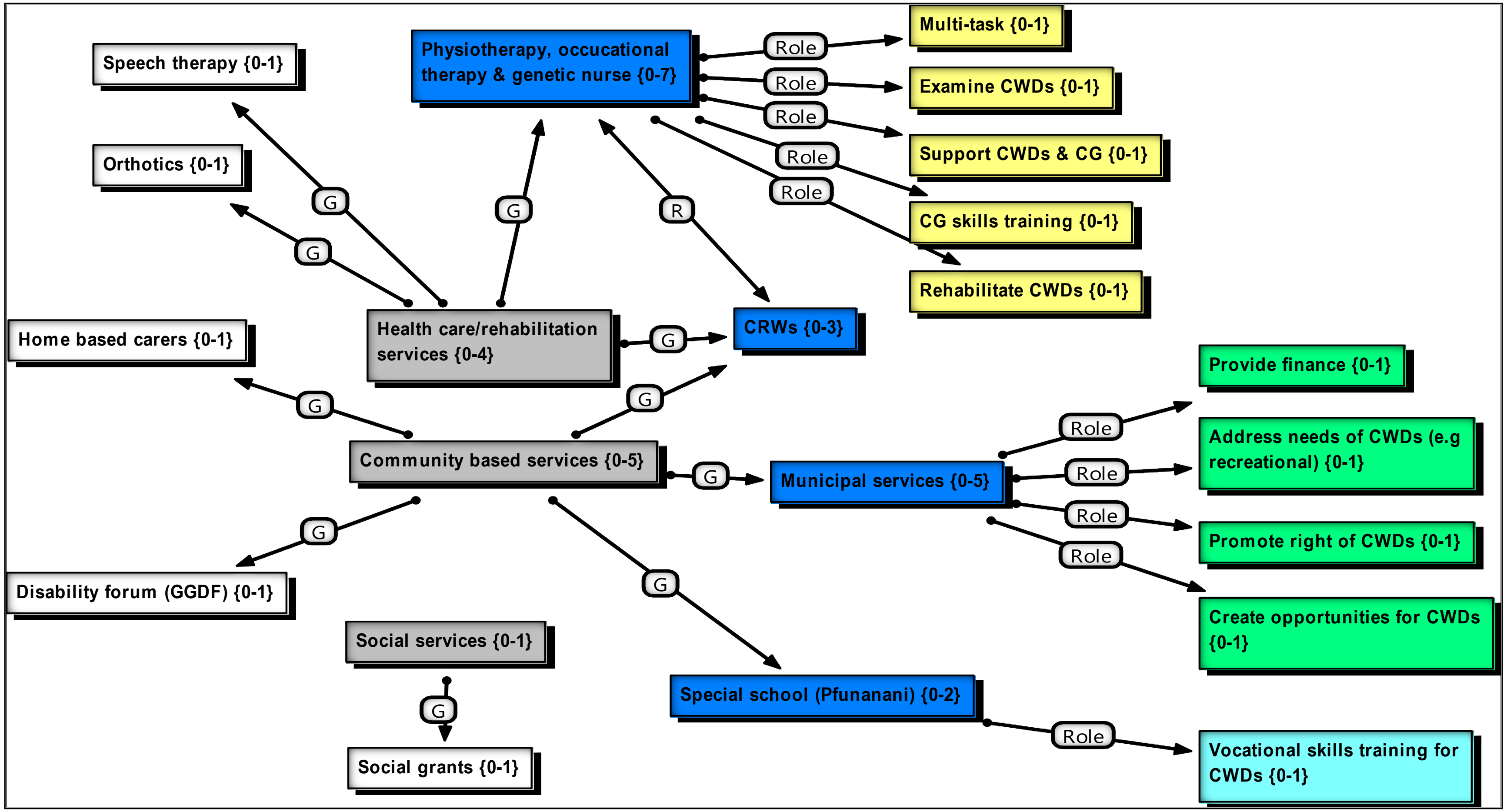


Figure 6.2 Relationships between available services and roles

(Refer to page 216 for figure legends)

6.2.3 Relational Statement on the Expectations and Satisfaction of Caregivers with Available Services

The relational statements in this subsection are based on the available service for CWDs and their caregivers (Section 5.4.2), caregivers' expectations from the available services (Section 5.4.7), and caregivers' level of satisfaction with the available services (Section 5.4.6).

Figure 6.3 shows the different expectations that caregivers of CWDs have from the health-care/rehabilitation services, social services, and community-based services. The graphic presentation (Figure 6.3) shows causality, co-existence/concurrency of the concepts, and probabilistic statement.

The adequate services that caregivers receive from the health-care/rehabilitation service increase their satisfaction (King *et al*, 2001; Schreiber *et al*, 2011). However, the inadequate services that caregivers receive decrease their satisfaction as shown in Figure 6.3.

Caregivers' expectations in the current study are based on the services that they believed to be inadequate. Moreover, based on the caregivers' expectations, a probabilistic statement is made that the inadequacies in social service and community-based services are also likely to decrease/reduce caregivers' satisfaction with the services that they received.

In conclusion, caregivers of CWDs had different expectations from the various available services such as health-care/rehabilitation services, social service and community-based services. The caregivers' expectations depended on their perception of the quality of the service that they received. In other words, caregivers expected to receive/get certain types of services which they felt they were entitled to but it was never offered to them. However, caregivers believed that some of the services that they received were adequate and as such they were satisfied with it. The health-care/rehabilitation services that caregivers perceived to be adequate increased the caregivers' satisfaction whereas services that they perceived to be inadequate decreased their satisfaction.

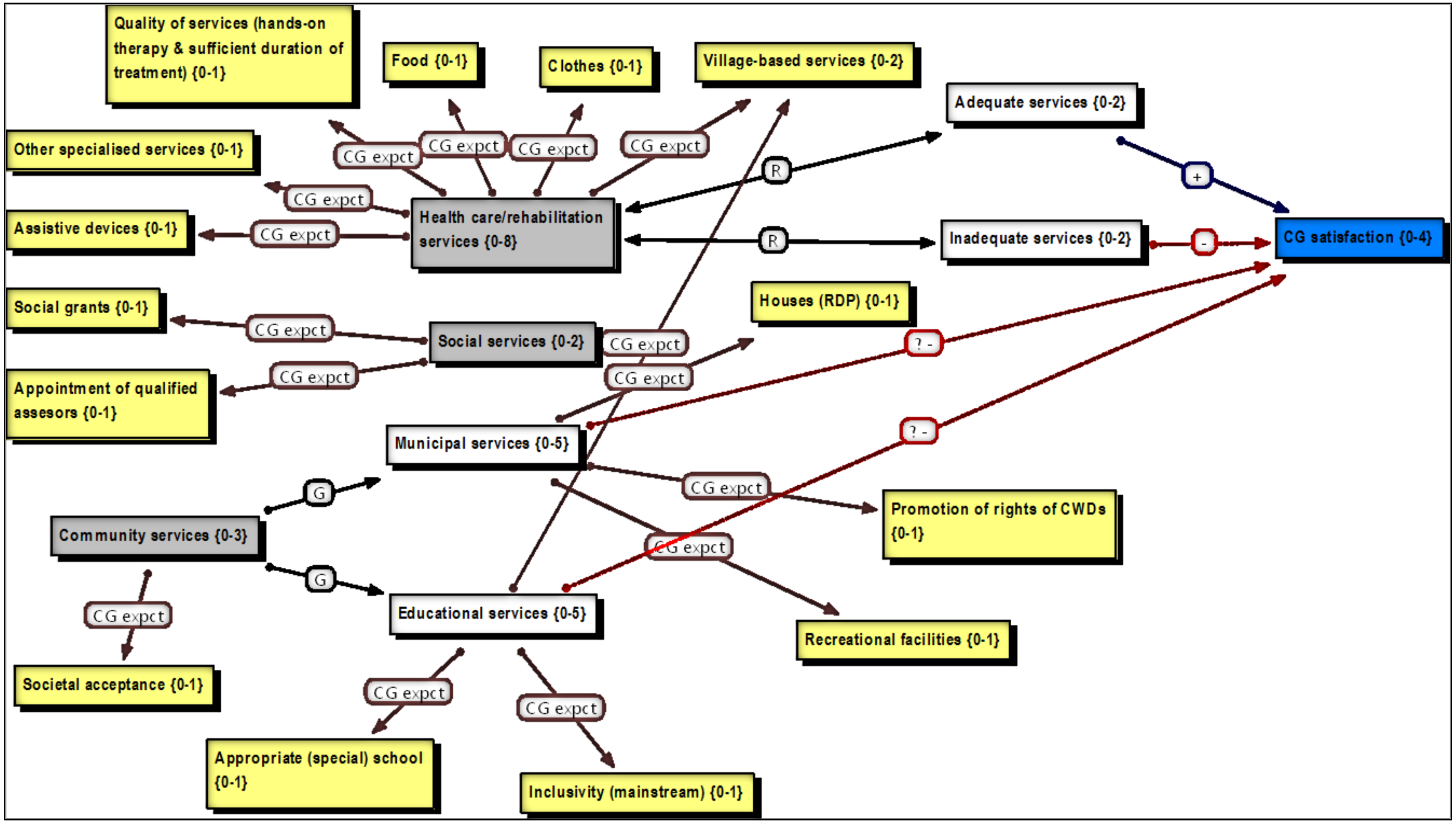


Figure 6.3 Relationships between caregivers’ expectation and satisfaction with available services

(Refer to page 216 for figure legends)

6.2.4 Relational Statements on the Challenges Experienced by Caregivers of CWDs and the Societal Perception/Attitude of CWDs

In this subsection, the causal and concurrent relationships between the challenges that caregivers and CWDs experienced (Section 5.4.15) as well as the societal perception of CWDs (Section 5.4.16) are shown (Figure 6.4). In the current study caregivers reported to experience child-related challenges, family-caregiver related challenges, health-care related challenges, and community related challenges as it was also found in other studies (Resch *et al*, 2010; Gona *et al*, 2011; Morgan & Tan, 2011; Pollack, 2011).

As shown in Figure 6.4 (on page 226), child-related challenges, health-related challenges and community-related challenges have the potential of increasing the family-caregiver related challenges. The implication of increased family-caregivers related challenges is that it may have a direct bearing on the CWDs because the caregiver/family is the most proximal support-structure for CWDs (Bronfenbrenner, 1979; Garbarino & Ganzel, 2000).

On the other hand, societal perception/attitude towards CWDs whether positive or negative has an impact on the challenges that caregivers and CWDs experience. As shown in Figure 6.4, positive societal attitude towards CWDs has a potential of decreasing community related as well as family-caregiver related challenges. Similarly, negative societal attitude towards CWDs has a potential of increasing community related as well as family-caregiver related challenges.

In conclusion child-related challenges, health related challenges and community related challenges as shown in Figure 6.4 have the potential of increasing the family-caregiver related challenges. A probabilistic statement was made about the likelihood of the societal attitude towards CWDs in influencing the challenges that CWDs and caregivers encounter. The negative societal attitudes are likely to increase family-caregivers related and community related challenges. Similarly, positive societal attitudes are likely to decrease family-caregivers related and community related challenges. Therefore, it can be concluded that societal attitude has a bearing on the challenges that CWDs and their caregivers' encounter.

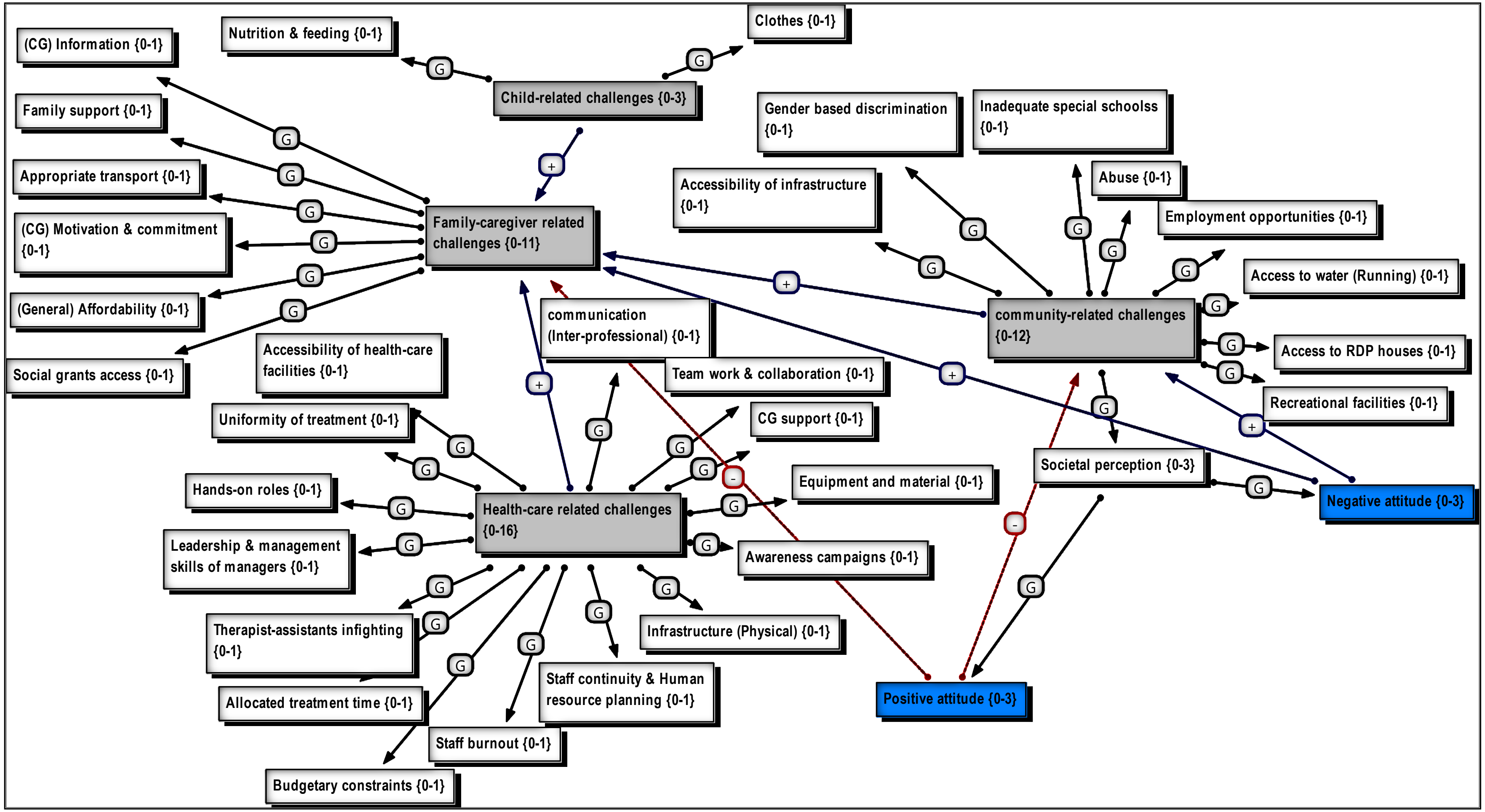


Figure 6.4 Relationship between the challenges experienced by caregivers of CWDs and societal perception/attitude of CWDs

(Refer to page 216 for figure legends)

6.2.5 Relational Statements on the Role of Caregivers, Sources of Support and Coping Strategies

The role of caregivers in the current study includes support for the CWD and to ensure that there is continuity of care (Section 5.4.3). As shown in Figure 6.5, the caregivers coping strategies (Section 5.4.5) such as patience, acceptance, fait accompli, and religion/religious belief has a potential of increasing the support for the child (Knight & Sayegh, 2010; Pillay, Girdler, Collins & Leonard, 2012) which in turn increase/improve the role of the caregivers. Similarly, the caregivers' sources of support (Section 5.4.4) such as religion/religious belief; family, friends, and neighbours; health-care services; and community-based services have a potential of also increasing support for the CWD which in turn increase/improve the role of caregivers. On the other hand, absence of caregiver support has the potential of decreasing/reducing support for the child.

In conclusion, causal statements were used to describe the relationship between the role of caregivers, their sources of support, and coping strategies. The causal relational statement was used to show how patience; acceptance; fait accompli; religion/religious belief; family, friends, and neighbours; health-care services; and community-based services increases support for the CWD. The lack or absence of support structures for caregivers of CWDs decreases support for the CWD. Lastly probabilistic statement was used to express the possible increase or improvement in the role of caregiver following an increase in the support for the CWD.

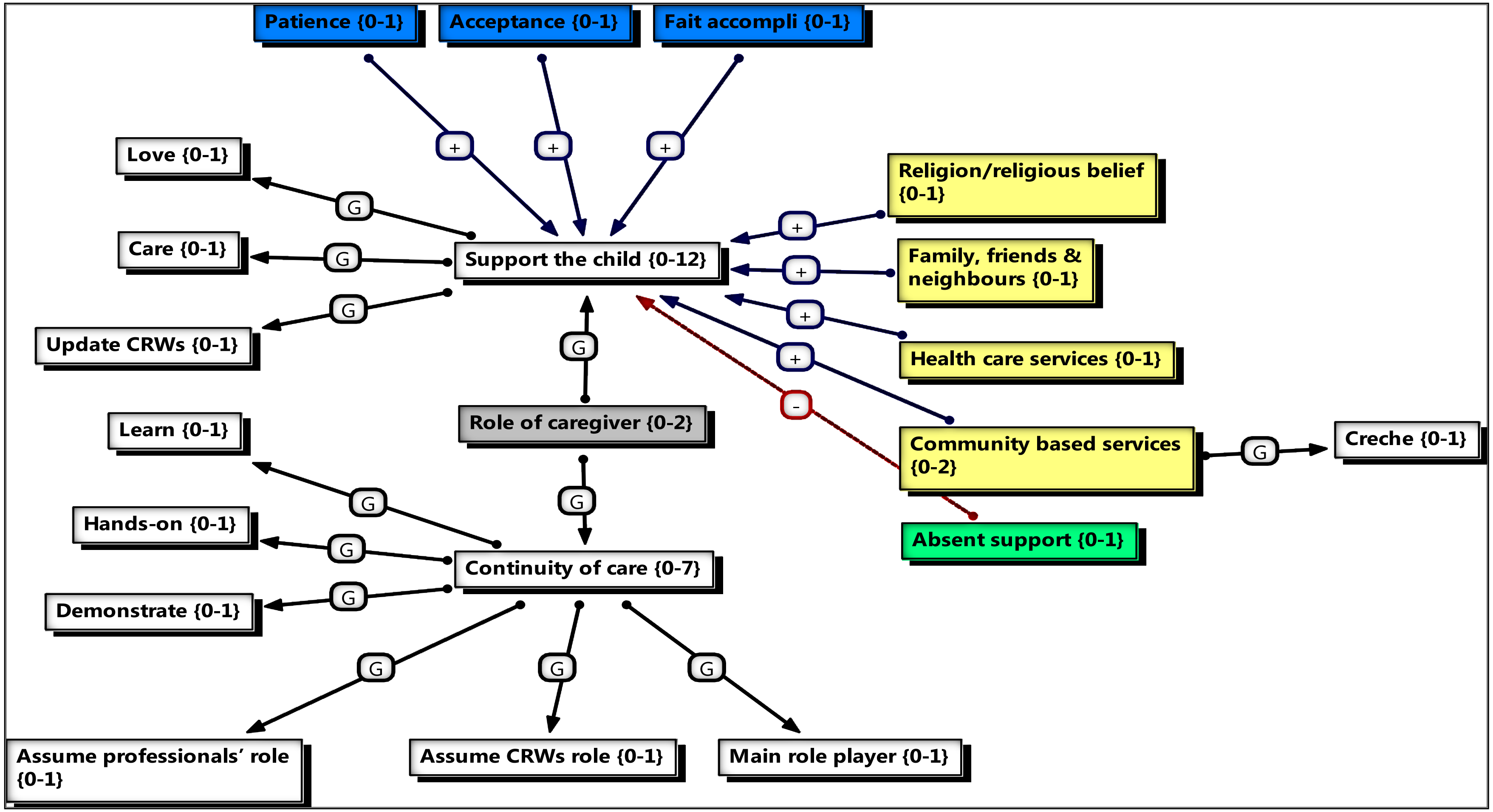


Figure 6.5 Relationships between the role of caregivers, sources of support, and coping strategies

(Refer to page 216 for figure legends)

6.2.6 Relational Statement on the Rehabilitation Professionals’ Work Ethics and Competencies

It has been reported in the current study that there were rehabilitation professionals who possessed adequate professional competencies whilst others had inadequate professional competencies. Furthermore, rehabilitation professionals’ work ethic was said to be influenced by either positive or negative factors.

Figure 6.6 shows the concurrent and causal relationship between the rehabilitation professionals’ work ethic and their competencies. As indicated in Figure 6.6, the positive factors that influence rehabilitation professionals’ work ethic have a potential of increasing/improving the rehabilitation professionals’ adequate competencies and decreasing their inadequate competencies. On the other hand, negative factors have the potential of decreasing/reducing the rehabilitation professionals’ competence and increasing their incompetence.

In conclusion, the relational statement in this section suggests that the factors that affect or influence the rehabilitation professionals’ work ethic have a bearing on the rehabilitation professionals’ competencies or skills (Seedhouse, 2002; Włoszczak-Szubzda & Jarosz, 2013).

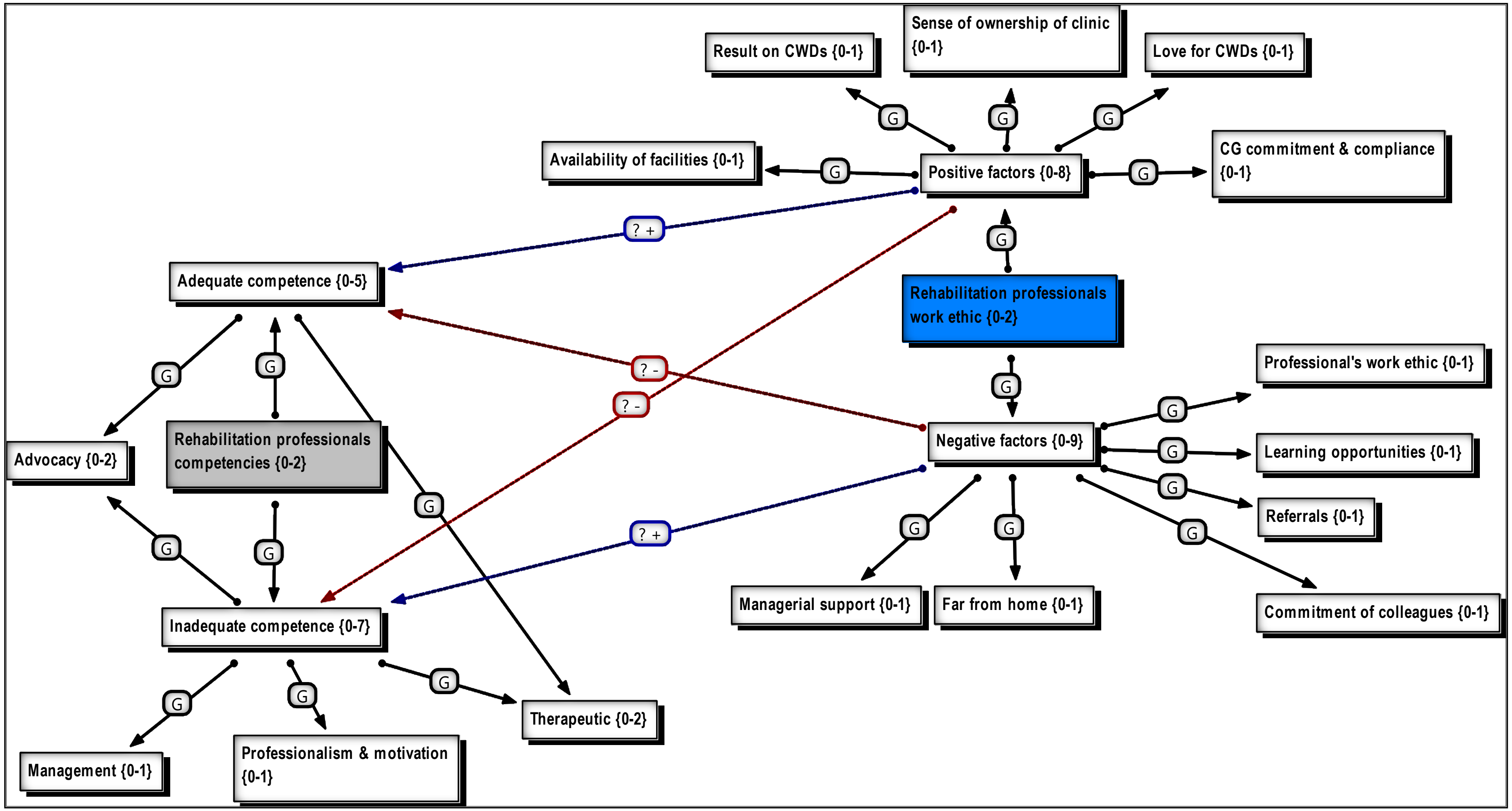


Figure 6.6 Relationship between rehabilitation professionals' competences and work ethic

(Refer to page 216 for figure legends)

6.2.7 Relational statement on the Rehabilitation professionals' plan of action and challenges experienced by caregivers of CWDs

The challenges that caregivers and CWDs experienced in the current study (Section 5.4.15) include child-related challenges, family-caregiver related challenges, health-care related challenges and community related challenges. However, the rehabilitation professionals' plan of action focused on addressing the family-caregiver related challenges, and health-care related challenges but not the child-related challenges nor the community related challenges.

Figure 6.7 shows the concurrent and the causal relationship between the rehabilitation professionals' plan of action and the challenges experienced by CWDs and their caregivers. As shown in Figure 6.7 (on page 233), health education which is one of the rehabilitation professionals' plans of action has the potential of increasing/improving the information (knowledge) that caregivers of CWDs have about the condition of their children. An increase/improvement in caregiver information is likely to decrease/reduce the family-caregiver related challenges. Furthermore, health education also has the potential of increasing/improving the caregivers' access to a social grant. The increase or improvement of access to social grants is likely to increase the caregivers' affordability which will in turn increase access to appropriate transportation. Improved affordability results in better access to appropriate transportation and increased accessibility to health-care facilities.

The formation of support groups and caregiver meetings as suggested by the rehabilitation professionals is likely to increase caregivers' motivation and compliance to treatment, as well as caregiver and family support.

Should the rehabilitation professionals support CRWs as proposed in the current study, it is likely that the accessibility of health-care facilities by caregivers and CWDs will be improved.

By querying the records of the previous treatment that the CWDs received, the uniformity of the treatments conducted by the rehabilitation professionals in the rehabilitation clinic is likely to be increased thus reducing the health-care related challenges. An increase in uniformity of treatment/intervention is likely to increase the treatment time that is allocated to CWDs and their caregivers in the rehabilitation clinic.

Conducting home visits as proposed by the rehabilitation professionals' is likely to increase family support which is also likely to reduce family-caregiver related challenges. In addition, home visits are also likely to increase accessibility of health-care services by CWDs and caregivers in the villages.

Communication as one of the rehabilitation professionals' plan of action is likely to increase teamwork and collaboration which will in turn increase the uniformity of treatment, and decrease staff burnout. Furthermore, if the rehabilitation professionals and other staff members communicate with their hospital leaders and managers regarding their work and or challenges, there is a likelihood that the hospital leadership and management skills will improve. An improvement in leadership and management skills is likely to decrease budgetary constraints, and ensure that there is an increase in awareness campaigns/health promotion, equipment and materials, and physical infrastructure for service delivery. Furthermore, improved leadership and management skills are also likely to decrease/reduce the therapist-assistants infighting. Therapist-assistants infighting may also be decreased/reduced if therapists and therapy assistants communicate about their differences and or challenges.

Lastly, the formation of an MDT as proposed by the rehabilitation professionals is likely to increase teamwork and collaboration.

In summary, relational statements were formulated to show the relationship between the rehabilitation professionals' plan of action and the (family-caregiver and health-care related) challenges experienced by CWDs and their caregivers. The different rehabilitation professionals' plan of action had a bearing on the family-caregiver and health-care related challenges.

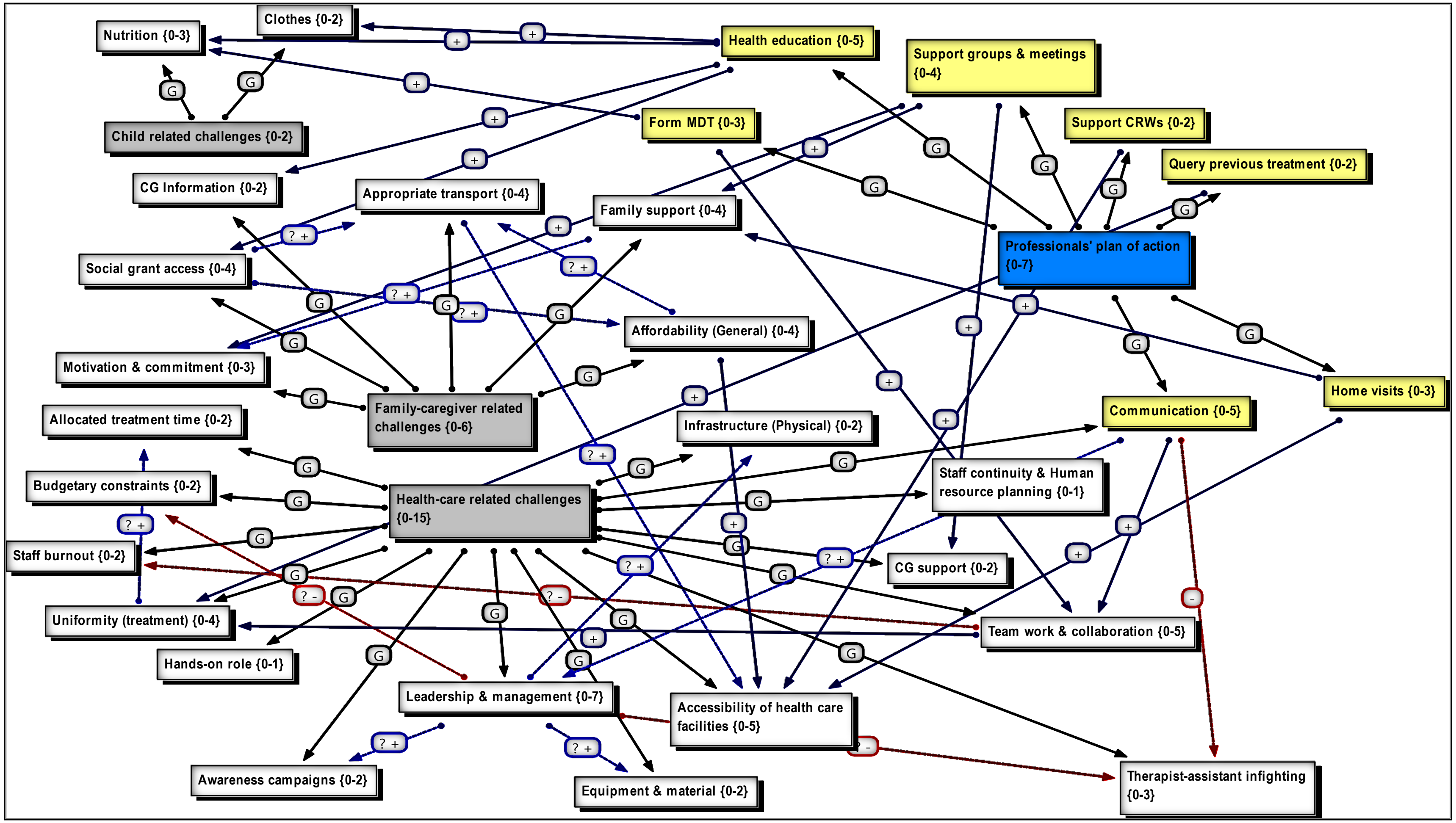


Figure 6.7 Relationships between rehabilitation professionals' plan of action and challenges experienced by caregivers of CWDs

(Refer to page 216 for figure legends)

6.3 SUMMARY OF THE CHAPTER

In Chapter 6, relational statements were formulated based on the 16 concepts which were developed in Chapter 5. Concepts were combined with one another in order to formulate seven relational statements which were also presented graphically by showing the type, sign and symmetry of the relationship. The seven relational statements related to the following: the cause(s) of childhood disability as perceived by the caregivers ; available services and roles; expectations and satisfaction of caregivers in terms of the available services; challenges encountered by CWDs and the societal perception/attitude towards CWDs; role of caregivers, caregivers' sources of support and coping strategies; rehabilitation professionals' work ethic and competencies; and rehabilitation professionals' plan of action and challenges experienced by CWDs.

In the next chapter, theory emanating from the current study is presented graphically as a model.

CHAPTER 7

MODEL DEVELOPMENT AND CONCLUSION

7.1 INTRODUCTION

Chapter 7 is the last chapter of this research report and comprises: (1) the evaluation of the study, (2) the context for the development of a model for the rehabilitation of CWDs in Giyani, (3) the conceptual basis of the model, (4) a description of the model, (5) the interpretation of the model, (6) a comparison of the model for the rehabilitation of CWDs in Giyani with others models, (7) the implications of the model, (8) and conclusion.

7.2 EVALUATION OF THE STUDY

The current study can be evaluated by following the theory-generation process of concept development, statement development, and theory development as described by Walker and Avant (2005).

The aim of the present study was to develop a descriptive model for the rehabilitation of CWDs by rehabilitation professionals and other health-care workers such as the CRWs in the rural municipality of the Greater Giyani in Limpopo Province, South Africa.

The objectives of the study were to: (1) synthesise and refine concepts on: the role of caregivers, rehabilitation professionals and CRWs in the rehabilitation of CWDs; challenges that CWDs and their caregivers encounter; other specialized and available services for CWDs; support structures for CWDs and caregivers; and caregivers' satisfaction and expectations of services, (2) synthesise non-relational theoretical statements, (3) systemise and organise the relational statements, and (4) present the theory diagrammatically as a model. The development of a model was not a once-off event, but a process where the first three objectives of the study had to be met first before the model was developed.

7.2.1 Objective 1 (Synthesise and Refine Concepts)

The first objective of the study was respectively addressed in Chapters 3 and 4 following face-to-face interviews with caregivers of CWDs, rehabilitation professionals, and CRWs, as well as the FGDs with caregivers of CWDs and rehabilitation professionals. The findings of the face-to-face interviews were presented in Chapter 3 whereas the findings of the FGDs were presented in Chapter 4.

As part of the first objective of the study, 16 concepts were synthesised, refined and are presented as follows:

- Cause(s) of childhood disability
- Available services for CWDs in Giyani
- Role of caregivers in the rehabilitation of CWDs
- Caregivers' source of support
- Caregivers' coping strategy
- Caregivers' level of satisfaction with services they received
- Caregivers' service expectations
- Role of rehabilitation professionals in the rehabilitation of CWDs
- Rehabilitation professionals' competency/skills
- Factors that affects the rehabilitation professionals' work ethic
- Rehabilitation professionals' plan of action to address identified challenges.
- Role of community rehabilitation workers in the rehabilitation of CWDs
- Role of the municipality towards people with disabilities and in particular CWDS
- Role of Pfunanani Special School in the lives of CWDS in Giyani
- Challenges experienced by CWDs and their caregivers in Giyani
- Societal perception of CWDs

7.2.1.1 Methodological limitations associated with objective 1

Methodological limitations associated with data collection phase or objective 1 were identified and described in the following paragraphs:

- It was initially planned that data collection from caregivers would be performed in the caregivers' naturalistic environment (Babbie & Mouton, 2001; McMillan & Schumacher, 2006) or their place of residence on condition that their partners or parents approved. However, the first three caregivers who were recruited to participate in the study were reluctant to be interviewed in their homes and as such interviews were conducted at Nkhensani Hospital. There is a possibility that caregivers would have felt more comfortable and provided rich data in their homes than in a hospital setting.
- The caregivers who participated in the face-to-face interviews and FGDs were homogeneous in terms of gender, educational level, employment status, sources of income, income bracket, and the availability of water and electricity. Similarly, the CWDs whose caregivers participated in the face-to-face interviews and FGDs were homogeneous in terms of their age and their diagnosis. The majority of children were diagnosed with cerebral palsy. Nonetheless, the homogeneity of the caregivers is not of a great concern because the aim of the study was not to generalise the findings to the general public (Myers, 2000), but to "generalise" findings to a similar context (Miller, 2010) which is referred to as transferability (Lincoln & Guba, 1985; Shenton, 2004). Shenton (2004) has also suggested that transferability can only be enhanced if the methodology of the study is presented in detail for readers to follow which was the case in the current study. However, the homogeneity of the diagnosis of CWDs is of concern because the focus of the study is on children with varying types of disabilities and not exclusive for children with cerebral palsy. Therefore, the transferability of the study will be limited to children with cerebral palsy and not all types of childhood disabilities.
- The sample size of the caregivers who participated in the FGDs was smaller at two, three and five respectively. The available literature suggests an ideal FGDs sample size of between five and eight participants (Sim & Snell, 1996; Millward, 2012). A small sample of participants is likely to have an adverse effect of the credibility of the study. Nonetheless, multiple data collection

strategies (triangulation) was used in this study. The triangulation included the collection of data using face-to-face interviews, FGDs and direct observations. In addition, different participants such as caregivers, rehabilitation professionals and CRWs were asked similar questions.

- The face-to-face interviews were scheduled for a maximum duration of 45 minutes. However, the caregivers, rehabilitation professionals, and CRWs' interviews averaged for about 18 minutes, 29 minutes, and 10 minutes respectively. The duration of an interview does not actually influence the richness and quality of the data: as long as the aims and objectives of the study were addressed and met (Gill, Stewart, Treasure & Chadwick, 2008). Gill *et al* (2008) have also suggested that the average interview for a health-related research should be between 20 and 60 minutes. The duration of the FGDs with caregivers and rehabilitation professionals were on average between 21 minutes and 60 minutes respectively.
- Follow-up interviews were conducted with some caregivers and rehabilitation professionals, but not all. In addition, follow-up interviews were not conducted with CRWs because data saturation had already been reached. Member checking that is one of the criteria to enhance the credibility of the study was compromised, because follow-up interviews were not conducted with all participants. Nonetheless, other strategies such as reflexivity and triangulation were used to ensure that the findings of the study are credible.

7.2.2 Objective 2 (Synthesise Non-Relational Statements)

The second objective of the study was to synthesise non-relational statements as earlier discussed in Chapter 5. Following the development of the 16 concepts as highlighted in Section 7.2.1, non-relational statement were developed in order to define the concepts (Walker & Avant, 2005). The non-relational statements are abstract and immeasurable (Walker & Avant, 2005).

7.2.3 Objective 3 (Systemise and Organise Relational Statements)

The third objective of the study was to systemize and organize relational statements as presented in Chapter 6. The 16 concepts and non-relational statements as presented in Chapter 5 were combined with one another in order to formulate seven relational statements which were presented graphically by showing the type, sign and symmetry of the relationship. The seven relational statements are: (1) the cause(s) of childhood disability as perceived by the caregivers; (2) available services and roles; (3) expectations and satisfaction of caregivers in terms of the available services; (4) challenges experienced by CWDs and the societal perception/attitude towards CWDs; (5) role of caregivers, caregivers' sources of support and coping strategies; (6) rehabilitation professionals' work ethic and competencies; and (7) rehabilitation professionals' plan of action and challenges experienced by CWDs.

In this section, seven relational statements as presented in Chapter 6 were rearranged and reorganised whilst using the existing literature in order to clearly show: (1) cause(s) of childhood disability, (2) available services for CWDs in Giyani, (3) the goal of rehabilitation from the WHO's perspective (4) challenges experienced by children with disabilities and their caregivers, (5) the role of rehabilitation professionals, (6) the role of CRWs, (7) the role of family/caregivers, (8) the role of local municipality (Greater Giyani municipality), and (9) the role of the education sector (Pfunanani) in assisting CWDs.

7.2.3.1 Causes of childhood disability

CWDs have been reported in the current study as well as in the literature to include children with physical impairments, intellectual impairments, neurological impairments, or a combination of these impairments (Law, Hanna, Anaby, Kertoy, King & Xu, 2014).

The caregivers' belief that religion may be responsible for causing childhood disabilities may imply that there is a lack of information and knowledge in that regards which requires intervention (Dellicour, Desai, Mason, Phillips-Howard, Laserson & ter Kuile, 2013). Even though the study by Dellicour et al (2013) was conducted in Africa (Kenya), it had total disregard of traditional African beliefs and customs. A study by Van Dyk (2001) in South African has suggested that disregarding traditional African beliefs and customs in health promotion can have serious consequences. Van Dyk (2001) is of the view that Western-based AIDS education and prevention programmes have failed dismally in Africa because traditional African beliefs and customs were not taken into account.

There is no evidence in the literature to suggest that religious and other beliefs are responsible for causing childhood disability as reported by the caregivers who participated in the present study (Croot *et al*, 2008; Hebert & Koulouglioti, 2010; Daudji *et al*, 2011). Childhood disability has been widely reported in the literature to be a result of biomedical factors and the pregnant mothers' lifestyle and habits (Maulik & Darmstadt, 2007; Croot *et al*, 2008; Nielsen *et al*, 2008; Fatemi & Folsom, 2009; Jauhari *et al*, 2011; Peadon *et al*, 2011; Rivara *et al*, 2011; Karthikeyan & Ramalingam, 2012; Underberg *et al*, 2012; Kristina *et al*, 2013; Loomans *et al*, 2013; Mcintyre *et al*, 2013; Khandaker *et al*,2014; Natarajan *et al*, 2014).

7.2.3.2 Available services for children with disabilities in Giyani

Services which are available for CWDs in Giyani such as that of the rehabilitation professionals, CRWs, the local municipality, and the educational sector (i.e. Pfunanani Special School) may reduce the challenges which caregivers and CWD's experience as earlier discussed in Section 6.2.2. If challenges are reduced, caregivers would be able to support the child and to ensure that there is continuity of care that will eventually improve their quality of life of CWDs.

7.2.3.3 Goal of rehabilitation

The ultimate goal of the rehabilitation of CWDs is to promote the children's health, function and participation in society (WHO, 2007). To a certain extent, factors that are responsible for causing childhood disabilities such as biomedical factors and the mother's lifestyle and habits will influence the child' s health, function and participation (Guralnick, 1997a; Guralnick, 1997b).

Information about the possible causes of childhood disabilities, as well as the consequences of childhood disabilities, has to be provided to the caregivers and or family through health education. The use of health education may also conscientise caregivers and or the family on how to promote the health, function and participation of their disabled children (Magaña, Li, Miranda, & Paradiso de Sayu, 2014).

The WHO (2014) suggests that to be able to meet the goal of promoting health, function and participation of PWDs and in particular CWDs, barriers and or challenges associated with access to health-care services, rehabilitation services, assistive technology, assistance and support services, and community-based rehabilitation have to be addressed and removed. These barriers and challenges as reported by the WHO (2014) are in a way similar to the child-related, family-caregiver related, health, and community related challenges as reported in the current study.

7.2.3.4 Challenges experienced by children with disabilities and their caregivers

As caregivers seek the rehabilitation services that their CWDs require, they encounter multiple challenges which limit their own abilities to get efficient and effective rehabilitation for the CWDs (Carter & Markham, 2001; Tervo, Palmer & Redinius, 2004; Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005; Briggs, 2006; Ledford & Gast, 2006; Reiter, Bryen, & Shachar, 2007; Saloojee *et al*, 2007; Jemta, Fugl-Meyer, & Oberg, 2008; Kvam & Braathen, 2008; Njambi, Kariuki, & Masinde, 2009; Fink, Gunther & Hill, 2011; Gona *et al*, 2011; WHO, 2011; Adams, Khan, Begum, Wirz, Hesketh & Pring, 2012; Dahlseng, Finbråten, Júlíusson, Skranes, Andersen & Vik, 2012; Mackintosh, Goin-Kochel & Myers, 2012; Reading, 2012; Anaby *et al*, 2013; Ataguba & McIntyre, 2013; Graham, Keys; Haveman, Tillmann, Stöppler, Kvas & Monninger, 2013; Sharp *et al*, 2013; UNICEF, 2013; Bunning *et al*, 2014; Donald, Samia, Kakooza-Mwesinge & Bearden, 2014; Hatcher, Onah, Kornik, Peacocke & Reid, 2014; McMahon & Brubacher, 2014).

The challenges that caregivers of CWDs encounter are categorised into child-related, family-caregiver related, health-care related, and community related challenges. These challenges directly or indirectly limit the caregivers from supporting the CWD and ensuring that there is continuity of care. In addition, some of these challenges limit the rehabilitation professionals from exercising their responsibilities and roles on CWDs thus compromising the quality of care (Drotar, 1998).

7.2.3.5 Role of rehabilitation professionals

The rehabilitation professionals have been reported in the current study to play multiple roles (multi-task), such as to examine CWDs, support CWDs and the caregiver, skills training for the caregivers, and to rehabilitate CWDs. However, to be able to play the various roles as indicated earlier, rehabilitation professionals must at least have the following competencies/skills: advocacy, therapeutic, teamwork and collaboration, communication, professionalism and motivation, and management.

It is also important that the positive and negative factors that affect or influence the rehabilitation professional's work ethic should be taken into consideration. This is because positive factors (such as: the availability of facilities, their love towards CWDs, results/progress of the CWDs, sense of ownership of the rehabilitation clinic) are likely to increase the rehabilitation professionals' competencies/skills whereas the negative factors (such as: the individual professionals' work ethic, lack of learning opportunities, lack of referrals, inadequate commitment of colleagues, working far from home, and the lack of management support) are likely to decrease the rehabilitation professionals' competencies/skills.

The adequacy of rehabilitation professional's competencies will to a certain extent influence or control how the rehabilitation professionals execute their roles of multi-tasking, examining CWDs, supporting CWDs and the caregiver, skills training for the caregivers, and rehabilitating CWDs as stated earlier.

The child-related challenge (nutrition) as reported in the current study can be managed by rehabilitation professionals or other health professionals, such as nutritionists and dieticians. Challenges associated with nutrition by CWDs can be addressed through surgical and non-surgical interventions (Ferluga, Archer, Sathe, Krishnaswami, Klint, Lindegren & McPheeters, 2013).

For children with moderate to severe aspiration or malnutrition related to oral-pharyngeal dysphagia and gastro-oesophageal reflux, surgical interventions, such as gastrostomy tubes, jejunostomy tubes, and anti-reflux procedures may be used to improve nutritional status and reduce risk of chronic aspiration (Sleigh & Brocklehurst, 2004; Snider, Majnemer, & Darsaklis, 2011).

The non-surgical interventions to overcome challenges, such as positioning, oral appliances, oral stimulation, sensorimotor facilitation, and caregiver training require the expertise of speech-therapists and to a lesser extent the knowledge of dieticians and or nutritionists (Ferluga *et al,* 2013). However, speech-therapists are not part of the staff at the rehabilitation clinic in Giyani. While considering the specialised role that speech-therapist can play towards swallowing and communication of CWDs as suggested by (Ferluga, et al., 2013), it is important that they form part of the rehabilitation clinic in Giyani or avail themselves should their service be required. None the less, the available rehabilitation professionals can provide nutritional information through health education as well as providing/teaching caregivers the necessary skills which will enable them to position, stimulate, and feed the CWDs. Dietitians are referred to as experts in the field of nutrition (Mihalynuk & Whiting, 2013), and they would assist CWDs if they are included as part of the rehabilitation clinic in Giyani. The inclusion of dietitians and speech-therapists in the rehabilitation clinic may be described as part of the MDT as proposed by the rehabilitation professionals (Figure 7.1).

Figure 6.4 in Chapter 6 has shown that child-related challenges (nutrition and clothing) have the potential of increasing family-caregiver related challenges. Figure 7.1 (on page 244) show that rehabilitation professionals may reduce the family-caregiver challenges through the use of health education, the formation of support groups and meetings, and by conducting home visits to the families of CWDs.

In addition, rehabilitation professionals may also reduce health-care related challenges by forming MDT, supporting CRWs, querying previous treatment notes in the patient’s file, conducting home visits in the communities, and improving communication amongst themselves as rehabilitation professionals, as highlighted in Figure 7.1.

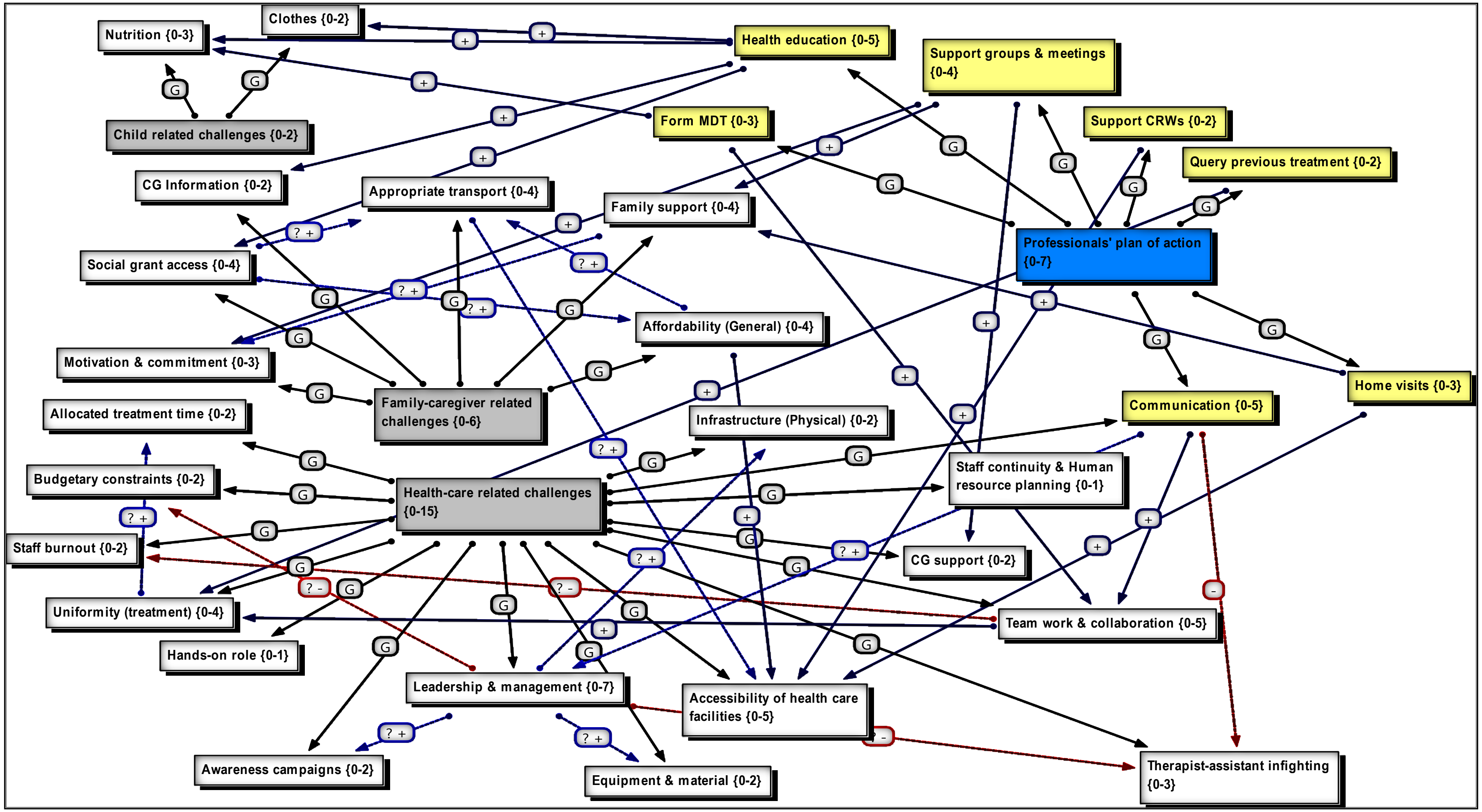


Figure 7.1 Relationships between rehabilitation professionals' plan of action and challenges experienced by caregivers of CWD

7.2.3.6 Role of community rehabilitation workers

The roles of CRWs as shown in Figure 7.2 are similar to that of rehabilitation professionals that include examining CWDs, supporting CWDs and the caregiver, skills training for the caregivers, and rehabilitating CWDs. The main difference between the role of CRWs and rehabilitation professionals is that the CRWs particularly engage with CWDs and caregivers in the community whilst rehabilitation professionals mainly engage with CWDs and their caregivers in the rehabilitation clinic/hospital. By virtue of similarities between the roles of CRWs and rehabilitation professionals, CRWs are likely to reduce child-related challenges, family-caregiver related challenges, and health-care challenges.

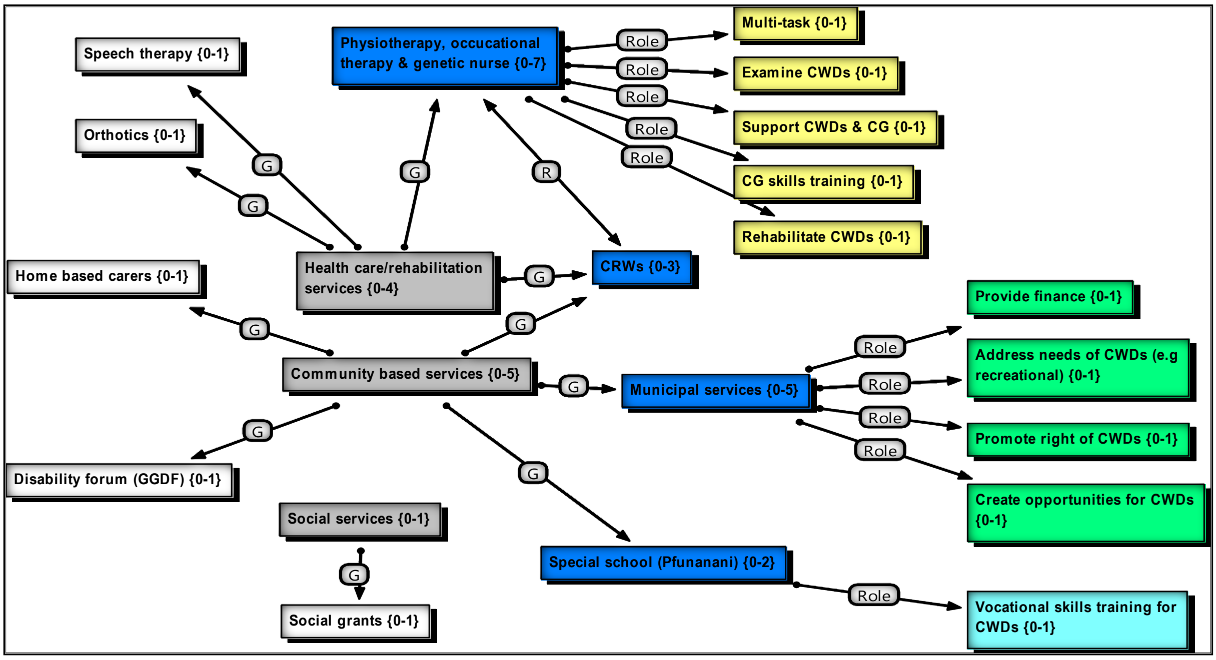


Figure 7.2 Relationships between available services and roles

7.2.3.7 Role of family/caregivers

Raising or caring for a typically developing, non-disabled child has been reported in the literature as a challenging task (Liamputtong, Yimyam, Parisunyakul, Baosoung & Sansiriphun, 2004; Marit, Elisabeth & Bjorg, 2011; Ngai, Chan & Eleanor, 2011). Caring for a CWD is even more challenging considering the multiple challenges that caregivers of CWDs are faced with (Chan, Lim & Ling, 2014) such as: child related challenges (McConachie, Randle, Hammal & Le Couteur, 2005), family-caregiver related challenges (Peres, Glazer, Landau, Marks, Abokaf, Belmaker, Cohen & Shoham-Vardi, 2014), health-care related challenges (Kuo, Bird & Tilford, 2011), and community related challenges (Almasri, O'Neil & Palisano, 2014; Majnemer, Shikako-Thomas, Lach, Shevell, Law, Schmitz, Poulin & QUALA, 2014).

As a result of child related, family-caregiver related, health-care related, and community related challenges, caregivers of CWDs can experience stress, anxiety disorder, depression, and poor sleep quality which is likely to compromise/decrease their ability to effectively provide support and care to their CWDs (Miodrag & Hodapp, 2010; Parkes, Caravale, Marcelli, Franco & Colver, 2011; Taylor & Warren, 2012; Bourke-Taylor, Pallant, Law & Howie, 2013; Gray, Edward, O'Callaghan, Cuskelly & Gibbons, 2013; Whittingham, Wee, Sanders & Boyd, 2013; Miodrag, Burke, Tanner-Smith & Hodapp, 2014) as well as ensuring that there is continuity of care.

A decreased ability of a caregiver to support the CWD is likely to have an adverse impact on the health, function and participation of that particular CWD (Giallo, Wood, Jellett & Porter, 2013) (Figure 7.3).

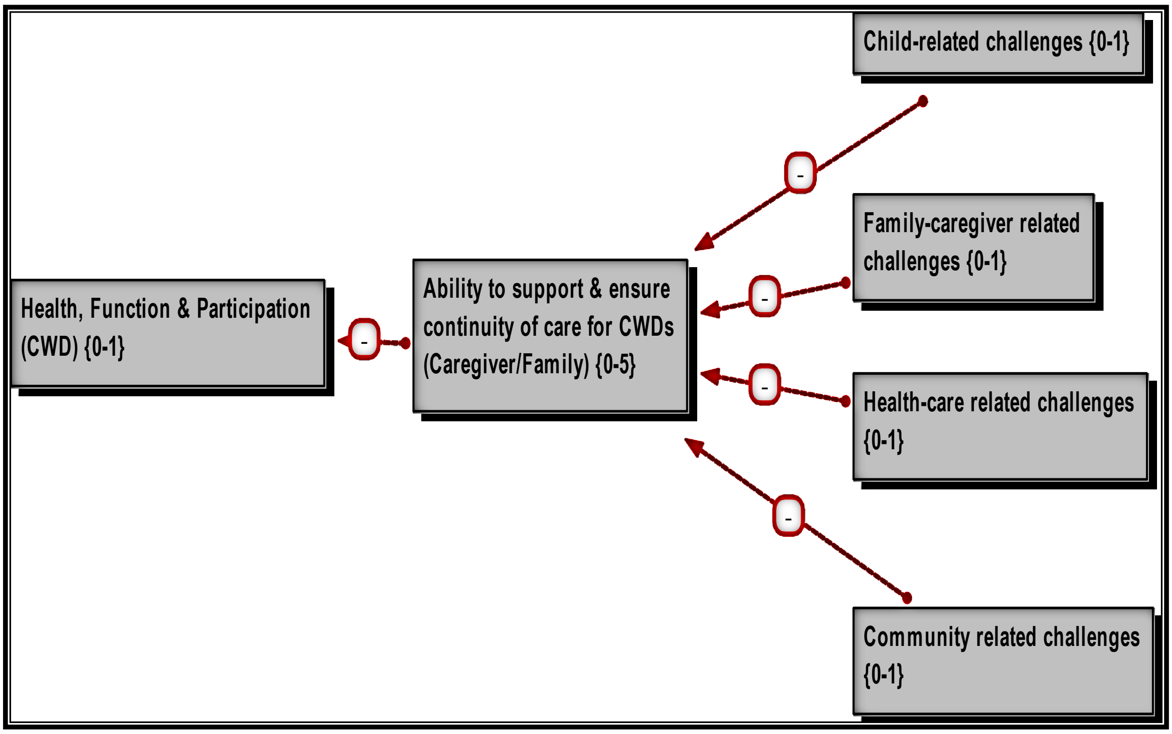


Figure 7.3 Impacts of various challenges on caregivers of CWDs

CWDs have been widely reported to rely on others and in particular caregivers to meet their health-care or rehabilitation needs (Orlin, Cicirello, O'Donnell & Doty, 2014; Piškur, Beurskens, Jongmans, Ketelaar & Smeets, 2014; Whiting, 2014). The caregivers who usually stay with the CWD have to ensure that the child get to the hospital or rehabilitation clinic where the rehabilitation is conducted. The role of the caregiver as suggested in the present study is to support the child and to ensure that the child receives the continuity of care. By ensuring that there is continuity of care, caregivers have to learn new hands-on skills from the rehabilitation professionals so as to ensure that they can participate in the rehabilitation process of the CWD at home. The rehabilitation professionals in the rehabilitation clinic only treat/rehabilitate CWDs once a month in a session that last for less than an hour. Furthermore, caregivers of CWDs have a bigger role to play in the rehabilitation of the child compared to rehabilitation professionals because they spend more time with the child at home than any other person or rehabilitation professionals.

7.2.3.9 Role of the local municipality

In the present study, the local municipality (Greater Giyani Municipality) has been reported to play various roles with regards to the services that enable efficient rehabilitation of CWDs. These roles include the provision of financial resources, the creation of opportunities for CWDs such as to learn and have job-related opportunities in later life, the promotion of rights for CWDs in the community, and addressing the needs of CWDs in the community that caregivers of such CWDs expect. The caregivers’ expectations include amongst others (RDP) houses for CWDs, promotion of the rights of CWDs and recreational facilities.

There are numerous community-related challenges that CWDs and their caregivers experience in the community. These challenges include the accessibility to infrastructure, access to running water, lack of recreational facilities, poor access to houses, lack of employment opportunities, gender-based discrimination of CWDs, abuse of CWDs, negative societal perception of CWDs, and inadequate (special) schools. Without the provision of finance by the municipality, it would not be possible to address the needs of CWDs such as accessibility to infrastructure, water, recreational facilities, and houses. In order to reduce gender-based discrimination and abuse of CWDs, the municipality must ensure that they promote the rights of

CWDs. The promotion of the rights of CWDs can also be achieved by involving the community with the hope of improving societal perception towards CWDs.

Figure 6.4 in Chapter 6 has illustrated that a positive societal perception has the potential of reducing/decreasing community related challenges, as well as family-caregiver related challenges. Similarly, negative societal perception has the potential of increasing community related challenges as well as family-caregiver related challenges.

The mayor of the local municipality indicated that the municipality has a responsibility of creating opportunities for CWDs. Considering that CWDs/PWDs have been reported to lack employment opportunities; the municipality can assist in creating or facilitating the creation of employment opportunities for disabled people.

7.2.3.10 Role of education (Pfunanani)

As reported earlier, inadequate special schools were one of the community challenges which CWDs and their caregivers experienced in Giyani. Caregivers of CWDs expect their children to attend school; there were even caregivers who preferred to send their child to mainstream (inclusive) schools. However, the majority of caregivers who participated in the current study preferred special schools. Pfunanani Special School is the only school for CWDs in Giyani and mainly focuses on children with intellectual impairment/disability. Children with intellectual impairment/disability in Giyani are likely to receive vocational training that may improve their chances of employability.

7.2.4 Objective 4 (Present Theory as a Model)

The last objective of the study was to present the emerging theory graphically as a model in this chapter. Different authors have different ways of presenting theory in the form of a model. For an example, Chiarello *et al* (2011) presented their model in terms of the conceptual model, rational for the model, implication for practice, and conclusion. King, Curran, and McPherson (2012) presented their model in terms of the context for the development of the model, conceptual basis to the model, description of the model, implication of the model, and conclusion. King *et al* (2002) presented their model in terms of an overview of the model, the development of the model, values and assumption of the model, description of the model, and utility and implication of the model. Baldwin *et al* (2013) presented their model in terms of the context for the development of the model, overview of the model, implication of the model, and conclusion.

It, therefore, seems that the presentation of theory and/or a model by various authors as highlighted in this section followed the same trend or logic. It is for this reason that the model for the rehabilitation of CWDs in Giyani will be arranged in terms of the context for the development of the model, conceptual basis of the model, description of the model, implication of the model, and conclusion.

7.3 CONTEXT FOR THE DEVELOPMENT OF A MODEL FOR THE REHABILITATION OF CHILDREN WITH DISABILITIES IN GIYANI

Different models and approaches for the rehabilitation of CWDs exist in both HIC and LMIC. Some of the models are exclusively used in HIC whereas others have been modified to suit the context of LMIC. However, the models which have been developed or modified for implementation in the context of LMIC such as the: (1) model for community health service development, (2) PHC approach, (3) COPC, (4) model for community mental health services, (5) CBR strategy, and (6) Malamulele outreach model (Rispel *et al*, 1996; ILO, UNISCO, & WHO, 2004; Levin, 2006; Lund & Flisher, 2009; Saloojee *et al*, 2009; Saloojee, 2012; Zhaokang *et al*, 2012; Bam *et al*, 2013) have limitations which are likely to make them inappropriate for use in a rural South African context like Giyani.

The main limitations of the existing models include amongst others: (1) the requirement for a large number of health professionals for service delivery (Dovlo, 2007; Lehmann, 2008; Scheffler, Mahoney, Fulton, Dal Poz, & Preker, 2009; George, Quinlan, Reardon, & Aguilera, 2012); (2) Models are being developed for an urban setting which tends to have more resources compared to the rural areas (Lemie're, Herbst, Dolea, Zurn, & Soucat, 2013); (3) Excluding young children with physical and neurological disabilities (Lund & Flisher, 2009); (4) Focusing on hospital-based rehabilitation and following the medical model of disability, which is contrary to the principles of CBR (Levin, 2006; Saloojee *et al*, 2007; Roush & Sharby, 2011); and (5) The reliance on volunteer rehabilitation professionals.

Despite the availability of rehabilitation models and approaches, CWDs in LMIC such as Giyani still do not have access to an adequate range of interventions which are available in HIC (Patel, Kieling, Maulik, & Divan, 2013).

For these reasons, it seemed necessary to develop a rehabilitation model for CWDs in Giyani.

7.4 CONCEPTUAL BASIS OF THE MODEL

The conceptual framework that was used in the current study was to provide a clear logic underpinning the design of the study (Burns & Grove, 2003). There were two conceptual frameworks underpinning this research: (1) Dunst and Trivette's resource-based model (Trivette, Dunst, & Deal, 1997), and (2) Guralnick's early development and risk factor model (Guralnick, 1997b).

7.4.1 Dunst and Trivette's Resource-Based Model

Dunst and Trivette's resource-based model suggests that intervention for CWDs consists of formal or informal social support networks to both the family of a CWD as well as the CWD (Trivette, Dunst, & Deal, 1997). Furthermore, Wolery (2000) suggests that the different types of social support that the families of CWDs receive, directly or indirectly have an impact on how the CWD functions and participate in society. Dunst and Trivette's resource-based model has three components: (1) sources of support, (2) community resource mapping, and (3) building community capacity.

For the purpose of the current study, the focus was on sources of support and community resource mapping. The sources of support component are divided into four categories that have an impact on how CWDs function and participate in society. The four categories are: (1) Personal social network such as friends or relatives; (2) Associational groups such as a church or support group; (3) Community programmes and professionals, such as a hospital, clinic or rehabilitation professionals, and (4) Specialised services, such as referral services (Trivette, Dunst, & Deal, 1997; Wolery, 2000).

Community resource mapping “involves identifying various kinds of resources that exists in a given locale” (Wolery, 2000, p. 196), such as recreational, and other facilities which are typically provided for by the local sphere of government or municipalities in South Africa (RSA, 2000).

7.4.2 Guralnick’s Early Development and Risk Factor Model

Guralnick’s model has three components: family patterns, family characteristics and potential stressors or challenges (Guralnick, 1997b) as depicted in Figure 7.4. Guralnick’s model implies that the characteristics of the family, such as the caregiver’s financial background, social status, educational level, and potential stressors or challenges have a bearing on the family patterns (Wolery, 2000). Family patterns entail the way in which the caregiver/family interacts with the child, how they provide for the child and what they do for the child to promote health and safety as well as to participate in the rehabilitation of a CWD (Guralnick, 1997b).

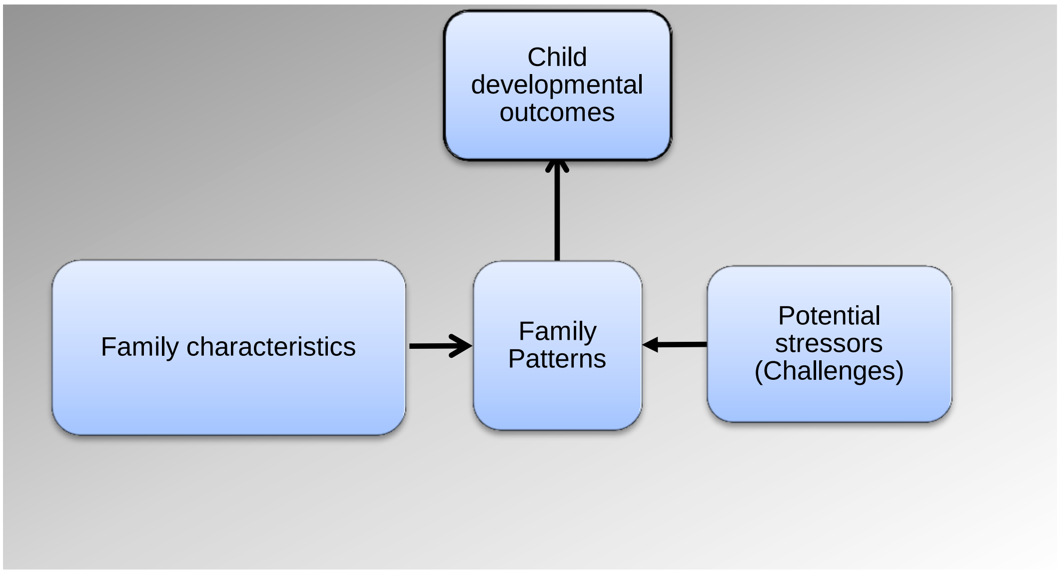


Figure 7.4 Guralnick's early development and risk factor model

Dunst and Trivette’s resource-based model and Guralnick’s model recognise the family and or a caregiver as major role players in the life of a CWD. However, Guralnick’s model also suggests that the challenges that the caregivers or CWDs encounter influences how the caregivers interact with the child. The rehabilitation professionals, CRWs and other health workers are recognised by the Dunst and Trivette’s resource-based model (Trivette, Dunst, & Deal, 1997) as primary sources of support for CWDs. Furthermore, Dunst and Trivette values community resources like the hospital, rehabilitation clinics and schools as an important component in bettering/improving the quality of life for CWDs. Equally so the community in the form of local government has an important role to play in the lives of CWDs.

Based on Dunst and Trivette's resource-based model (Trivette, Dunst, & Deal, 1997) and Guralnick's (1997) model, a conceptual framework this study was developed (Figure 7.5). This conceptual framework takes into consideration the ultimate goal of the rehabilitation for CWDs as suggested by the ICF conceptual framework which include amongst others to optimise health, improve function and promote participation of CWDs (WHO, 2001). Furthermore, the conceptual framework suggest that the caregivers, rehabilitation professionals, CRWs, the local government, and the challenges that caregivers of CWDs and CWDs experiences influences the health, function, and participation of the CWDs.

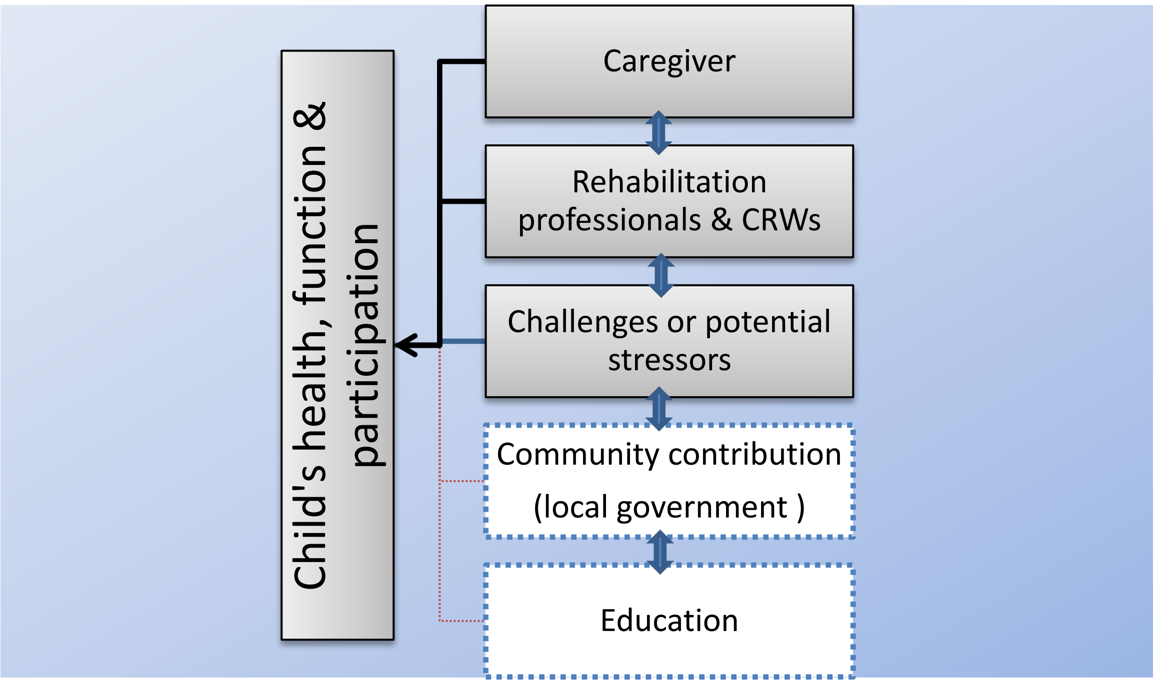


Figure 7.5 Conceptual framework of the current study

7.5 DESCRIPTION OF THE MODEL FOR THE REHABILITATION OF CHILDREN WITH DISABILITIES IN GIYANI

The model for the rehabilitation of CWDs in Giyani was developed based on the relationship between the: (1) roles of rehabilitation professionals, CRWs, local government (Greater Giyani municipality), and education sector (Pfunanani); (2) challenges experience by CWDs and caregivers, and (3) caregiver/family's ability to support the CWDs and ensure continuity of care (Figure 7.6).

The model suggests that the rehabilitation professionals, CRWs, local government (Greater Giyani Municipality), and the education sector (Pfunanani Special School) have an important role in addressing the challenges that caregivers and CWDs experiences.

In the next subsection, the different roles that the rehabilitation professionals, CRWs, local government, and the education sector play in the model for the rehabilitation of CWDs in Giyani is discussed.

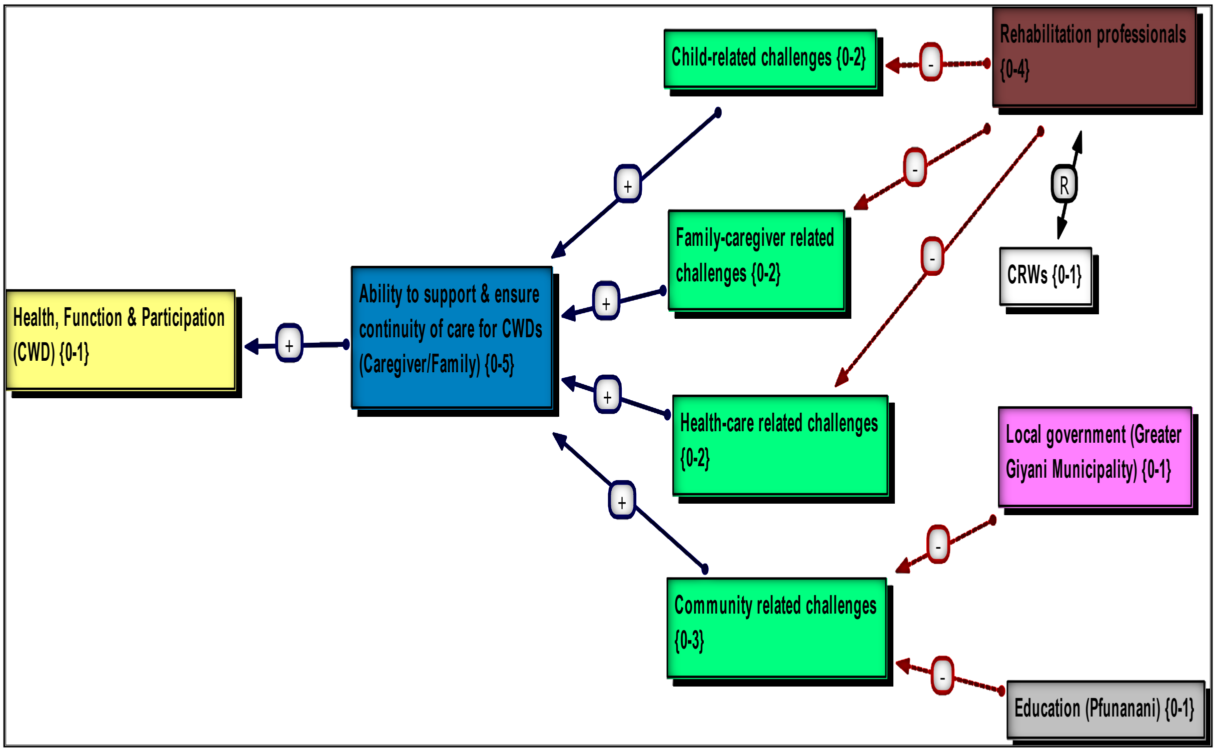


Figure 7.6 Model for the rehabilitation of CWDs in Giyani

7.5.1 The Role of Rehabilitation Professionals and Community Rehabilitation Workers

The rehabilitation professionals have a responsibility of reducing/decreasing child-related challenges, family-caregiver related challenges, and health-care related challenges. Considering that the role of CRWs is associated with or is similar to that of rehabilitation professionals; CRWs are responsible for ensuring that child-related challenges, family-caregiver related challenges, and health-care related challenges are reduced as well.

There are different strategies that rehabilitation professionals can use to reduce child-related challenges, family-caregiver related challenges, and health-care related challenges as shown in Figure 7.1. The strategies include:

- The use of health education on caregivers of CWDs
- The formation of multi-disciplinary teams (MDT) which will include other health-care professionals such as speech-therapists and dieticians
- The formation of support groups for caregivers of CWDs and having regular meetings between rehabilitation professional and caregivers where matters that concern either of the parties are discussed
- The formation of support structures by rehabilitation professionals where CRWs in the community are supported with resources
- The querying or assessment of previous notes written by other rehabilitation professionals in the hospital patient (child) file, in order to ensure that CWDs receive relevant or similar treatment
- Conducting home visits where the CWDs and the caregivers reside with the hope of assisting or even treating the CWDs at home
- Improving communication between rehabilitation professionals and other health professionals

7.5.2 Role of Local Government (Greater Giyani Municipality)

The local government and in particular the Greater Giyani municipality has a responsibility of reducing/decreasing community related challenges experienced by CWDs and their caregivers. These challenges include accessibility to (public) infrastructure, gender-based discrimination of CWDs, inadequate schools for CWDs, abuse of PWD/CWDs, employment opportunities for PWDs, reduced access to (running) water, reduced access to (RDP) housing, negative societal attitude toward CWDs, and lack of recreational facilities.

The Greater Giyani municipality has an important role to play in assisting CWDs and their families as shown in Figure 7.2. Community related challenges may be reduced if the Greater Giyani municipality ensures that they:

- Provide financial resources towards programmes for CWDs
- Address the needs of CWDs such as providing recreational facilities
- Promote the rights of CWDs
- Create opportunities of CWDs

7.5.3 Role of Education Sector (Pfunanani)

The education sector or Pfunanani Special School may reduce some of the community related challenges such as inadequate special schools by providing vocational training to CWDs.

7.5.4 Role of Caregivers of Child with Disabilities

A reduction in child-related, family-caregiver related, health-care related, and community related challenges through the efforts of rehabilitation professionals, CRWs, local government, and the education sector is likely to enhance the caregivers ability to support the CWDs and ensure that there is continuity of care. An improvement in the caregiver's ability to support and ensure that there is continuity of care for the CWDs is likely to improve the health, function, and participation of the CWDs.

7.6 INTERPRETATION OF THE MODEL FOR THE REHABILITATION OF CHILDREN WITH DISABILITIES IN GIYANI

The interpretation of the model for the rehabilitation of CWDs in Giyani as depicted in Figure 7.6 is that:

- The strategies that the rehabilitation professionals and CRWs implement reduces/decreases child related, family-caregiver related, and health-care related challenges. Similarly the strategies that the local government (Greater

Giyani municipality) and the education sector (Pfunanani Special School) reduces/decreases community related challenges.

- A decrease in child related, family-caregiver related, health-care related, and community related challenges improves/increases the ability of the caregiver or family to support the CWDs and ensures that there is continuity of care.
- A caregiver or family that support the CWD and ensure that there is continuity of care promotes/increase the health, function, and participation of the CWD.

The model for the rehabilitation of CWDs in Giyani can also be expressed in terms of the logic model (Table 7.1). Table 7.1 indicates the inputs, activities, output, and outcome of the newly developed model of rehabilitation (Kellogs, 2004; Schalock, Keith, Verdugo & Gomez, 2011).

Table 7.1 Interpretation of the model for the rehabilitation of CWDs in Giyani

Outcome	**Output**	**Activities**	**Inputs**
Health, function, and participation of CWD	Caregiver/family's ability to support the CWD and ensures continuity of care or treatment	Decrease/reduce child-related, family-caregiver related, and health-care related challenges	Rehabilitation professionals CRWs
		Decrease/reduce community related challenges	Local government (Greater Giyani municipality)
		Decrease/reduce community related challenges (Education)	Education (Pfunanani)

7.7 COMPARISON OF THE MODEL FOR REHABILITATION OF CHILDREN WITH DISABILITIES IN GIYANI WITH OTHERS MODELS

The model for the rehabilitation of CWDs in Giyani is comparable with other existing models for the rehabilitation of CWDs. The model is comparable with the: (1) Malamulele onward outreach model (Saloojee, 2012) (Table 7.2); (2) Life need model of paediatric service delivery (King *et al*, 2002) (Table 7.3); (3) Model of determinants of change in gross-motor abilities and engagement in self-care (Chiarello *et al*, 2011) (Table 7.3); (4) Ecological model of community-focused therapeutic recreation and life skills services (King, Curran, & McPherson, 2012) (Table 7.4), and ; (5) Solution-focused coaching in paediatric rehabilitation (Baldwin *et al*, 2013) (Table 7.4).

The comparison between the model for the rehabilitation of CWDs and the other five models is made in terms of the aim, goal, emphasis, and the targeted area as respectively presented in Tables 7.2, 7.3, and 7.4.

Table 7.2 Comparison between models for the rehabilitation of CWDs (1)

Name of the model	Aim	Goal	Emphasis	Targeted area
Model for the rehabilitation of CWDs in Giyani (Place of origin: South Africa)	To guide rehabilitation professionals and other health-care workers such as CRWs on how to provide rehabilitation services CWDs in the rural community of Giyani	To promote health, function, and participation of CWDs	(1) Reduce child related, family-caregiver, health-care related, and community related challenges in order to enable the caregivers to support the CWDs and ensure continuity of care (2) Use multi-sectoral collaboration	(1) Rehabilitation professionals (2) CRWs (3) Local municipality (4) Education sector (5) Caregivers of CWDs
Malamulele Onward Outreach model (Saloojee, 2012). (Place of origin: South Africa)	To guide rehabilitation professionals on how to provide rehabilitation services for children with cerebral palsy in under-resourced areas and rural communities	To promote the health, function, and participation of CWDs in society	(1) To provide therapy to CWDs (2) To provide training, empowerment and capacity-building for caregivers of CWDs (3) To strengthen existing rehabilitation services for CWDs within a chosen site (e.g. provide equipment like wheelchairs)	(1) Cerebral palsy clinic in a public hospital, (2) Skills and empowerment of Caregivers of CWDs in rural communities

Table 7.3 Comparison between models for the rehabilitation of CWDs (2)

Name of the model	Aim	Goal	Emphasis	Targeted area
A life need model of paediatric service delivery (King et al, 2002). (Place of origin: Canada)	Guide rehabilitation professionals, caregivers, board members and community partners on how paediatric service delivery should be conducted	Enhance community participation of CWDs	The emphasis is on coordination of health, social and educational services for CWDs	(1) Skills needs of the CWD (e.g. mobility), (2) The applied skills of the CWD (e.g. day-to-day function) (3) CWDs' needs for support and information (e.g. mentorship) (4) Caregivers' needs for support, information & skills development (5) Community members' needs for information and education on disability issues
Model of determinants of change in gross-motor abilities and engagement in self-care (Chiarello et al, 2011). (Canada & USA)	Guide physiotherapists (PT) and occupational therapists (OT) with a framework for intervention and support for children with cerebral palsy and their families	Enhance the participation of CWDs in daily activities and routine	PTs and OTs collaborate with caregivers to gather comprehensive information on the child and family	(1) Body structure and function (2) Secondary impairments (3) Comorbidities (4) Adaptive behaviour (5) Family ecology (6) Rehabilitation and community services (7) Motor abilities

Table 7.4 Comparison between models for the rehabilitation of CWDs (3)

Name of the model	Aim	Goal	Emphasis	Targeted area
An ecological model of community-focused therapeutic recreation and life skills services (King, Curran, & McPherson, 2012). (Place of origin: Canada)	To guide managers and service organizations oh how to develop an integrated programme of community-focused therapeutic recreation and life skills services for CWDs based on a collaborative capacity-building approach	To attain community-focused therapeutic recreation and life skills for CWDs	Collaborative capacity-building approach	(1) Provide community outreach services (2) Provide community development services (3) Sharing of physical and educational resources with community partners (4) Community facility that provides adapted physical space and specialized instruction
Solution-focused coaching in paediatric rehabilitation (Baldwin et al, 2013). (Place of origin: Canada)	To guide paediatric rehabilitation professionals of all disciplines, the youth, the caregivers, and the key decision makers such as managers on how paediatric rehabilitation should be provided	Enhance the well-being and the participation of CWDs in society	Focuses on family-professionals collaboration where the client's expertise (family), strengths and resources are acknowledged.	Family-professional collaboration

7.8 IMPLICATIONS OF THE MODEL FOR THE REHABILITATION OF CHILDREN WITH DISABILITIES IN GIYANI

The model for the rehabilitation of CWDs in Giyani comprises multiple role players such as the rehabilitation professionals, CRWs, local government, education sector, and caregivers/families. Therefore, the model has different implications for the different role players.

7.8.1 Implication of the Model for Rehabilitation Professionals

In the present study and other studies, rehabilitation professionals have been reported to play an important role in the rehabilitation of CWDs (Stucki, 2005; Dabrowska & Pisula, 2010; Caravale *et al*, 2011; WHO, 2011; Einfeld *et al*, 2012; Parkes, Hayes & Watson, 2013; Bunning *et al*, 2014). To be able to play the different roles such as to examine CWDs, support CWDs and caregivers, provide skills training for caregivers of CWDs, as well as to rehabilitate CWDs requires a certain level of competencies or skills from the rehabilitation professionals (Effgen *et al*, 2007; Milteer & Ginsburg, 2012; Chen *et al*, 2013; Kelland *et al*, 2014). It was reported in the current study that rehabilitation professionals should have the following skills: advocacy, therapeutic, teamwork and collaboration, communication, management, and professionalism.

The category of rehabilitation professionals such as therapists and therapy assistants have different levels of training where the latter have a two-year diploma training whereas the former have four-year degree training (Krause, Viljoen, Nel & Joubert, 2006).

Therefore, the implication of the model is that rehabilitation professionals should be adequately trained, and have appropriate skills (Pless & Granlund, 2012) to be able to provide adequate rehabilitation to CWDs. The skills training of rehabilitation professionals can be done through the revision of the curriculum for the various health professions (Futter, 2003; Krause, Viljoen, Nel & Joubert, 2006; Ramklass, 2009) or through continuous professional development (CPD) (Boud & Hager, 2012; Gordon, Uppal, Holt, Lythgoe, Mitchell & Hollins-Martin, 2013).

7.8.2 Implication of the Model for Community Rehabilitation Workers

Considering that the role of CRWs is similar to that of rehabilitation professionals, the implication of the model on CRWs should be similar to that of rehabilitation professionals. CRWs skills should be updated through CPD.

7.8.3 Implication of the Model for Local Government

The local government (Greater Giyani municipality) is not directly involved in rehabilitating CWDs, but has been reported in the current study and other studies to play an important role in providing resources (Bhorat, Oosthuizen & van der Westhuizen, 2012; Hästbackaa & Nygårda, 2013) which are likely to reduce community related challenges. The local government should provide financial resources, address the needs for CWDs such as recreational facilities, promote the right of CWDs, and create opportunities for CWDs.

7.8.4 Implication of the Model for the Education Sector

The South African National Department of Education's White Paper 6 on inclusive education seeks to reverse the injustices of the apartheid government where children were discriminated in terms of race and disability. In addition the White Paper 6 advocates for (1) children's differences to be recognised and respected, and to strengthen or build on their similarities, (2) the teaching and learning that is intended to benefit all learners, (3) overcoming barriers in the system that prevent it from meeting the learning needs of (all) children (DOE, 2001). However, inclusive education is not yet a reality in South Africa (Pillay & Di Terlizzi, 2009).

Currently, Pfunanani is the only special school for CWDs in Giyani. The school only focuses on children with intellectual disabilities. Children with other forms of disabilities would benefit if the school was not exclusive for children with intellectual disabilities but open for all CWDs.

7.8.5 Implication of the Model for Caregivers of Children with Disabilities

Caregivers have been reported to play a significant role in the rehabilitation of a CWD in this study. Caregivers have to support the CWDs and ensure that the child gets the necessary treatment and or required rehabilitation from the designated rehabilitation facilities or at home.

7.8.6 Implication of the Model for Hospital Managers

The rehabilitation of CWDs in Giyani takes place in the hospital as well as in the communities where CWDs resides. Rehabilitation professionals and CRWs are responsible for rehabilitating CWDs as well as imparting caregivers with the necessary skills to continue with the rehabilitation at home. However, hospital managers are responsible for the services provided by both the rehabilitation professionals and CRWs, and should therefore ensure that the rehabilitation professionals and CRWs are adequately skilled and knowledgeable through CPD programs to be able to rehabilitate CWDs.

In addition, hospital managers should ensure that factors that reduce the rehabilitation professionals' work ethic such as: (1) Lack of commitment of colleagues, (2) Lack of managerial support, (3) Budgetary constraints, (4) Commitment and compliance of caregivers, (5) Poor patient referral, and (6) Lack of learning opportunities are addressed and minimised.

Considering that the rehabilitation of CWDs requires the effort or input of the multiple role players like the municipality and the education sector; the hospital managers should liaise with the municipality and the education sector so as to encourage multi-sectoral collaboration.

7.8.7 Implication of the Model for Research

First, the model for the rehabilitation of CWDs in Giyani has not been tested in practices. Therefore, the model has to be established in practice whether: (1) the rehabilitation professionals and or CRWs have the ability to reduce child related challenges, family-caregiver related challenges, and health-care related challenges, (2) the local government (Greater Giyani municipality) has the ability to reduce community related challenges, (3) the education sector (Pfunanani) has the ability to reduce community related challenges considering that Pfunanani Special School is exclusive for children with intellectual disabilities, (4) a reduction in child-related challenges, family-caregiver related challenges, health-care related challenges, and community related challenges improves the caregivers' ability to support the CWDs and ensure that there is continuity of care, (5) the caregivers' ability to support the CWD and ensure continuity of care have a bearing or an impact on the health, function, and participation of a CWDs.

Second, it is recommended that:

- Further studies or similar studies should be conducted in the caregivers in their naturalistic environment (i.e. place of residence) where it is presumed that participant will be more comfortable to provide rich data.
- A more representative and heterogeneous sample of caregivers (in terms of: gender, educational level, employment status, sources of income, income bracket, and the availability of water and electricity) as well as CWDs (in terms of age and diagnoses) should be used in order to improve the transferability of the study in other contexts.
- The sample size per FDG should be larger and between five and eight participants.
- The duration of interviews should be between 20 and 60 minutes as recommended by Gill *et al* (2008).
- Follow-up interviews should be conducted with all participants with the aim of "member checking" which is one of the criteria used to enhance credibility of the study.
- The model has to be tested in practice.

7.9 CONCLUSIONS

The model for the rehabilitation of CWDs in Giyani is an outcome of the theory-generation process as described by Walker and Avant (2005). The theory-generation process was made up of the three stages: concept development, statement development and theory development. This study had four objectives where each of the objectives coincided with the different stages of theory-generation.

The four objectives were to: (1) synthesise and refine concepts, (2) synthesise non-relational statements, (3) systemise and organise relational statements, and (4) present theory as a model for the rehabilitation of CWDs.

The outcomes of the first objective were presented in Chapters 3 and 4, second objective in Chapter 5, the third objective in Chapter 6, and the fourth objective in Chapter 7.

The model for the rehabilitation of CWDs suggests that the rehabilitation of CWDs requires multi-sectoral collaboration between the rehabilitation professionals, CRWs, the local municipality, and the education sector. The different role players (rehabilitation professionals, CRWs, local municipality, and the education sector) have to ensure that they reduce the child related, family-caregiver related, health-care related, and the community related challenges that caregivers and CWDs experiences. The model also suggests that a reduction in challenges will enable the caregiver to support the CWDs and ensure that there is continuity of care, thus improving the health (body structure and function) , function (activity limitation), and participation of the CWDs. The model for the rehabilitation of CWDs in Giyani is comparable with other existing models for the rehabilitation of CWDs.

Several strategies will be used to disseminate the findings of the study as highlighted in the next subsection.

7.9.1 Recommendations for the Dissemination of the Findings of the Study

- The findings of this study will be submitted for publication in scientific journals
- Presentation at national and international conferences such as the Rural Doctors Association of South Africa (RUDASA), SASP and / or the WCPT.
- A copy of this study will be presented to the Limpopo Provincial Department of Health and Nkhensani Hospital.
- A CPD activity will be organised to which other rehabilitation professionals within the Mopani district will be invited.

REFERENCES

Adams, M. S., Khan, N. Z., Begum, S. A., Wirz, S. L., Hesketh, T., & Pring, T. R. (2012). Feeding difficulties in children with cerebral palsy: Low-cost caregiver training in Dhaka, Bangladesh. *Child: Care, Health and Development, 38*(6), 878-888.

Adelugba, J. K., Ayodiipo, I. O., Ogunbameru, T. D., Oni, O. A., Akinsiku, O. A., & Akinrem, A. (2011). Paediatric neurological conditions seen at the physiotherapy department of Federal Medical Centre, Ido Ekiti, Nigeria: A five year review. *African Journal of Biomedical Research, 14*(3), 183 -186.

Algood, C. L., Harris, C., & Hong, J. S. (2013). Parenting success and challenges for families of children with disabilities: An ecological systems analysis. *Journal of Human Behavior in the Social Environment, 23*(2), 126-136.

Allais, S. (2012). Will skills save us? Rethinking the relationships between vocational education, skills development policies, and social policy in South Africa. *International Journal of Educational Development, 32*(4), 632–642.

Almasri, N. A., O’Neil, M., & Palisano, R. J. (2014). Predictors of needs for families of children with cerebral palsy. *Disability and Rehabilitation, 36*(3), 210–219.

Almasri, N., Palisano, R. J., Dunst, C., Chiarello, L. A., O’Neil, M. E., & Polansky, M. (2012). Profiles of family needs of children and youth with cerebral palsy. *Child: Care, Health and Development, 38*(6), 798-806.

Alriksson-Schmidt, A., Hägglund, G., Rodby-Bousquet, E., & Westbom, L. (2014). Follow-up of individuals with cerebral palsy through the transition years and description of adult life: The Swedish experience. *Journal of Pediatric Rehabilitation Medicine, 7*(1), 53-61.

An, M., & Palisano, R. J. (2014). Family–professional collaboration in pediatric rehabilitation: A practice model. *Disability and Rehabilitation, 36*(5), 434-440.

Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., et al. (2013). The effect of the environment on participation of children and youth with disabilities: A scoping review. *Disability and Rehabilitation, 35*(19), 1589-1598.

Anastasiou, D., & Kauffman, J. M. (2011). A social constructionist approach to disability: Implications for special education. *Exceptional Children, 77*, 367–384.

Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy, 38*, 441-459.

Anderson, L. S. (2009). Mothers of children with special health care needs: Documenting the experience of their children's care in the school setting. *The Journal of School Nursing, 25*(5), 342–351.

Andrade, P. M., Ferreira, F. O., Mendonca, A. P., & Haase, V. G. (2012). Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disability and Rehabilitation, 34*(21), 1790-1801.

Aranda, M. P., & Knight, B. G. (1997). The influences of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist, 37*(3), 342–354.

Arnold, E. C., & Boggs, K. I. (2011). *Interpersonal Relationships: Professional Communication Skills for Nurses* (6th ed.). St Louse, Missouri: Elsevier Saunders.

Ataguba, J. E.-O., & McIntyre, D. (2013). Who benefits from health services in South Africa? *Health Economics, Policy and Law, 8*(1), 21-46.

Babbie, E. R., & Mouton, J. (2001). *The Practice of Social Research: South African Edition.* Cape Town: Oxford University Press.

Bachmann, M. O., & Barron, P. (1997). Why wait so long for child care? An analysis of waits, queues and work in a South African urban health centre. *Tropical Doctor, 27*(1), 34-38.

Baker, T., Haines, S., Yost, J., DiClaudio, S., Braum, C., & Holt, S. (2012). The role of family-centered therapy when used with physical or occupational therapy in children with congenital or acquired disorders. *Physical Therapy Reviews, 17*(1), 29-36.

Baldwin, P., King, G., Evans, J., McDougall, S., Tucker, M. A., & Servais, M. (2013). Solution-focused coaching in pediatric rehabilitation: An intergrated model for practice. *Physical & Occupational Therapy in Pediatrics, 33*(4), 467-483.

Bam, N., Marcus, T., Hugo, J., & Kinkel, H. (2013). Conceptualizing Community Oriented Primary Care (COPC)-the Tshwane, South Africa, health post model. *African Journal of Primary Health Care & Family Medicine, 5*(1), 1-3.

Banskota, B., Foltz, M., Gosselin, R. A., & Spiegel, D. A. (2014). Cerebral palsy and other neuromuscular conditions. *Global Orthopedics*, 423-427.

Barnes, C. (1991). *Disabled People in Britain and Discrimination: A Case Study for Anti-Descrimination Legislation.* London: Hurst and Co.

Barnes, C. (1999). Disability studies: New or not so new directions? *Disability & Society, 14*(4), 577-580.

Bartlett, D. J., Chiarello, L. A., McCoy, S. W., Palisano, R. J., Jeffries, L., Fiss, A. L., et al. (2014). Determinants of gross motor function of young children with cerebral palsy: A prospective cohort study. *Developmental Medicine & Child Neurology, 56*(3), 275-282.

Bateman. (2012). "One size fits all" health policies crippling rural rehab-therapists. *South African Medical Journal, 102*(4), 200-208.

Baugh, K. (1990). *The Methodology of Herbert Blumer: Critical Interpretation and Repair.* Cambridge: Cambridge University Press.

Bax, M. C., Flodmark, O., & Tydeman, C. (2007). From syndrome towards disease. *Developmental Medicine & Child Neurology, 49*(s109), 39-41.

Berendes, S., Heywood, P., Oliver, S., & Garner, P. (2011). Quality of private and public ambulatory health care in low and middle income countries: Systematic review of comparative studies. *PLoS Medicine, 8*(4), e1000433.

Bhorat, H., Oosthuizen, M., & van der Westhuizen, C. (2012). Estimating a poverty line: An application to free basic municipal services in South Africa. *Development Southern Africa, 29*(1), 77-96.

Biritwum, R. B., Devres, J. P., Ofosu-Amaah, S., Marfo, C., & Essah, E. R. (2001). Prevalence of children with disabilities in central region, Ghana. *West African Journal of Medicine, 20*(3), 249-255.

Birks, M., & Mills, J. (2011). *Grounded Theory A Practical Guide.* London: Sage.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method.* Englewood Cliff, NJ: Prentice-Hall.

Bonnier, C. (2008). Evaluation of early stimulation programs for enhancing brain development. *Acta Paediatrica, 97*(7), 853-858.

Bossaert, G., Colpin, H., Pijl, S. J., & Petry, K. (2011). The attitudes of Belgian adolescents towards peers with disabilities. *Research in Developmental Disabilities, 32*(2), 504-509.

Boud, D., & Hager, P. (2012). Re-thinking continuing professional development through changing metaphors and location in professional practices. *Studies in Continuing Education, 34*(1), 17-30.

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2014). Young children with cerebral palsy: Families self-reported equipment needs and out-of-pocket expenditure. *Child: Care, Health and Development, 40*(5), 654-662.

Bourke-Taylor, H., Howie, L., & Law, M. (2010). Impact of caring for a school-aged child with disability: Understanding mothers' perspective. *Australian Occupational Therapy Journal, 57*(2), 127-136.

Bourke-Taylor, H., Pallant, J. F., Law, M., & Howie, L. (2013). Relationships between sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities. *Journal of Paediatrics and Child Health, 49*(9), 775–782.

Braga, L. W., Da Paz Junior, A. C., & Ylvisaker, M. (2005). Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: A randomised controlled trial. *Brain Injury, 19*(10), 819-831.

Braga, L., & Rochette, A. (2013). A qualitative study of rehabilitation professionals optimal social participation and factors perceived as influencing. *The Open Rehabilitation Journal, 71*(1), 26-34.

Brewer, K., Pollock, N., & Wright, F. V. (2014). Addressing the challenges of collaborative goal setting with children and their families. *Physical & Occupational Therapy in Pediatrics, 34*(2), 138-152.

Briggs, F. (2006). Safety issues in the lives of children with learning disabilities. *Social Policy Journal of New Zealand*(29), 43-59.

Brito-Argáez, L., Moguel-Salazar, F., Zamudio, F., González-Estrada, T., & Islas-Flores, I. (2009). Characterization of a Capsicum chinense seed peptide fraction with broad antibacterial activity. *Asian Journal of Biochemistry, 4*(3), 77-87.

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*(1), 38-49.

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design.* Cambridge: Harvard University Press.

Brooks, V., Rhodes, B., & Tefft, N. (2014). When opposites don't attract: One rehabilitation hospital's journey to improve communication and collaboration between nurses and therapists. *Creative Nursing, 20*(2), 90-95.

Brothers, K. B., Glascoe, F. P., & Robertshaw, N. S. (2008). PEDS: Developmental milestones- An accurate brief tool for surveillance and screening. *Clinical Pediatrics, 47*(8), 271-279.

Bunning, K., Gona, J. K., Odera-Mung'ala, V., Newton, C. R., Geere, J., Hong, C. S., et al. (2014). Survey of rehabilitation support for children 0–15 years in a rural part of Kenya. *Disability and Rehabilitation, 36*(12), 1033-1041.

Burns, N., & Grove, S. K. (2003). *Understanding Nursing Research* (3rd ed.). Philadelphia, PA: W.B Saunders.

Butt, L., & Caplan, B. (2010). The rehabilitation team. In R. G. Frank, M. Rosenthal, & B. Caplan, *Handbook of Rehabilitation Psychology* (2nd ed., pp. 451-457). Washington, DC: American Psychological Association.

Campbell, L. M. (2011). Experiences of nurses practising home-based palliative care in a rural South African setting. *International Journal of Palliative Nursing, 17*(12), 593-598.

Carter, J., & Markham, N. (2001). Disability discrimination: The UK's act requires health services to remove barriers to access and participation. *British Medical Journal, 323*(7306), 178-179.

Cesario, S. (1997). The impact of the electronic domain on theory construction. *Journal of Theory Construction and Testing, 1*(2), 60-63.

Chadwick, D. D., Mannan, H., Iriarte, E. G., McConkey, R., O'Brien, P., Finlay, F., et al. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26*(2), 119-132.

Chan, K. G., Lim, K. A., & Ling, H. K. (2014). Care demands on mothers caring for a child with Down syndrome: Malaysian (Sarawak) mothers' perspectives. *International Journal of Nursing Practice*, 1-10.

Chang, Y.-C., Lin, J.-D., Tung, H.-J., Chiang, P.-H., & Hsu, S.-W. (2014). Outpatient physical therapy utilization for children and adolescents with intellectual disabilities in Taiwan: A population-based nationwide study. *Research in Developmental Disabilities, 35*(2), 498–505.

Chappel, P., & Johannsmeier, C. (2009). The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disability and Rehabilitation, 31*(1), 7-13.

Charmaz, K. (2002). Qualitative interviewing and grounded theory analysis. In J. F. Gubrium, & J. A. Holstein, *Handbook of Interview Research: Context and Method* (ed., pp. 675-693). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* Thousand Oaks, CA: Sage.

Chen, C. L., Kang, L. J., Hong, W. H., Chen, F. C., Chen, H. C., & Wu, C. Y. (2013). Effect of therapist-based constraint-induced therapy at home on motor control, motor performance and daily function in children with cerebral palsy: A randomized controlled study. *Clinical Rehabilitation, 27*(3), 236-245.

Chiarello, L. A., Huntington, A., & Bundy, A. (2006). A comparison of motor behaviors, interaction, and playfulness during mother-child and father-child play with children with motor delay. *Physical & Occupational Therapy in Pediatrics, 26*(1), 129–151.

Chiarello, L. A., Palisano, R. J., Bartlett, D. J., & McCoy, S. W. (2011). A multivariate model of determinants of change in gross-motor abilities and engagement in self-care and play of young children with cerebral palsy. *Physical & Occupational Therapy in Pediatrics, 31*(2), 150-168.

Colves, A. F., Dickinson, H. O., Parkinson, K., Arnaud, C., Beckung, E., Fauconnier, J., et al. (2011). Access of children with cerebral palsy to the physical, social and attitudinal environment they need: A cross-sectional European study. *Disability and Rehabilitation, 33*(1), 28-35.

Concha, M. E. (1993). The introduction of a training programmme for community rehabilitation workers-the Wits Tintswalo model. *South African Journal of Occupational Therapy, 23*, 38-46.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet, 374*(9692), 817-834.

Correa, V. I., Bonilla, Z. E., & Reyes-MacPherson, M. E. (2011). Support networks of single Puerto Rican mothers of children. *Journal of Child and Family Studies, 20*(1), 66-77.

Couper, J. (2002). Prevalence of childhood disabilities in rural KwaZulu-Natal. *South African Medical Journal, 92*(7), 549-552.

Cowie, L., Morgan, M., White, P., & Gulliford, M. (2009). Experience of continuity of care of patients with multiple long-term conditions in England. *Journal of Health Services Research & Policy, 14*(2), 82–87.

Crnic, K. A., Gaze, C., & Hoffman, C. (2005). Cumulative parenting stress across the preschool period: relations to maternal parenting and child behaviour at age 5. *Infant and Child Development, 14*(2), 117–132.

Crooks, D. L. (2001). The importance of symbolic interaction in grounded theory research on women's health. *Health Care for Women International, 22*(1-2), 11-27.

Croot, E. J., Grant, G., Cooper, C. L., & Mathers, N. (2008). Perceptions of the causes of childhood disability among Pakistani families living in the UK. *Health and Social Care in the Community, 16*(6), 606-613.

Crowe, T., & Florez, S. (2006). Time use of mothers with school-aged children: A continuing impact of a child's disability. *American Journal of Occupational Therapy, 60*(2), 194–203.

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266–280.

Dahlseng, M. O., Finbråten, A.-K., Júlíusson, P., Skranes, J., Andersen, G., & Vik, T. (2012). Feeding problems, growth and nutritional status in children with cerebral palsy. *Acta Paediatrica, 101*(1), 92–98.

Dattilo, J., & Kleiber, D. A. (1993). Psychological perspectives for therapeutic recreation research: The psychology of enjoyment. In M. J. Malkin, & C. Z. Howe, *Research in Therapeutic Recreation: Concepts and Methods* (. ed., pp. 57-76). State College, PA: Venture.

Dattilo, J., Kleiber, D., & Williams, R. (1998). Self-determination and enjoyment enhancement: A psychologically based service delivery model for therapeutic recreation. *Therapeutic Recreation Journal, 32*, 258-271.

Daudji, A., Eby, S., Foo, T., Ladak, F., Sinclair, C., Laundry, M. D., et al. (2011). Perceptions of disability among South Asian Immigrant mothers of children with disabilities in Canada: Implications for rehabilitation services delivery. *Disability and Rehabilitation, 33*(6), 511-521.

Dawad, S., & Jobson, G. (2011). Community-based rehabilitation programme as a model for task-shifting. *Disability and Rehabilitation, 33*(21–22), 1997-2005.

De Laata, S., Freriksen, E., & Vervloed, M. P. (2013). Attitudes of children and adolescents toward persons who are deaf, blind, paralyzed or intellectually disabled. *Research in Developmental Disabilities, 34*(2), 855-863.

De Vos, A. S. (1998). *Research at Grass Roots: A Primer for the Caring Professions.* Pretoria: J.L Van Schaik.

DeJong, P., & Berg, I. K. (2002). *Interviewing Solutions* (2nd ed.). Belmont, CA: Brooks/Cole.

Dellicour, S., Desai, M., Mason, L., Phillips-Howard, P. A., Laserson, K. F., & ter Kuile, F. O. (2013). Exploring risk perception and attitudes to miscarriage and congenital anomaly in rural Western Kenya. *Plos One, 8*(11), e80551-e80558.

Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centred services for children with a disability. *Topics in Early Childhood Special Education, 28*(1), 42-52.

Denzin, N. (1978). *The Research Act: A Theoretical Introduction to Sociological Methods* (2nd ed.). New York: McGraw Hill.

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of Qualitative Research* (. ed.). Thousand Oaks, CA: Sage.

Devereux, J. M., Hastings, R. P., Noone, S. J., Firth, A., & Totsika, V. (2009). Social support and coping as mediators or moderators of the impact of work stressors on burnout in intellectual disability support staff. *Research in Developmental Disabilities, 30*(2), 367-377.

Devers, E., & Robinson, K. M. (2002). The making of a grounded theory: After-death communication. *Death Studies, 26*(3), 241-254.

Dey, I. (1999). *Grounding Grounded Theory Guidelines for Qualitative Inquiry.* San Diego: Academic Press.

DHSD. (2011). *Limpopo Provincial Department of Health: 2011/12-2013/14: Annual Performance Plan: Vote 7 Health.* Polokwane: Limpopo Provincial Department of Health.

Dirks, T., & Hadders-Algra, M. (2011). The role of the family in intervention of infants at high risk of cerebral palsy: A systematic analysis. *Developmental Medicine and Child Neurology, 53*(s4), 62-67.

DOE. (2001). Education WHITE PAPER 6 Special Needs Education Building an Inclusive Education and Training System. South Africa: Department of Education.

DOH. (2000). *National Rehabilitation Policy.* Department of Health. Pretoria: Government Printers.

DOH. (2002). *A District Hospital Service Package for South Africa: A Set of Norms and Standards.* Pretoria: Department of Health.

Dolan, C., Concha, M. E., & Nyathi, E. (1995). Community rehabilitation workers: Do they offer hope to disabled people in South Africa's rural areas? *International Journal of Rehabilitation Research, 18*(3), 187-200.

Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology, 21*(1), 30-35.

Donohue, D. K., Bornman, J., & Granlund, M. (2014). Examining the rights of children with intellectual disability in South Africa: Children's perspectives. *Journal of Intellectual and Developmental Disability, 39*(1), 55-64.

Dovlo, D. (2007). Migration of nurses from sub-Saharan Africa: A review of issues and challenges. *Health Services Research, 42*(3 p 2), 1373–1388.

Drotar, D. (1998). *Measuring Health-Related Quality of Life in Children and Adolescents: Implication for Research and Practice.* New Jersey: Lawrence Erlbaum Associates.

Dubin, R. (1978). *Theory Building* (2nd ed.). New York: Free Press.

Durkin, M. S., & Maenrer, M. J. (2014). Screening for developmental disabilities in epidemiological studies in Low- and middle- income countries. In S. O. Okpaku (Ed.), *Essentials of Global Mental Health* (pp. 187-194). New York: Cambridge University Press.

Duvdevany, I., & Vudinsky, H. (2005). Out-of-home placement of children with intellectual disability: Israeli-born parents vs. new immigrants from the ex-USSR. *International Journal of Rehabilitation Research, 28*(4), 321-330.

Eagly, A. H., & Chaiken, S. (2007). The advantages of an inclusive definition of attitude. *Social Cognition, 25*(5), 582-602.

Eason, F., Connell, A., & Barry, M. (2014). Reported use of family centred behaviours amongst service providers working in children's disability services in Ireland. *Physiotherapy Practice and Research, 35*(2), 123-132.

Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: A qualitative study from Vellore, South India. *Journal of Intellectual Disability Research, 54*(8), 736-748.

Effgen, S. K., Chiarello, L., & Milbourne, S. A. (2007). Updated competencies for physical therapists working in schools. *Pediatric Physical Therapy, 19*(4), 266-274.

Egilson, S. (2011). Parent perspectives of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences*(25), 277-284.

Einfeld, S. L., Stancliffe, R. J., Gray, K. M., Sonfronoff, K., Rice, L., Emerson, E., et al. (2012). Interventions provided by parents for children with intellectual disabilities in low and middle income countries. *Journal of Applied Research in Intellectual Disabilities, 25*(2), 135-142.

Eisenhardt, K. M. (1989). Building theories from case study research. *Academy of Management Review, 14*(4), 532-550.

Eldar, R., Marincek, C., & Kullmann, L. (2008). Need for rehabilitation teamwork training in Europe. *Croatian Medical Journal, 49*(3), 352-357.

Ellenberg, J. H., & Nelson, K. B. (2013). The association of cerebral palsy with birth asphyxia: A definitional quagmire. *Developmental Medicine & Child Neurology, 55*(3), 210–216.

Emerson, E., & Hatton, C. (2009). Socioeconomic position, poverty and family research. *International Review of Research in Mental Retardation, 37*, 97-129.

Erbaydar, N. P., Caman, O. K., & Cilingiroglu, N. (2013). How do municipality employees in Ankara approach persons with disabilities. *Disability and Health Journal, 6*(4), 391-398.

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., et al. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain and Development, 35*(2), 133-138.

Ezzy, D. (2002). *Qualitative Analysis: Practice and Innovation.* Crows Nest, Australia: Allen & Unwin.

Falvo, D. R. (2014). *Medical and Psychosocial Aspects of Chronic Illness and Disability* (5th ed.). Burlington, MA: Jones & Bartlet Learning.

Fatemi, S. H., & Folsom, T. D. (2009). The neurodevelopmental hypothesis of schizophrenia, revisited. *Schizophrenic Bulletin, 35*, 528–548.

Fawcett, J. (2013). Thoughts about multidisciplinary, interdisciplinary, and transdisciplinary research. *Essays on Nursing Science, 26*(4), 376-379.

Ferluga, E. D., Archer, K. R., Sathe, N. A., Krishnaswami, S., Klint, A., Lindegren, M. L., et al. (2013). Interventions for feeding and nutrition in cerebral palsy. In *Comparative Effectiveness Reviews* (Vol. 94). Rockville (MD): Agency for Healthcare Research and Quality.

Fink, G., Gunther, I., & Hill, K. (2011). The effect of water and sanitation on child health: Evidence from the demographic and health surveys 1986–2007. *International Journal of Epidemiology, 40*(5), 1196-1204.

Fleisch, B., Shindler, J., & Perry, H. (2012). Who is out of school? Evidence from the Statistics South Africa Community Survey. *International Journal of Educational Development, 32*(4), 529–536.

Fujiura, G. T., & Yamaki, K. (2000). Trends in demography of childhood poverty and disability. *Exceptional Children, 66*(2), 187-199.

Futter, M. J. (2003). Developing a curriculum module to prepare students for community-based physiotherapy rehabilitation in South Africa. *Physiotherapy, 89*(1), 13-24.

Gallagher, S., Phillips, A. C., Lee, H., & Carroll, D. (2014). The association between spirituality and depression in parents caring for children with developmental disabilities: Social support and/or last resort. *Journal of Religion and Health*, 1-13.

Galman, S. C. (2007). *Shane, the Lone Ethnographer: A beginner's Guide to Ethnographys.* Walnut Creek, CA: AltaMira Press.

Gao, H., Stiller, C. K., Scherbaum, V., Biesalski, H. K., Wang, Q., Hormann', E., et al. (2013). Dietary intake and food habits of pregnant women residing in urban and rural areas of Deyang City, Sichuan Province, China. *Nutrients, 5*(8), 2933-2954.

Garbarino, J., & Ganzel, B. (2000). The muman ecology of early risk. In J. P. Shonkoff, & S. J. Meisels, *Handbook of Early Childhood Intervention* (2nd ed., pp. 76-93). Cambridge: Cambridge University Press.

Garwick, A. W., Patterson, J. M., Bennett, F. C., & Blum, R. W. (1998). Parents' perceptions of helpful vs unhelpful types of support in managing the care of preadolescents with chronic conditions. *Archives of Pediatrics & Adolescent Medicine, 152*(7), 665-671.

Gautam, N. S., Rao, D. S., Gautam, N. R., Koganti, R., Thota, H. R., & Goud, A. S. (2014). Lip position and drooling of saliva in children with cerebral palsy. *Journal of Research and Advancement Dentistry, 3*(1), 212-215.

GCIS. (2013). *South Africa Yearbook 2012/13.* Pretoria: Government Communication and Information System (GCIS).

George, G., Quinlan, T., Reardon, C., & Aguilera, J.-F. (2012). Where are we short and who are we short of? A review of the human resources for health in South Africa. *Health SA Gesondheid, 17*(1), 1-7.

Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2013). Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism, 17*(4), 465-480.

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitatiove research: Interviews and focus groups. *British Dental Journal, 204*(6), 291-295.

Giza, C. C., Mink, R. B., & Madikians, A. (2007). Pediatric traumatic brain injury: Not just little adults. *Current Opinion in Critical Care, 13*(2), 143-152.

Gladstone, M. (2010). A review of the incidence and prevalance, types and aetiology of childhood cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics: International Child Health, 30*(3), 181-196.

Glaser, B. G. (1978). *Advances in the Methodology of Grounded Theory: Theoretical Sensitivity.* Mill Valley, CA: The Sociology Press.

Glaser, B. G. (1992). *Basics of Grounded Theory Analysis: Emergence Versus Forcing.* Mill Valley, CA: The Sociology Press.

Glaser, B. G., & Strauss, A. A. (1967). *The Discovery of Grounded Theory Strategies of Qualitative Research.* Chicago, IL: Aldine Publishing.

Goebel, A. (2007). Sustainable urban development? Low-cost housing challenges in South Africa. *Habitat International, 31*(3-4), 291-302.

Gohar, S. F., Comito, M., Price, J., & Marchese, V. (2011). Feasibility and parent satisfaction of a physical therapy intervention program for children with acute lymphoblastic leukemia in the first 6 months of medical treatment. *Pediatric Blood & Cancer, 56*(5), 799-804.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child: Care, Health and Development, 37*(2), 175-183.

Gordon, M., Uppal, E., Holt, K., Lythgoe, J., Mitchell, A., & Hollins-Martin, C. (2013). Application of the team objective structured clinical encounter (TOSCE) for continuing professional development amongst postgraduate health professionals. *Journal of Interprofessional Care, 27*(2), 191-193.

Goreczny, A. J., Bender, E. E., Caruso, G., & Feinstein, C. S. (2011). Attitudes toward individuals with disabilities: Results of a recent survey and implications of those results. *Research in Developmental Disabilities, 32*(5), 1596–1609.

Gosseries, O., Demertzi, A., Ledoux, D., Bruno, M.-A., Vanhaudenhuyse, A., Thibaut, A., et al. (2012). Burnout in healthcare workers managing chronic patients with disorders of consciousness. *Brain Injury, 26*(12), 1493-1499.

Goyen, T. A., & Lui, K. (2009). Developmental coordination disorder in ‘apparently normal’ schoolchildren born extremely preterm. *Archive of Diseases on Childhood, 94*(4), 298–302.

Gözüm, S. A., & Büyükavcı, M. (2007). Complementary and alternative medicine use in pediatric oncology patients in eastern Turkey. *Cancer Nursing, 30*(1), 38-44.

Graham, B. C., Keys, C. B., McMahon, S. D., & Brubacher, M. R. (2014). Transportation challenges for urban students with disabilities: Parent perspectives. *Journal of Prevention & Intervention in the Community, 42*(1), 45-57.

Grantham-McGregor, S., Cheung, V., & Cueto, S. (2007). Developmental potential in the first 5 years for children in developing countries. *The Lancet, 369*(9555), 60-70.

Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents’ experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development, 33*(3), 296–307.

Gray, P. H., Edward, D. M., O'Callaghan, M. J., Cuskelly, M., & Gibbons, K. (2013). Parenting stress in mothers of very preterm infants — Influence of development, temperament and maternal depression. *Early Human Development, 89*(9), 625–629.

Grbich, C. (2013). *Qualitative Data Analysis: An Introduction* (2nd ed.). London: Sage.

Grieger, J. A., Wood, L. G., & Clifton, V. L. (2013). Improving asthma during pregnancy with dietary antioxidants: The current evidence. *Nutrients, 5*(8), 3212-3234.

Guralnick, M. J. (1997a). Effectiveness of early intervention for vulnerable children. *American Journal on Mental Retardation, 102*(4), 319-345.

Guralnick, M. J. (1997b). Second generation research in the field of early intervention. In M. J. Guralnick, *The Effectiveness of Early Intervention* (1 ed.). Baltimore, MD: Paul. H Brookes.

Haig, A. J., Im, J., Adewole, D., Nelson, V., & Krabak, B. (2009). The practice of physical and rehabilitation medicine in sub-Saharan Africa and Antarctica: A white paper or a black mark? *Journal of Rehabilitation Medicine, 41*(6), 401-405.

Hansen, A. M., Chaki, A. P., & Mlay, R. (2013). Occupational therapy synergy between comprehensive community based rehabilitation Tanzania and Heifer International to reduce poverty. *African Journal of Disability, 2*(1), 1-7.

Harkness, S., & Super, C. (1995). Culture and parenting. In M. Borstein, *Handbook of Parenting: Biology and Ecology of Parenting* (1 ed., Vol. 2, pp. 211–234). Newark, NJ: Lawrence Erlbaum,.

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development, 31*(2), 167-180.

Hasnat, M. J., & Graves, P. (2000). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. *Journal of Paediatrics and Child Health, 36*(1), 32–35.

Hästbackaa, E., & Nygårda, M. (2013). Disability and citizenship. Politicians' views on disabled persons' citizenship in Finland. *Scandinavian Journal of Disability Research, 15*(2), 125-142.

Hatcher, A. M., Onah, M., Kornik, S., Peacocke, J., & Reid, S. (2014). Placement, support, and retention of health professionals: National, cross-sectional findings from medical and dental community service officers in South Africa. *Human Resources for Health, 12*(14), 1-13.

Haveman, M., Tillmann, V., Stöppler, R., Kvas, S., & Monninger, D. (2013). Mobility and public transport use abilities of children and young adults with intellectual disabilities: Results from the 3-year Nordhorn public transportation intervention study. *Journal of Policy and Practice in Intellectual Disabilities, 10*(4), 289–299.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642.

Holstein, J. A., & Gubrium, J. F. (1995). *The Active Interview.* California: Sage.

Huitt, W. (2007). *Maslow's Hierarchy of Needs.* Valdosta, GA: Valdosta State University.

Hussein, I., Kerrshaw, A. E., Tahmasebi, J. F., & Fayle, S. A. (1998). The management of drooling in children and patients with mental and physical disabilities: A literature review. *International Journal of Paediatric Dentistry, 8*(1), 3-11.

Ibrahim, S. H., & Bhutta, Z. A. (2013). Prevalence of early childhood disability in a rural district of Sind, Pakistan. *Developmental Medicine & Child Neurology, 55*(4), 357-363.

ILO, UNISCO, & WHO. (2004). *CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities: Joint Position Paper .* Geneva: World Health Organization.

Janesick, V. (2003). The choreography of qualitative research: Minutes, improvisations and crystallization. In N. Denzin, & Y. S. Lincoln, *Strategies of Qualitative Inquiry* (pp. 46–79). Thousand Oaks, CA: Sage.

Jankowicz-Szymanska, A., Mikolajczyk, E., & Wojtanowski, W. (2012). The effect of physical training on static balance in young people with intellectual disability. *Research in Developmental Disabilities, 33*(2), 675–681.

Jauhari, P., Boggula, R., Bhave, A., Bhargava, R., Singh, C., Kohli, N., et al. (2011). Aetiology of intellectual disability in paediatric outpatients in Northern India. *Developmental Medicine and Child Neurology, 53*(2), 167-172.

Jemta, L., Fugl-Meyer, K. S., & Oberg, K. (2008). On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairments. *Acta Paediatrica, 97*(5), 641-646.

Karthikeyan, P., & Ramalingam, K. (2012). Meningitis: Is a major cause of disability amongst Papua New Guinea children? *Disability and Rehabilitation, 34*(18), 1585-1588.

Kehler, J. (2001). Women and poverty: The South African experience. *Journal of International Women's Studies, 3*(1), 41-53.

Kelland, K., Hoe, E., McGuire, M. J., Yu, J., Andreoli, A., & Nixon, S. A. (2014). Excelling in the role of advocate: A qualitative study exploring advocacy as an essential physiotherapy competency. *Physiotherapy Canada, 66*(1), 74-80.

Kellogs. (2004). *Using Logic Models to Bring Together Planning, Evaluation, and Action: Logic Model Development Guide.* Michigan: WK Kellogs Foundation.

Kenny, K., & McGilloway, S. (2007). Caring for children with learning disabilities: An exploratory study of parental strain and coping. *British Journal of Learning Disabilities, 35*(4), 221-228.

Khamis, V. (2007). Psychological distress among parents of children with mental retardation in the United Arab Emirates. *Social Science and Medicine, 64*(4), 850–857.

Khandaker, G., Muhit, M., Rashid, H., Khan, A., Islam, J., Jones, C., et al. (2014). Infectious causes of childhood disability: Results from a pilot study in rural Bangladesh. *Journal of Tropical Pediatrics, 60*(5), 363-369.

Kilgo, J. L., Aldridge, J., Benton, B., Vogtel, J. V., Burke, C., & Unanue, R. (2003). Transdisciplinary teaming: A vital component of inclusive services. *Focus on Inclusive Education, 1*(1), 1-5.

King, G., Cathers, T., King, S., & Rosenbaum, P. (2001). Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care, 30*(2), 111–134.

King, G., Curran, C. J., & McPherson, A. (2012). A four-part ecological model of community-focused therapeutic recreation and life skills services for children and youth with disabilities. *Child: Care, Health and Development, 39*(3), 325-336.

King, G., Law, M., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability Development and Education, 57*(1), 77-107.

King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics, 22*(2), 53-77.

King, G., Wright, V., & Russell, D. J. (2011). Understanding paediatric rehabilitation therapists' lack of use of outcome measures. *Disability and Rehabilitation, 33*(25-26), 2662–2671.

King, S., King, G., & Rosenbaum, P. (2004). Evaluating health service delivery to children with chronic conditions and their families: Development of a refined measure of processes of care (MPOC-20). *Children's Health Care, 33*(1), 35–57.

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology, 11*(1), 78–86.

Kitenge, G., & Govender, L. (2013). Nurses' monitoring of the road to health chart at primary healthcare level in Makhado, Limpopo Province. *South African Family Practitioner, 55*(3), 275-280.

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *Journal of Gerontology: Psychological Sciences, 65B*(1), 5-13.

Kongolo, M., & Bamgose, O. O. (2002). Participation of rural women in development: A case study of Tsheseng, Thintwa, and Makhalaneng villages, South Africa. *Journal of International Women's Studies, 4*(1), 79-92.

Kristina, A., Kate, H., Gudrun, H., Marian, K., Teresa, C., Ulla-Britt, W., et al. (2013). Cerebral palsy and perinatal infection in children born at term. *Obstetrics & Gynecology, 122*(1), 41–49.

Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities, 5*(2), 89–95.

Kropiwnick, J. O., Elphick, J., & Elphick, R. (2014). Standing by themselves: Caregivers' strategies to ensure the right toeducation for children with disabilities in Orange Farm, South Africa. *Childhood*, 1-15.

Kuo, D. Z., Bird, T. M., & Tilford, J. M. (2011). Associations of family-centered care with health care outcomes for children with special health care needs. *Maternal and Child Health Journal, 15*(6), 794-805.

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*(2), 297-305.

Kvam, M. H., & Braathen, S. H. (2008). 'I thought . . . maybe this is my chance': Sexual abuse against girls and women with disabilities in Malawi. *Sexual Abuse: A Journal of Research and Treatment, 20*(1), 5-24.

Larson, R. W., & Verma, S. (1999). How children and adolescents spend time across the world: Work, play, and developmental opportunities. *Psychological Bulletin, 125*(6), 701-736.

Law, M., Anaby, D., Dematteo, C., & Hanna, S. (2011). Participation patterns of children with acquired brain injury. *Brain Injury, 25*(6), 587-595.

Law, M., Hanna, S., Anaby, D., Kertoy, M., King, G., & Xu, L. (2014). Health-related quality of life of children with physical disabilities: A longitudinal study. *BMC Pediatrics, 14*(1), 26-36.

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., et al. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development, 29*(5), 357–366.

Ledford, J. R., & Gast, D. L. (2006). Feeding problems in children with autism spectrum disorders: A review. *Focus on Autism and Other Developmental Disabilities, 21*(3), 153-166.

Lehmann, U. (2008). Strengthening human resources for primary health care. In P. Barron, J. Roma-Reardon, & . (Ed.), *South African Health Review* (pp. 163-177). Durban: Health Systems Trust.

Lemie're, C., Herbst, C. H., Dolea, C., Zurn, P., & Soucat, A. (2013). Rural-urban imbalance of health workers in sub-Saharan Africa. In A. Soucat, R. Scheffle, & T. Ghebreyesus, *The Labor Market for Health Workers in Africa: A New Look at the Crisis* (pp. 147-168). Washington, DC: World Bank Publications.

Leonald, K. L. (2002). When both states and markets fail: Asymmetric information and the role of NGOs in African health care. *International Review of Law and Economics, 22*(1), 61–80.

Levin, K. (2006). ' I am what I am because of who we all are': International perspectives on rehabilitation: South Africa. *Pediatric Rehabilitation, 3*(9), 285-292.

LGHSA. (2013). *The Local Government Handbook South Africa 2013* (3rd ed.). Mowbray: Yes Media.

Liamputtong, P., Yimyam, S., Parisunyakul, S., Baosoung, C., & Sansiriphun, N. (2004). When I become a mother! Discourses of motherhood among Thai women in Northern Thailand. *Women's Studies International Forum, 27*(5), 589-601.

Lie, K. K., Grøholt, E.-K., & Eskild, A. (2010). Association of cerebral palsy with Apgar score in low and normal birthweight infants: Population based cohort study. *BMJ, 341*, 1-6.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry.* California: Sage.

Lizarralde, G., & Massyn, M. (2008). Unexpected negative outcomes of community participation in low-cost housing projects in South Africa. *Habitat International, 32*(1), 1–14.

Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2013). Disability, embodiment and ableism: Stories of resistance. *Disability & Society, 28*(2), 190-203.

Loman, L. A., & Siegel, G. L. (2012). Effects of anti-poverty services under the differential response approach to child welfare. *Children and Youth Services Review, 34*(9), 1659–1666.

Loomans, E. M., Van Dijk, A. E., Vrijkotte, T. G., Van Eijsden, M., Stronks, K., Gemke, R. J., et al. (2013). Psychosocial stress during pregnancy is related to adverse birth outcomes: Results from a large multi-ethnic community-based birth cohort. *European Journal of Public Health, 23*(3), 485-491.

Lorenzo, T. (1994). The identification of continuing education needs for community rehabilitation workers in rural health district in the Republic of South Africa. *International Journal of Rehabilitation Research, 17*(3), 241-250.

Lund, C., & Flisher, A. J. (2009). A model for community mental health services in South Africa. *Tropical Medicine and International Health, 14*(9), 1040-1047.

Lutenbacher, M., Karp, S., Ajero, G., Howe, D., & Williams, M. (2005). Crossing community sectors: Challenges faced by families of children with special health care needs. *Journal of Family Nursing, 11*(2), 162-182.

Lutz, B. J., & Bowers, B. J. (2003). Understanding how disability is defined and conceptualized in the literature. *Rehabilitation Nursing, 28*(3), 74-78.

Lynham, S. A. (2002). The general method of theory-building research in applied disciplines. *Advances in Developing Human Resources, 4*(3), 221-241.

Mac Donald, E., Fitzsimons, E., & Walsh, P. N. (2006). Use of respite care and coping strategies among Irish families of children with intellectual disabilities. *British Journal of Learning Disabilities, 35*(1), 62-68.

Mackintosh, V. H., Goin-Kochel, R. P., & Myers, B. J. (2012). “What do you like/dislike about the treatments you’re currently using?”A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 27*(1), 51-60.

Magaña, S., Li, H., Miranda, E., & Paradiso de Sayu, R. (2014). Improving health behaviours of Latina mothers of youths and adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 1-14.

Maggs, J., Palisano, R., Chiarello, L., Orlin, M., Chang, H., & Polansky, M. (2011). Comparing the priorities of parents and young people with cerebral palsy. *Disability and Rehabilitation, 33*(17-18), 1650-1658.

Mahoney, J. L., Schweder, A. E., & Stattin, H. (2002). Structured after-school activities as a moderator of depressed mood for adolescents with detached relations to their parents. *Journal of Community Psychology, 30*(1), 69-86.

Maimburg, R. D., Bech, B. H., Vaeth, M., Møller-Madsen, B., & Olsen, J. (2010). Neonatal jaundice, autism, and other disorders of psychological development. *Pediatrics, 126*(5), 872–878.

Majnemer, A., Shikako-Thomas, K., Lach, L., Shevell, M., Law, M., Schmitz, N., et al. (2014). Rehabilitation service utilization in children and youth with cerebral palsy. *Child: Care, Health and Development, 40*(2), 275-282.

Mannan, H., Boostrom, C., MacLachlan, M., McAuliffe, E., Khasnabis, C., & Gupta, N. (2012). A systematic review of the effectiveness of alternative cadres in community based rehabilitation. *Human Resources for Health, 10*(20), 1-8.

Margareta, A. (2014). The development of social strengths in children with cerebral palsy. *Developmental Medicine & Child Neurology, 56*(4), 300–301.

Marit, A., Elisabeth, S., & Bjorg, K. (2011). Readjusting one's life in the tension inherent in work and motherhood. *Journal of Advanced Nursing, 67*(10), 2151–2160.

Marshall, E. S., Olsen, S. F., Mandleco, B. L., Dyches, T. T., Allred, K. W., & Sansom, N. (2003). This is a spiritual experience: Perspectives of latter-day saint families living with a child with disabilities. *Qualitative Health Research, 13*(1), 57-76.

Masasa, T., Irwin-Carruthers, S., & Faure, M. (2005). Knowledge of, beliefs about and attitudes to disability: Implications for health professionals. *South African Family Practitioner, 47*(7), 40-44.

Mateos, R. M., Jiménez, A., Román, P., Romojaro, F., Bacarizo, S., Leterrier, M., et al. (2013). Antioxidant systems from pepper (Capsicum annuum L.): Involvement in the response to temperature changes in ripe fruits. *International Journal of Molecular Sciences, 14*(5), 9556-9580.

Maulik, P. K., & Darmstadt, G. L. (2007). Childhood disability in low- and middle-income countries: Overview of screening, prevention, services, legislation, and epidemiology. *Pediatrics, 120*(s1), 1-55.

Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disabilities, 21*(4), 341-350.

Mays, N., & Pope, C. (1995). Rigour and qualitative research. *British Medical Journal, 311*(6997), 109-112.

McConachie, H. R., Randle, V., Hammal, D., & Le Couteur, A. S. (2005). A controlled trial of a training course for parents of children with suspected autism spectrum disorder. *The Journal of Pediatrics, 147*(3), 335-340.

McDermott, S., & Turk, M. A. (2011). The myth and reality of disability prevalence: Measuring disability for research and service. *Disability and Health Journal, 4*(1), 1-5.

McEwen, M., & Willis, E. M. (2002). *Theoretical Basis for Nursing.* Philadelphia: Lippincott Williams & Wilkins.

McIntyre, D., Thiede, M., Nkosi, M., Mutyambizi, V., Castillo-Riqueline, M., Goudge, J., et al. (2007). *A Critical Analysis of the Current South African Health System.* Health Economics Unit & Centre for Health Policy. Cape Town & Johannesburg: University of Cape Town & Wits University.

Mcintyre, S., Taitz, D., Keogh, J., Goldsmith, S., Badawi, N., & Blair, E. (2013). A systematic review of risk factors for cerebral palsy in children born at term in developed countries. *Developmental Medicine and Child Neurology, 55*(6), 499-508.

Mckenzie, J. A., McConkey, R., & Adnams, C. (2013). Intellectual disability in Africa: Implications for research and service development. *Disability and Rehabilitation, 35*(20), 1750-1755.

McLean, T. M., & Kemper, J. K. (2006). Lifestyle, biomechanical, and bioenergetic complementary therapies in pediatric oncology. *Journal of the Society for Integrative Oncology, 4*(4), 187-193.

McMillan, J. H., & Schumacher, S. (2006). *Research in Education: Evidence-Based Inquiry* (6th ed.). Boston: Pearson.

McPherson, M., Weissman, G., Strickland, B. B., Van Dyck, P. C., Blumberg, S. J., & Newacheck, P. W. (2004). Implementing community-based systems of services for children and youths with special health care needs: How well are we doing? *Pediatrics, 113*(s4), 1538-1544.

Meisels, S. J., & Atkins-Burnett, S. (2000). The elements of early childhood assessment. In J. P. Shonkoff, & S. J. Meisels, *Handbook of Early Childhood Intervention* (pp. 231-257). Cambridge: Cambridge University Press.

Meleis, A. I. (1997). *Theoretical Nursing: Development and Progress* (3rd ed.). Philadelphia, PA: Wolters Kluwer Health| Lippincott Williams and Wilkins.

Meleis, A. I. (2012). *Theoretical Nursing: Development and Progress* (5th ed.). Philadelphia, PA: Wolters Kluwer Health| Lippincott Williams and Wilkins.

Meningaud, J. P., Pitak-Arnnop, P., Chikhani, L., & Bertrand, J. C. (2006). Drooling of saliva: A review of the etiology and management options. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, and Endodontology, 101*(1), 48-57.

Mihalynuk, T., & Whiting, S. (2013). The role of dietitians in providing guidance: On the use of natural health products. *Canadian Journal of Dietetic Practice and Research, 74*(2), 58-62.

Miles, D. R., Steiner, M. J., Luken, K. J., Sanderson, M. R., Coyne-Beasley, T., Herrick, H., et al. (2011). Health and educational status of children raised by a caregiver with a disability. *Disability and Health Journal, 4*(3), 185-191.

Miles, M. B., & Huberman, M. A. (1994). *Qualitative Data Analysis: An Expanded Source Book.* Beverley Hills: Sage.

Miller, W. R. (2010). Qualitative research findings as evidence: Utility in nursing practice. *Clinical Nurse Specialist CNS, 24*(4), 191-193.

Millward, L. (2012). Focus Groups. In G. M. Breakwell, J. A. Smith, & D. B. Wright, *Research Methods in Psychology* (4th ed., pp. 411-438). London: Sage.

Milteer, R. M., & Ginsburg, K. R. (2012). The importance of play in promoting healthy child development and maintaining strong parent-child bond: Focus on children in poverty. *Pediatrics, 129*(1), e204 -e213.

Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry, 23*(5), 407-411.

Miodrag, N., Burke, M., Tanner-Smith, E., & Hodapp, R. M. (2014). Adverse health in parents of children with disabilities and chronic health conditions: A meta-analysis using the parenting stress index's health sub-domain. *Journal of Intellectual Disability Research*, 1-15.

Mogotlane, S. M., Chauke, M. E., Van Rensburg, G. H., Human, S. P., & Kganakga, C. M. (2010). A situational analysis of child-headed households in South Africa. *Curationis, 33*(3), 24-32.

Mondal, M. N., Ferdous, S., Islam, M. Z., Hossain, M. S., Shahiduzzaman, M., & Choudhary, M. S. (2014). Childhood disabilities and child protection in Rajshahi City, Bangladesh. *Bangladesh e-Journal of Sociology, 11*(1), 89-100.

Monson, J., Hall, K., Smith, C., & Shung-King, M. (2006). *South African Child Gauge 2006.* Cape Town: Children's Institute, University of Cape Town.

Morgan, P., Pogrebnoy, D., & McDonald, R. (2014). Health service experiences to address mobility decline in ambulant adults ageing with cerebral palsy. *Journal of Intellectual and Developmental Disability, 39*(3), 282-289.

Morse, J. M. (1994a). *Critical Issues in Qualitative Research Methods.* Thousand Oarks, CA: Sage.

Morse, J. M. (1994b). Designing funded qualitative research. In N. Denzin, & Y. S. Lincoln, *Book Designing Funded Qualitative Research* (pp. 220-235). Thousand Oaks, CA: Sage.

Muhr, T. (2004). *Atlas.ti: The Knowledge Workbench: V5.0 User's Guide and Reference.* Berlin: Scientific Software Development.

Myers, M. (2000). Qualitative research and the generalizability question: Standing firm with proteus. *The Qualitative Report, 4*(3/4), 1-9.

Nair, M. K., & Radhakrishnan, S. R. (2004). Early childhood development in deprived urban settlement. *Indian Pediatrics, 41*(3), 227-237.

Nandiwada, D. R., & Dang-Vu, C. (2010). Transdisciplinary health care education: Training team players. *Journal of Health Care for the Poor and Underserved, 21*(1), 26-34.

Natarajan, G., Shankaran, S., Pappas, A., Bann, C., Tyson, J. E., McDonald, S., et al. (2014). Functional status at 18 months of age as a predictor of childhood disability after neonatal hypoxic-ischemic encephalopathy. *Developmental Medicine & Child Neurology, 56*(11), 1052-1058.

Nel, P. S., Werner, A., Haasbroek, G. D., Poisat, P., Sono, T., & Schultz, H. B. (2008). *Human Resources Management* (7th ed.). Cape Town: Oxford University Press.

Nelson, A. (2002). A metasynthesis: Mothering other than normal children. *Qualitative Health Research, 12*(4), 515-530.

Nemutandani, M. S., Maluleke, F. R., & Rudolph, M. J. (2006). Community services doctors in Limpopo Province. *South Africa Medical Journal, 96*(3), 180-182.

Ngai, F. W., Chan, S. W., & Eleanor, H. (2011). Chinese primiparous women's experiences of early motherhood: Factors affecting maternal role competence. *Journal of Clinical Nursing, 20*(9-10), 1481-1489.

Nielsen, L. F., Schendel, D., Grove, J., Hvidtjørn, D., Jacobsson, B., Josiassen, T., et al. (2008). Asphyxia-related risk factors and their timing in spastic cerebral palsy. *BJOG: An International Journal of Obstetrics & Gynaecology, 115*(12), 1518-1528.

Njambi, L., Kariuki, M., & Masinde, S. (2009). Ocular findings in children attending occupational therapy clinic at Kenyatta National Hospital, Nairobi, Kenya. *Middle East African journal of ophthalmology, 15*(1), 21-26.

Noga, J., & Wolbring, G. (2012). The economic and social benefits and the barriers of providing people with disabilities accessible clean water and sanitation. *Sustainability, 4*(11), 3023-3041.

O’Neil, M., Palisano, R., & Westcott, S. (2001). Relationship of therapists’ attitudes, children's motor ability, and parenting stress to mothers' perceptions of therapists' behaviors during early intervention. *Physical Therapy, 81*(8), 1412-1424.

Omolo, M. A., Wong, Z.-Z., Mergen, A. K., Hastings, J. C., Le, N. C., Reiland, H. A., et al. (2014). Antimicrobial properties of chili peppers. *Infectious Diseases & Therapy, 2*(4), 145-153.

Orlin, M. N., Cicirello, N. A., O'Donnell, A. E., & Doty, A. K. (2014). The continuum of care for individuals with lifelong disabilities: Role of the physical therapist. *Physical Therapy*.

Paley, B., & O'Connor, M. J. (2011). Behavioral interventions for children and adolescents with fetal alcohol spectrum disorders. *Alcohol Research and Health, 34*(1), 64-75.

Parker, J. A., Mandleco, B., Roper, S. O., Freeborn, D., & Dyches, T. T. (2011). Religiosity, spirituality, and marital relationships of parents raising a typically developing child or a child with a disability. *Journal of Family Nursing, 17*(1), 82-104.

Parkes, J., Caravale, B., Marcelli, M., Franco, F., & Colver, A. (2011). Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Developmental Medicine & Child Neurology, 53*(9), 815–821.

Patel, V., Kieling, C., Maulik, P. K., & Divan, G. (2013). Global child health: Improving access to care for children with mental disorders: A global perspective. *Archives of Disease in Childhood, 98*(5), 323-327.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5 p 2), 1189–1208.

Peadon, E., Payne, J., Henley, N., D'Antoine, H., Bartu, A., O'Leary, C., et al. (2011). Attitudes and behaviour predict women's intention to drink alcohol during pregnancy: The challenge for health professionals. *BMC Public Health, 11*(584), 1-10.

Penny, N., Zulianello, R., Dreise, M., & Steenbeek, M. (2007). Community-based rehabilitation and orthopaedic surgery for children with motor impairment in an African context. *Disability and Rehabilitation, 29*(11-12), 839-843.

Peres, H., Glazer, Y., Landau, D., Marks, K., Abokaf, H., Belmaker, I., et al. (2014). Understanding utilization of outpatient clinics for children with special health care needs in Southern Israel. *Maternal and Child Health Journal, 18*(8), 1831-1845.

Perrin, J. M., Romm, D., Bloom, S. R., Homer, C. J., Kuhlthau, K. A., Cooley, C., et al. (2007). A family-centered, community-based system of services for children and youth with special health care needs. *Archives of Pediatrics & Adolescent Medicine, 161*(10), 933-936.

Petrick, M., Sichangwa, K., Pickford, K., & Collinson, M. (2002). How community rehabilitation workers see their work. *South African Journal of Physiotherapy, 58*(2), 25-31.

Pfeifer, L. I., Silva, D. B., Lopes, P. B., Matsukura, T. S., Santos, J. L., & Pinto, M. P. (2014). Social support provided to caregivers of children with cerebral palsy. *Child: Care, Health and Development, 40*(3), 363-369.

Pillay, D., Girdler, S., Collins, M., & Leonard, H. (2012). "It’s not what you were expecting, but it’s still a beautiful journey”: The experience of mothers of children with Down syndrome. *Disability & Rehabilitation, 34*(18), 1501-1510.

Pillay, J., & Di Terlizzi, M. (2009). ‘A case study of a learner’s transition from mainstream schooling to a school for learners with special educational needs (LSEN): Lessons for mainstream education’. *South African Journal of Education, 29*(4), 491-509.

Piškur, B., Beurskens, J. H., Jongmans, M. J., Ketelaar, M., & Smeets, R. J. (2014). What do parents need to enhance participation of their school-aged child with a physical disability? A cross-sectional study in the Netherlands. *Child: Care, Health and Development*, 1-9.

Pless, M., & Granlund, M. (2012). Implementation of the international classification of functioning, disability and health (ICF) and the ICF children and youth version (ICF-CY) with the context of augmentative and alternative communication. *Augmentative and Alternative Communication, 28*(1), 11-20.

Pollack, H. A. (2011). Health policy and the community safety net for individuals with intellectual disability. *Developmental Disabilities Research Reviews, 17*(1), 44-51.

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care. *British Medical Journal, 320*(7227), 114-116.

Porter, G. (2002). Living in a walking world: Rural mobility and social equity issues in Sub-Saharan Africa. *World Development, 30*(2), 285-300.

Powers, B. A., & Knapp, T. R. (1995). *A Dictionary of Nursing Theory and Research* (2nd ed.). Thousand Oaks, CA: Sage.

Presidency. (1997). *Government of South Africa.* Retrieved 09 11, 2013, from www.info.gov.za

Raghavendra, P., Virgo, R., Olsson, C., Connell, T., & Lane, A. E. (2011). Activity participation of children with complex communication needs, physical disabilities and typically-developing peers. *Developmental Neurorehabilitation, 14*(3), 145-155.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., et al. (2005). The health and the well-being of caregiver of children with cerebral palsy. *Pediatrics, 115*(6), e626-e636.

Raina, S. K., Razdan, S., & Nanda, R. (2011). Prevalence of cerebral palsy in children <10 years of age in RS Pura town of Jammu and Kashmir. *Journal of Tropical Pediatrics*.

Ramklass, S. S. (2009). An investigation into the alignment of a South African physiotherapy curriculum and the expectations of the healthcare system. *Physiotherapy, 95*(3), 215-222.

Rao, S. (2004). Faculty attitudes and students with disabilities in higher education: A literature review. *College Student Journal, 38*(2), 191-199.

Reading, R. (2012). Feeding difficulties in children with cerebral palsy. *Child: Care, Health and Development, 38*(3), 455-456.

Reiter, S., Bryen, D. N., & Shachar, I. (2007). Adolescents with intellectual disabilities as victims of abuse. *Journal of Intellectual Disabilities, 11*(4), 371-387.

Reithmuller, A. M., Jones, R., & Okely, A. D. (2009). Efficacy of interventions to improve motor development in young children: A systematic review. *Pediatrics, 124*(4), e782-e792.

Rimmer, J. H., Rowland, J. L., & Yamaki, K. (2007). Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health, 41*(3), 224–229.

Rispel, Doherty, Makiwane, & Webb. (1996). Developing a plan for primary health care facilities in Soweto, South Africa. Part I: Guiding principles and methods. *Health, Policy and Planning, 11*(4), 385-393.

Rivara, F. P., Koepsell, T. D., Wang, J., Temkin, N., Dorsch, A., Vavilala, M. S., et al. (2011). Disability 3, 12, and 24 months after traumatic brain injury among children and adolescents. *Pediatrics, 128*(5), e1129-e1138.

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*(4), 383-394.

Robertson, J., Emerson, E., Hatton, C., & Yasamy, M. T. (2012). Efficacy of community-based rehabilitation for children with or at significant risk of interllectual disabilities in low- and middle-income countries: A review. *Journal of Applied Research in Intellectual Disabilities, 25*(2), 143-154.

Rogers-Dulan, J. (1998). Religious connectedness among urban African American families who have a child with disabilities. *Mental Retardation, 36*(2), 91-103.

Rosen, C., Miller, A. C., Pit-ten Cate, I. M., Bicchieri, S., Gordon, R. M., & Daniele, R. (1998). Team approaches to treating children with disabilities: A comparison. *Archives of Physical Medicine and Rehabilitation, 79*(4), 430-434.

Rosenbaum, P., Armstrong, R., & King, S. (1988). Determinants of children's attitude toward disability: A review of evidence. *Child: Care, Health, and Development, 17*(1), 32-39.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service a conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics, 18*(1), 1-20.

Rosenberg, A. E. (2000). Conducting an inventory of informal community-based resources for children with physical disabilities. *Physical & Occupational Therapy in Pediatrics, 20*(1), 59-79.

Roush, S. E., & Sharby, N. (2011). Disability reconsidered: The paradox of physical therapy. *Advances in Disability Research, 91*(12), 1715-1727.

RSA. (1996). *Constitution of the Republic of South Africa No 108 of 1996*. Cape Town, Republic of South Africa: Presidency.

RSA. (2000). *Local Government: Municipal Systems Act, No 32 of 2000*. Cape Town, South Africa: The Presidency.

RSA. (2010). *Social Assistance Act, No 5 of 2010*. Cape Town, Republic of South Africa: The Presidency.

Ruck, M. D., Keating, D. P., Abramovitch, R., & Koegl, C. J. (1998). Adolescents' and children's knowledge about rights: Some evidence for how young people view rights in their own lives. *Journal of Adolescence, 21*(3), 275–289.

Rule, S., Lorenzo, T., & Wolmarans, M. (2006). Community-based rehabilitation: new challenges. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley, *Disability and Social Change: A South African Agenda* (pp. 273-290). Cape Town: HSRC.

Saldana, J. (2013). *The Coding Manual for Qualitative Researchers* (2nd ed.). Thousand Oaks, CA: Sage.

Saloojee, G. (2012). *Malamulele Onward*. Retrieved December 05, 2012, from Malamulele Onward: www.malamuleleonward.org

Saloojee, G. M., Rosenbaum, P. R., Westaway, M. S., & Stewart, A. V. (2009). Development of a measure of family-centred care for resource-poor South African settings: the experience of using a modified version of the MPOC-20. *Child: Care, Health and Development, 35*(1), 23-32.

Saloojee, G., Phohole, M., Saloojee, H., & IJsselmuiden, C. (2007). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health and Development, 33*(3), 230-235.

Sandy, P. T., Kgole, J. C., & Mavundla, T. R. (2013). Support needs of caregivers: Case studies in South Africa. *International Nursing Review, 60*(3), 344-350.

Sawyer, M. G., Bittman, M., Greca, A. M., Crettenden, A. D., Borojevic, N., Raghavendra, P., et al. (2011). Time demands of caring for children with cerebral palsy: What are the implications for maternal mental health? *Developmental Medicine & Child Neurology, 53*(4), 338–343.

Schalock, R. L., Keith, K. D., Verdugo, M. A., & Gomez, L. E. (2011). Quality of life model development and use in the field of intellectual disability. *Enhancing the Quality of Life of People with Intellectual Disabilities Social Indicators Research Series, 41*, 17-32.

Schatz, E., Madhavan, S., & Williams, J. (2011). Female-headed households contending with AIDS-related hardship in rural South Africa. *Health & Place, 17*(2), 598-605.

Scheffler, R. M., Mahoney, C. B., Fulton, B. D., Dal Poz, M. R., & Preker, A. S. (2009). Estimates of health care professional shortages in Sub-Saharan Africa by 2015. *Health Affairs, 28*(5), 849–862.

Scherzer, A. L., Chhagan, M., Kauchali, S., & Susser, E. (2012). Global perspective on early diagnosis and intervention for children with developmental delays and disabilities. *Developmental Medicine and Child Neurology, 54*(12), 1079-1084.

Schetter, C. D., & Tanner, L. (2012). Anxiety, depression and stress in pregnancy: Implications for mothers, children, research, and practice. *Current Opinion in Psychiatry, 25*(2), 141–148.

Schreiber, J., Benger, J., Salls, J., Marchetti, G., & Reed, L. (2011). Parent perspectives on rehabilitation services for their children with disabilities: A mixed methods approach. *Physical & Occupational Therapy in Pediatrics, 31*(3), 225-238.

Seedhouse, D. (2002). Commitment to health: A shared ethical bond between professionals. *Journal of Interprofessional Care, 16*(3), 249-260.

Sen, A. (2009). *The Idea of Justice.* Cambridge, MA: Harvard University Press.

Shackleton, C. M., Hebinck, P., Kaoma, H., Chishaleshale, M., Chinyimba, A., Shackleton, S. E., et al. (2014). Low-cost housing developments in South Africa miss the opportunities for household level urban greening. *Land Use Policy, 36*, 500-509.

Shakespeare, T., Lezzoni, L. I., & Groce, N. E. (2009). Disability and the training of health professionals. *The Lancet, 374*(9704), 1815-1816.

Sharp, W. G., Berry, R. C., McCracken, C., Nuhu, N. N., Marvel, E., Saulnier, C. A., et al. (2013). Feeding problems and nutrient intake in children with autism spectrum disorders: A meta-analysis and comprehensive review of the literature. *Journal of Autism and Developmental Disorders, 43*(9), 2159-2173.

Sharts-Hopko, N. (2002). Assessing rigor in qualitative research. *Journal of the Association of Nurses in AIDS Care, 13*(4), 84-86.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63-75.

Shevell, M. I., Majnemer, A., Rosenbaum, P., & Abrahamowicz, M. (2001). Etiologic determination of childhood developmental delay. *Brain and Development, 23*(4), 228-235.

Shields, N., & Synnot, A. J. (2014). An exploratory study of how sports and recreation industry personnel perceive the barriers and facilitators of physical activity in children with disability. *Disability and Rehabilitation*, 1-5.

Shonkoff, J. P., & Marshall, P. C. (2000). The biology of developmental vulnerability. In J. P. Shonkoff, & S. J. Meisels, *Handbook of Early Childhood Intervention* (2nd ed., pp. 35-53). New York: Cambridge University Press.

Shortman, R. I., Beringer, A., Penn, A., Malson, H., Lowis, S. P., & Sharples, P. M. (2013). The experience of mothers caring for a child with a brain tumour. *Child: Care, Health and Development, 39*(5), 743-749.

Silver, E. J., Westbrook, L. E., & Stein, R. E. (1998). Relationship of parental psychological distress to consequences of chronic health conditions in children. *Journal of Pediatric Psychology, 23*(1), 5-15.

Silverman, D. (2000). *Doing Qualitative Research: A Practical Handbook.* London: Sage.

Simons, L. E., Sieberg, C. B., Pielech, M., Conroy, C., & Logan, D. E. (2013). What does it take? Comparing intensive rehabilitation to outpatient treatment for children with significant pain-related disability. *Journal of Pediatric Psychology, 38*(2), 213-223.

Skinner, D. G., Correa, V., Skinner, M., & Bailey, D. B. (2001). Role of religion in the lives of Latino families of young children with developmental delays. *American Journal of Mental Retardation, 106*(4), 297-313.

Skirrow, P., & Hatton, C. (2007). ‘Burnout’ amongst direct care workers in services for adults with intellectual disabilities: A systematic review of research findings and initial normative data. *Journal of Applied Research in Intellectual Disabilities, 20*(2), 131–144.

Sleigh, G., & Brocklehurst, P. (2004). Gastrostomy feeding in cerebral palsy: A systematic review. *Archives of Disease in Childhood, 89*(6), 534-539.

Smith, M. J., & Liehr, P. R. (2014). *Middle Range Theory for Nursing* (3rd ed.). New York: Springer Publishing Company.

Snider, L., Majnemer, A., & Darsaklis, V. (2011). Feeding interventions for children with cerebral palsy: A review of the evidence. *Physical & Occupational Therapy in Pediatrics, 31*(1), 58-77.

Speziale, H. J., & Carpenter, D. R. (2007). *Qualitative Research in Nursing: Advancing the Humanistic Imperative* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.

STATSSA. (2005). *Census 2001.* Statistic South Africa. Pretoria: Statistic South Africa.

STATSSA. (2011). *General Household Survey, July 2010.* Pretoria: Statistics South Africa.

STATSSA. (2012). *Census 2011.* Statistic South Africa. Pretoria: Statistic South Africa.

Stiker, H.-J. (2002). *A History of Disability.* Ann Arbor: University of Michigan Press.

Strauss, A. A. (1991). *Qualitative Analysis for Social Scientists.* Cambridge: Cambridge University Press.

Strauss, A. A., & Corbin, J. (1990). *Basics of Qualitative Research. Grounded Theory Procedures and Techniques.* London: Sage.

Strauss, A. A., & Corbin, J. G. (1994). Grounded theory methodology: An overview. In N. K. Denzin, & Y. S. Lincoln, *Handbook of Qualitative Research* (1st ed.). Newbury Park, CA: Sage.

Strauss, A. A., & Corbin, J. G. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (2nd ed.). Thousand Oaks, CA: Sage.

Streja, E., Miller, J. E., Bech, B. H., Greene, N., Pedersen, L. H., Yeargin-Allsopp, M., et al. (2013). Congenital cerebral palsy and prenatal exposure to self-reported maternal infections, fever, or smoking. *American Journal of Obstetrics and Gynecology, 209*(4), 332e 1-10.

Stricklin, M. L. (1997). Community-based care: Back to the future! *Disability and Rehabilitation, 19*(4), 158-162.

Stucki, G. (2005). International classification of functioning, disability, and health (ICF): A promising framework and classification for rehabilitation medicine. *American Journal of Physical Medicine & Rehabilitation, 84*(10), 733–740.

Summers, J. A., Marquis, J., Mannan, H., Turnbull, A. P., Fleming, K., Poston, D. J., et al. (2007). Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. *International Journal of Disability, Development and Education, 54*(3), 319–338.

Sumner, A. (2010). Global poverty and the new bottom billion: What if three-quarters of the world's poor live in middle-income countries? *IDS Working Paper* (349), pp. 1-43.

Tadema, A. C., & Vlaskamp, C. (2010). The time and effort in taking care for children with profound intellectual and multiple disabilities: A study of care load and support. *British Journal of Learning Disabilities, 38*(1), 41-48.

Tarakeshwar, N., & Pargament, K. I. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities, 16*, 247-260.

Taylor, J. L., & Warren, Z. E. (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism and Developmental Disorders, 42*(7), 1411-1418.

Ted, B., & Brett, W. (2013). Team member style preferences of occupational therapy students. *New Zealand Journal of Occupational Therapy, 60*(2), 13-20.

Tervo, R., Azuma, S., Palmer, G., & Redinius, P. (2002). Medical students' attitudes toward persons with disability: A comparative study. *Archives of Physical Medicine and Rehabilitation, 83*(11), 1537–1542.

Tervo, R., Palmer, G., & Redinius, P. (2004). Health professional student attitudes towards people with disability. *Clinical Rehabilitation, 18*(8), 908–915.

Theron, L. C., & Theron, A. M. (2010). A critical review of studies of South African youth resilience, 1990–2008. *South African Journal of Science, 106*(7/8), 1-8.

Thomas, C. (2007). *Sociologies of Disability and Illness.* New York: Palgrave Macmillan.

Thomas, C., & Rose, J. (2010). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities, 23*(2), 167-178.

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237-246.

Todd, S. (2009). Learning to take the world seriously: An ethnographic study of the management of knowledge in a special school for children with intellectual disabilities. *Journal of Intellectual Disabilities, 13*(3), 221-38.

Tokem, Y. A., Yıldırım, Y., & Fadiloglu, C. (2012). Investigation into the use of complementary and alternative medicine and affecting factors in Turkish asthmatic patients. *Journal of Clinical Nursing, 21*(5-6), 698–707.

Tornbom, M., Jonsson, U., & Sunnerhagen, K. S. (2013). Increasing symptoms, met and unmet needs in adults with cerebral palsy or meningomyelocele a longitudinal follow-up. *Scandinavian Journal of Disability Research, 15*(3), 249-263.

Torraco, R. J. (1997). Theory-building research methods. In R. A. Swanson, & E. F. Holton L, *Human Resource Development Research Handbook: Linking Research and Practice* (pp. 114-138). San Francisco, CA: Berrett-Koehler Publishers.

Trivette, C. M., Dunst, C. J., & Deal, A. G. (1997). Resource based approach to early intervention. In S. K. Thurman, J. R. Cornwell, & S. R. Gottwald, *Contexts of Early Intervention: Systems and Settings* (pp. 73-92). Baltimore, MD: Paul H Brookes.

Trivette, C. M., Dunst, C. J., & Deal, A. G. (1997). Resource-based approach to early intervention. In S. K. Thurman, J. R. Cornwell, & S. R. Gottwald, *Contexts of Early Intervention: Systems and Settings* (pp. 73-92). Baltimore, MD: Paul H. Brookes.

Trovato, M. K., Bradley, E., Slomine, B. S., Salorio, C. F., Christensen, J. R., & Suskauer, S. J. (2013). Physical abilities and mobility scale: Reliability and validity in children receiving inpatient rehabilitation for acquired brain injury. *Archives of Physical Medicine and Rehabilitation, 94*(7), 1335–1341.

Tsai, C., Wu, S. K., & Huang, C.-H. (2008). Static balance in children with developmental coordination disorder. *Human Movement Science, 27*(1), 142-153.

Tumbo, J. M., Couper, I. D., & Hugo, J. F. (2009). Rural-origin health science students at South African universities. *South African Medical Journal, 99*(1), 54-56.

Twine, R. (2007). Number of people seeing detected by community rehbilitation workers in the Limpopo Province of South Africa, with special reference to cataracts. *Masters Research Report (MPH)*. Johannesburg, South Africa: University of the Witwatersrand.

Twine, R., Collinson, M. A., Polzer, T. J., & Kahn, K. (2007). Evaluating access to a child-oriented poverty alleviation intervention in rural South Africa. *Scandanavian Journal of Public Health, 35*(s69), 118-127.

Uccelli, M. M., Traversa, S., Trojano, M., Viterbo, R. G., Ghezzi, A., & Signori, A. (2013). Lack of information about multiple sclerosis in children can impact parents' sense of competency and satisfaction within the couple. *Journal of the Neurological Sciences, 324*(1-2), 100-105.

UN. (2006). United Nations Conversion on the rights of persons with disabilities. *Resolution 60/232.* New York: United Nations.

Underbjerg, M., Kesmodel, U., Landrø, N., Bakketeig, L., Grove, J., Wimberley, T., et al. (2012). The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on selective and sustained attention in 5-year-old children. *BJOG: An International Journal of Obstetrics and Gynaecology, 119*(10), 1211–1221.

UNICEF. (2005). *The State of the World's Children 2005: Childhood Under Threat.* New York: United Nations Children's Fund.

UNICEF. (2008). *The State of the World's Children 2009.* New York: United Nations Children's Fund.

UNICEF. (2013). *The State of the World's Children: Children with Disabilities.* New York: United Nations Children's Fund.

Van den Hoonard, W. C. (1997). *Working with Sensitizing Concepts: Analytical Field Research.* Thousand Oaks, CA: Sage.

Van Dyk, A. C. (2001). Traditional African beliefs and customs: Implications for AIDS education and prevention in Africa. *South Africa Journal of Psychology, 31*(2), 60-66.

Vignes, C., Godeau, E., Sentenac, M., Coley, N., Navarro, F., Grandjean, H., et al. (2009). Determinants of students' attitudes towards peers with disabilities. *Developmental Medicine & Child Neurology, 51*(6), 473-479.

Vorster, H. H., & Kruger, A. (2007). Poverty, malnutrition, underdevelopment and cardiovascular disease: A South African perspective: Review article. *Cardiovascular Journal of Africa, 18*(5), 321-324.

Walker, L. O., & Avant, K. C. (2005). *Strategies for Theory Construction in Nursing* (4th ed.). Boston: Pearson/Prentice Hall.

Walsh, C. E., & O'Leary, D. K. (2013). A comparative study of the marital relationship between parents with children with autism and those with children without autism. *Good Autism Practice, 14*(1), 28-33(6).

Walshe, M., Smith, M., & Pennington, L. (2012). Interventions for drooling in children with cerebral palsy. *The Cochrane Library*(11).

Wang, P., Michaels, C. A., & Day, M. S. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism and Developmental Disorder, 41*(6), 783-795.

WCPT. (2003). *The 14th International Congress of WCPT, World Physical Therapy 2003.* Barcelona: WCPT.

WCPT. (2011a). *World Confederation of Physical Therapy.* Retrieved March 15, 2014, from Policy statement: Description of physical therapy: www.wcpt.org/policy/ps-descriptionPT

WCPT. (2011b). *World Confederation for Physical Therapy.* Retrieved March 15, 2014, from Policy statement: Education: http://www.wcpt.org/policy/ps-education

WFOT. (2010). *World Federation of Occupational Therapy.* Retrieved March 15, 2014, from Statement on Occupational Therapy: http://www.wfot.org/ResourceCentre.

WFOT. (2012). *World Federation of Occupational Therapy.* Retrieved March 15, 2014, from Definition of Occupational Therapy: http://www.wfot.org/ResourceCentre.

Whiting, M. (2014). Children with disability and complex health needs: The impact on family life. *Nursing Children and Young People, 26*(3), 26-30.

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development, 39*(3), 366-373.

WHO. (1978). *Declaration of Alma-Ata: International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978.* Geneva: World Health Organization.

WHO. (1982). *Community Based Rehabilitation: Report of a WHO interregional Consultation. Colombo, Sri Lanka, 28 June-3 July.* Geneva: World Health Organization.

WHO. (1995). *The World Health Report 1995: Bridging the Gaps.* Geneva: World Health Organization.

WHO. (2001). *International Classification of Functioning, Disability and Health (ICF).* Geneva: World Health Organization.

WHO. (2002). *Part 1: Community Based-Rehabilitation as we have Experienced it...* Geneva: World Health Organization.

WHO. (2007). *International Classification of Functioning, Disability and Health: Children and Youth Version.* Geneva: World Health Organization.

WHO. (2008). *The Global Burden of Disease 2004 Update.* Geneva: World Health Organization.

WHO. (2009). *Systems Thinking for Health Systems Strengthening.* Geneva: World Health Organization.

WHO. (2011). *World Report on Disability.* World Health Organisation. Geneva: World Health Organisation.

WHO. (2012). *Early Childhood Development and Disability: A Discussion Paper.* Geneva: World Health Organization.

WHO. (2014). *Disability: Draft WHO Global Disability Action Plan 2014–2021: Better Health for all People with Disability.* Geneva: World Health Organization.

WHO, UNESCO, ILO, & IDDC. (2010a). *Introductory Booklet Community-Based Rehabilitation: CBR Guidelines.* Geneva: World Health Organization.

WHO, UNESCO, ILO, & IDDC. (2010b). *Health Component: Community-Based Rehabilitation: CBR Guidelines.* Geneva: World Health Organization.

WHO, UNESCO, ILO, & IDDC. (2010c). *Education Component: Community-Based Rehabilitation: CBR Guidelines.* Geneva: World Health Organization.

Wiart, L., Church, J., Darrah, J., Ray, L., Magill-Evans, J., & Andersen, J. (2010). Cross-ministerial collaboration related to paediatric rehabilitation for children with disabilities and their families in one Canadian province. *Health and Social Care in the Community, 18*(4), 378-388.

Wilson, B. A. (2002). Towards a comprehensive model of cognitive rehabilitation. *Neuropsychological Rehabilitation, 12*(2), 97-110.

Włoszczak-Szubzda, A., & Jarosz, M. J. (2013). Professional communication competences of physiotherapists – practice and educational perspectives. *Annals of Agricultural and Environmental Medicine, 20*(1), 189-194.

Wolery, M. (2000). Behavioral and educational approaches to early intervention. In J. P. Shonkoff, & S. J. Meisels, *Handbook of Early Childhood Intervention* (pp. 179-203). New York: Cambridge University Press.

Woodside, J. M., Rosenbaum, P. L., King, S. M., & King, G. A. (2001). Family-centered services: Developing and validating a self-assessment tool for pediatric service providers. *Children's Health Care, 30*(3), 237–252.

Yin, R. K. (1994). *Case Study Research: Design and Methods.* Thousand Oaks, CA: Sage.

Zascavage, V. T., & Keefe, C. H. (2004). Students with severe speech and physical impairments: Opportunity barriers to literacy. *Focus on Autism and Other Developmental Disabilities, 19*(4), 223-234.

Zhaokang, Y., Yuxi, L., Yong, L., Yunchang, X., Yuanjum, G., & Harris, M. (2012). A model for community health service development in depressed rural areas in China. *BMC Health Services Research, 12*(1), 465-471.

Zonfrillo, M. R., Durbin, D. R., Winston, F. K., Zhao, H., & Stineman, M. G. (2013). Physical disability after injury-related inpatient rehabilitation in children. *Pediatrics, 131*(1), e206-e213.

APPENDIX A: Ethical clearance (University of Pretoria)

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 13 Jan 2012.
- IRB 0000 2235 IORG0001762 Approved dd Jan 2006 and Expires 13 Aug 2011.

100
1908 - 2008

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee
Fakulteit Gesondheidswetenskappe Navorsingsetiekkomitee

DATE: 29/04/2010

PROTOCOL NO.	**109/2009**
PROTOCOL TITLE	Development of a model for the (re)habilitation of children with disabilities in a rural area.
INVESTIGATOR	**Principal Investigator:** Mr D Mathey
SUBINVESTIGATOR	Not Applicable
SUPERVISOR	Dr C A Eksteen **E-Mail:** carina.eksteen@up.ac.za
DEPARTMENT	**Dept:** School of Health Care Sciences. **Phone:** 015-8124057 **E-Mail:** desphysio@hotmail.com **Cell:** 0824193309
STUDY DEGREE	Doctor of Philosophy (Physiotherapy)
SPONSOR	None
MEETING DATE	30 September 2009

This **Protocol** was considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and approved by a quorum of committee members on 30 September 2009.

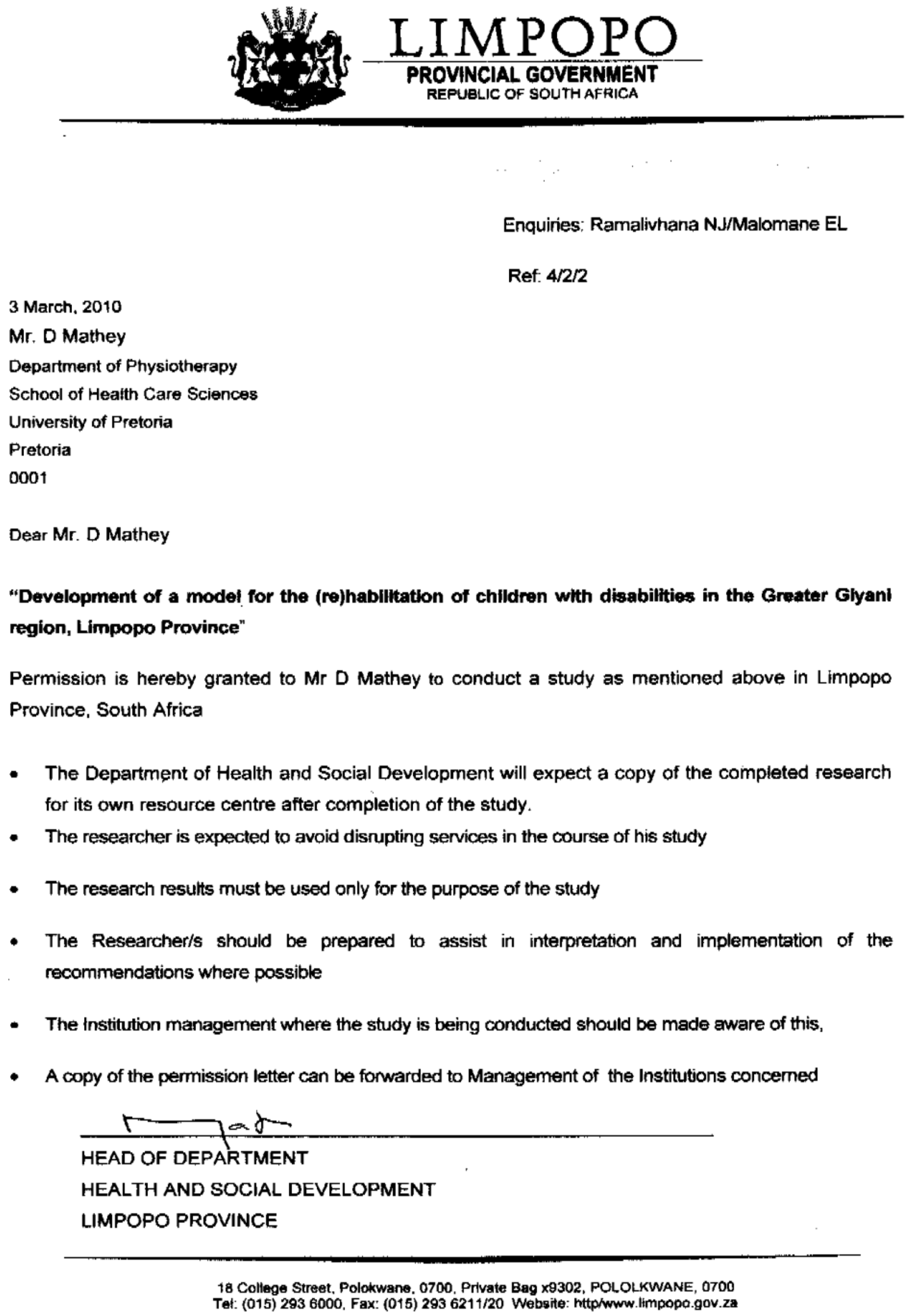
Members of the Research Ethics Committee:

Prof VOL Karusseit	MBChB; MFGP(SA); MMed(Chir); FCS(SA) - Surgeon
Prof JA Ker	MBChB; MMed(Int); MD – Vice-Dean (ex officio)
Dr NK Likibi	MBBCh – Representing Gauteng Department of Health)
Prof TS Marcus	(female) BSc(LSE), PhD (University of Lodz, Poland) – Social scientist
Dr MP Mathebula	(female) Deputy CEO: Steve Biko Academic Hospital
Prof A Nienaber	(female) BA(Hons)(Wits); LLB; LLM(UP); PhD; Dipl.Datametrics(UNISA) – Legal advisor
Mrs MC Nzeku	(female) BSc(NUL); MSc(Biochem)(UCL, UK) – Community representative
Snr Sr J Phatoli	(female) BCur(Eet.A); BTec(Oncology Nursing Science) – Nursing representative
Dr L Schoeman	(female) B.Pharm, BA(Hons)(Psych), PhD – Chairperson: Subcommittee for students' research
Mr Y Sikweyiya	MPH; SARETI Fellowship in Research Ethics; SARETI ERCTP; BSc(Health Promotion) Postgraduate Dip (Health Promotion) – Community representative
Dr R Sommers	(female) MBChB; MMed(Int); MPharmMed – **Deputy Chairperson**
Prof TJP Swart	BChD, MSc (Odont), MChD (Oral Path), PGCHE – School of Dentistry representative
Prof C W van Staden	MBChB; MMed (Psych); MD; FCPsych; FTCL; UPLM - **Chairperson**

DR R SOMMERS; MBChB; MMed(Int); MPharmMed.
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

31 Bophelo Road ◆ H W Snyman Building (South) Level 2-34 ◆ P.O.BOX 667, Pretoria, South Africa, 0001 ◆ Tel:(012)3541330 ◆
◆ Fax: (012)3541367 / 0866515924 ◆ E-Mail: manda@med.up.ac.za ◆ Web: //www.healthethics-up.co.za ◆

APPENDIX B: Permission to conduct the study (Limpopo Provincial Department of Health)



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Enquiries: Ramalivhana NJ/Malomane EL

Ref: 4/2/2

3 March, 2010

Mr. D Mathey
Department of Physiotherapy
School of Health Care Sciences
University of Pretoria
Pretoria
0001

Dear Mr. D Mathey

"Development of a model for the (re)habilitation of children with disabilities in the Greater Giyani region, Limpopo Province"

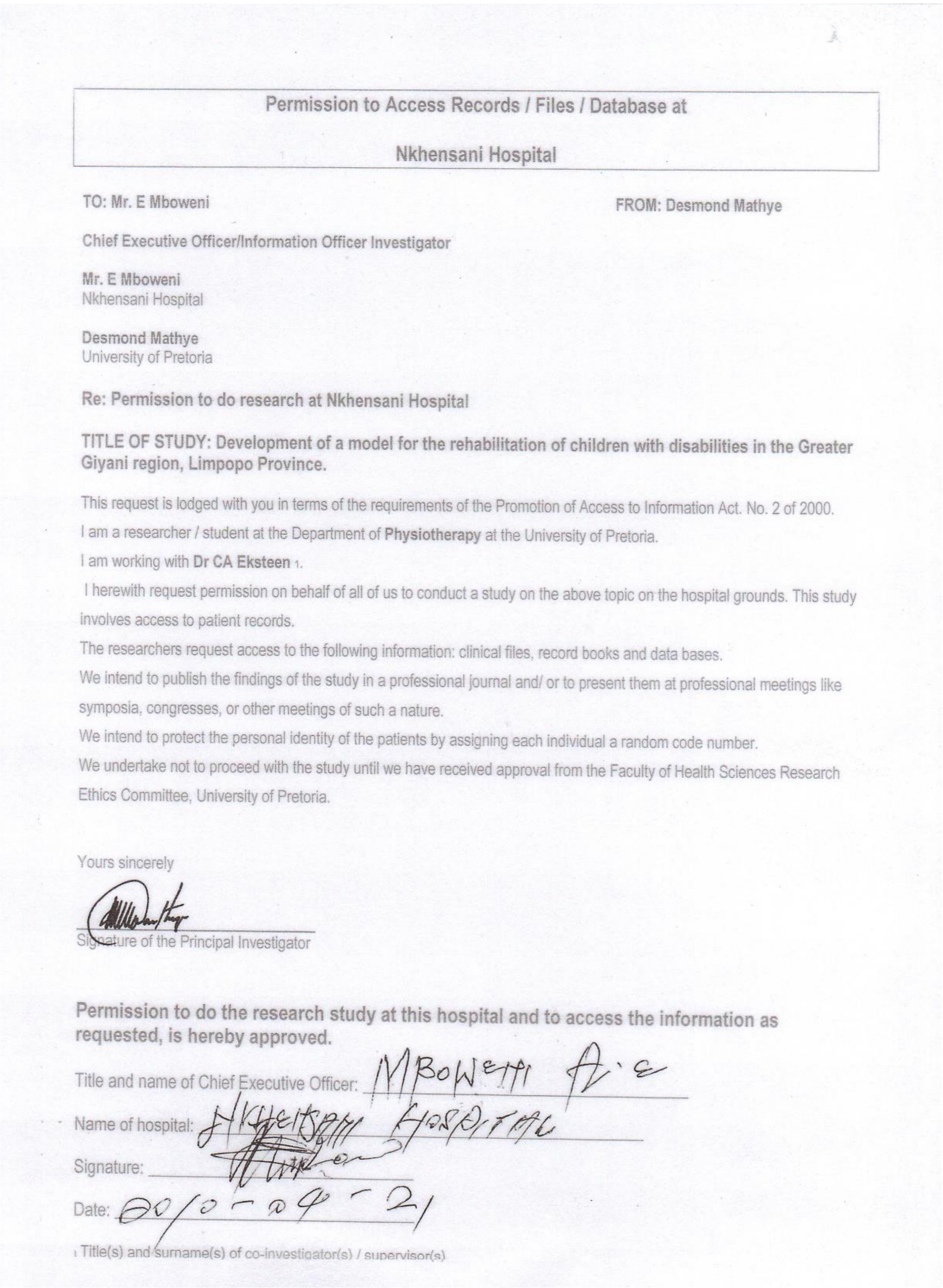
Permission is hereby granted to Mr D Mathey to conduct a study as mentioned above in Limpopo Province, South Africa

- The Department of Health and Social Development will expect a copy of the completed research for its own resource centre after completion of the study.
- The researcher is expected to avoid disrupting services in the course of his study
- The research results must be used only for the purpose of the study
- The Researcher/s should be prepared to assist in interpretation and implementation of the recommendations where possible
- The Institution management where the study is being conducted should be made aware of this,
- A copy of the permission letter can be forwarded to Management of the Institutions concerned

HEAD OF DEPARTMENT
HEALTH AND SOCIAL DEVELOPMENT
LIMPOPO PROVINCE

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

APPENDIX C: Permission to conduct the study (CEO: Nkhensani Hospital)



Permission to Access Records / Files / Database at

Nkhensani Hospital

TO: Mr. E Mboweni **FROM: Desmond Mathye**

Chief Executive Officer/Information Officer Investigator

Mr. E Mboweni
Nkhensani Hospital

Desmond Mathye
University of Pretoria

Re: Permission to do research at Nkhensani Hospital

TITLE OF STUDY: Development of a model for the rehabilitation of children with disabilities in the Greater Giyani region, Limpopo Province.

This request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a researcher / student at the Department of **Physiotherapy** at the University of Pretoria.

I am working with **Dr CA Eksteen** [1].

I herewith request permission on behalf of all of us to conduct a study on the above topic on the hospital grounds. This study involves access to patient records.

The researchers request access to the following information: clinical files, record books and data bases.

We intend to publish the findings of the study in a professional journal and/ or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the patients by assigning each individual a random code number.

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

Signature of the Principal Investigator

Permission to do the research study at this hospital and to access the information as requested, is hereby approved.

Title and name of Chief Executive Officer: MBOWENI A.E

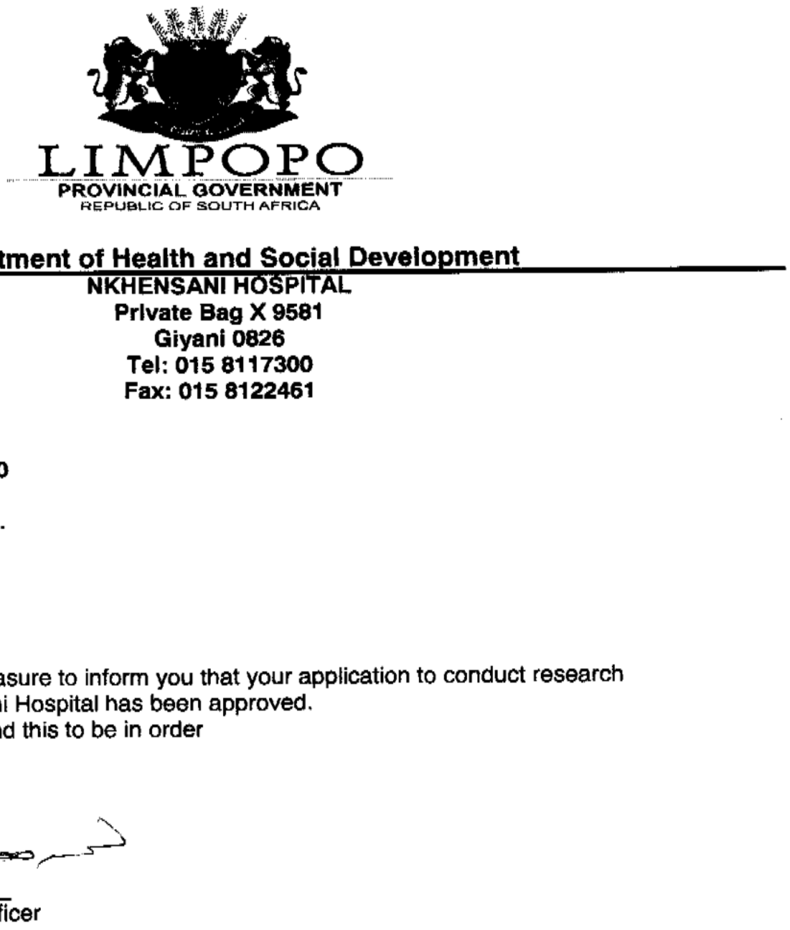
Name of hospital: NKHENSANI HOSPITAL

Signature:

Date: 2010-04-21

[1] Title(s) and surname(s) of co-investigator(s) / supervisor(s)

APPENDIX D: Permission to conduct the study (Deputy Manager Clinical Support: Nkhensani Hospital)



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health and Social Development
NKHENSANI HOSPITAL
Private Bag X 9581
Giyani 0826
Tel: 015 8117300
Fax: 015 8122461

Date: 20 April 2010

Enq.: Shilumani R.

To: Mathye D

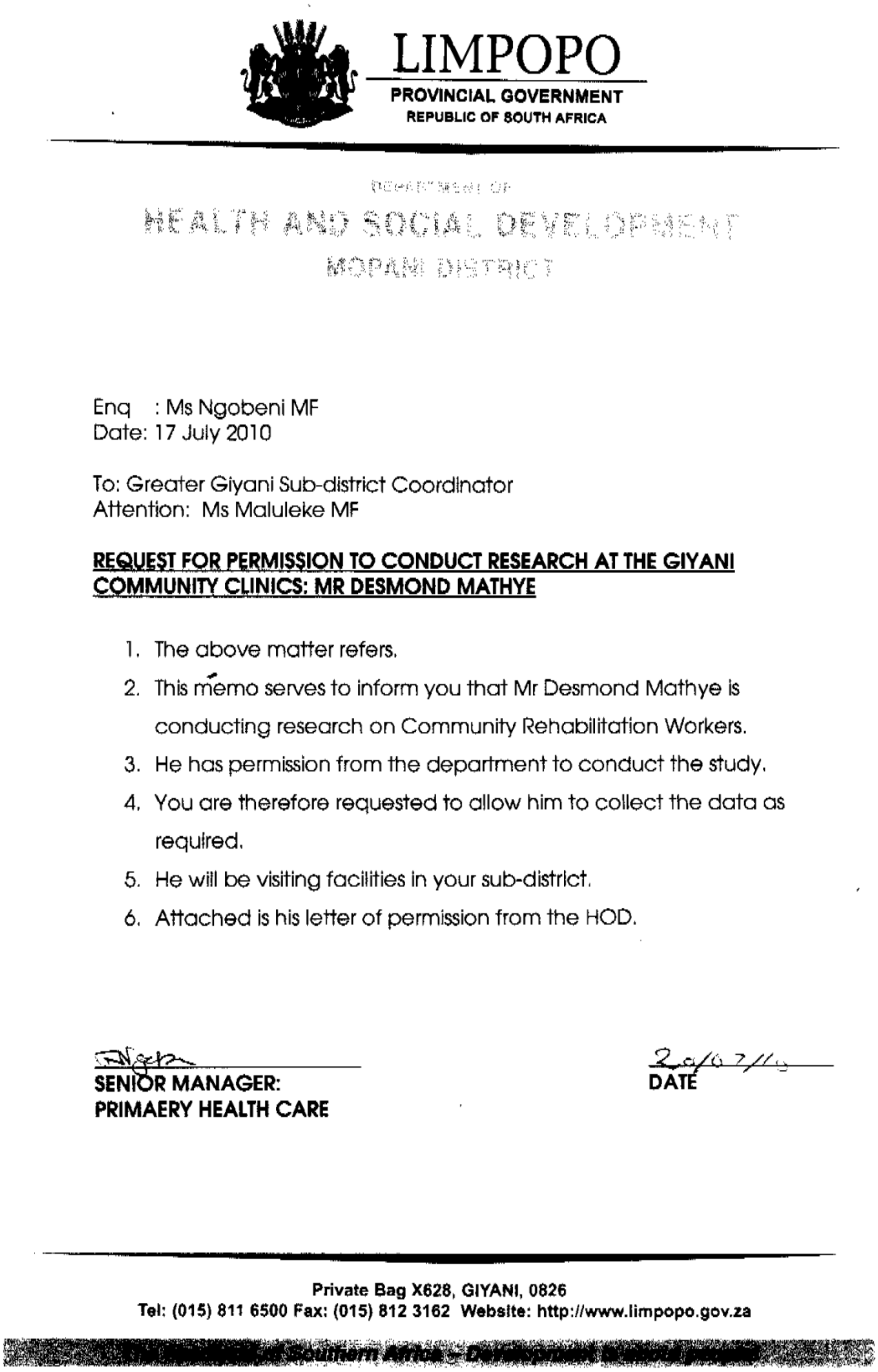
Re: Research

1. It is with pleasure to inform you that your application to conduct research at Nkhensani Hospital has been approved.
2. Hope you find this to be in order

Regards

Chief Executive Officer

APPENDIX E: Permission to conduct the study (PHC Senior Manager: Mopani District)



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF
HEALTH AND SOCIAL DEVELOPMENT
MOPANI DISTRICT

Enq : Ms Ngobeni MF
Date: 17 July 2010

To: Greater Giyani Sub-district Coordinator
Attention: Ms Maluleke MF

REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT THE GIYANI COMMUNITY CLINICS: MR DESMOND MATHYE

1. The above matter refers.
2. This memo serves to inform you that Mr Desmond Mathye is conducting research on Community Rehabilitation Workers.
3. He has permission from the department to conduct the study.
4. You are therefore requested to allow him to collect the data as required.
5. He will be visiting facilities in your sub-district.
6. Attached is his letter of permission from the HOD.

SENIOR MANAGER:
PRIMAERY HEALTH CARE

20/07/10
DATE

Private Bag X628, GIYANI, 0826
Tel: (015) 811 6500 Fax: (015) 812 3162 Website: http://www.limpopo.gov.za

[illegible] Southern Africa – Development [illegible]

APPENDIX F: Caregivers’ information leaflet and informed consent form

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

A: INFORMATION LEAFLET

Development of a Model for the rehabilitation of children with disabilities in the Greater Giyani Municipality in Limpopo Province, South Africa

Dear Participant

1) Introduction

My name is Desmond Mathye and I am a doctoral (PhD) student in the Department of Physiotherapy at the University of Pretoria. You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) The nature and purpose of this study

Families of children with disabilities in rural areas face many challenges when seeking treatment for their children. Health-care workers are not sure on how to best address the needs of children with disabilities considering the limited resources in rural communities. The main aim of this study is to develop a guide that will be used by health-care workers on how to best address the health-care needs of children with disabilities in rural communities.

In order to address the problem mentioned above, the following should be done first:

a) Identify and describe the role that you as a caregiver of a child living with disability play during the rehabilitation/treatment of the child.
b) Identify and describe services that are available in the Greater Giyani area for children with disabilities and their caregivers.
c) Identify and describe how CRW’s impacts on the lives of children with disabilities and their caregivers in Giyani.
d) Identify and describe challenges or barriers that caregivers are faced with in their attempt to access (re)habilitation services for their children with disabilities in the hospital and the community.
e) Describe caregiver’s expectations and satisfaction with the available services for children with disabilities in the Greater Giyani area.
f) Describe the way in which caregivers are coping with regard to meeting the needs of their children with disabilities.

3) Explanation of procedures to be followed

I would like you to participate in an interview where you will be asked questions with regard to you, the child you brought to the hospital and the services you received. The first interview will be conducted in the hospital where you bring the child for treatment. This interview will be scheduled to last for about 30-45 minutes. The second interview will be conducted where you and the child reside on condition that: (a) you agree to be interviewed at home, and (b) the head of your family or spouse agrees that you can be interviewed at home. Should we not get enough information during the second interview, we will schedule other interviews until we get enough information.

4) Risk and discomfort involved.

There is no risk and discomfort involved when participating in this study.

5) Possible benefits of this study.

The study has no therapeutic benefits but the outcome can be used in improving the quality of services that physiotherapist, occupational therapist and other therapists working in rehabilitation centres are offering to the children with disabilities and their families

6) Your rights as participant

Your participation in this study is voluntary. You can refuse to participate or stop at any time without giving reason and this will not affect the quality of treatment that you receive in the hospital.

7) Has the study received ethical approval?

This research study was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki which deals with the recommendations guiding doctors and other health professionals in research involving human subjects. A copy of the Declaration may be obtained from me should you wish to review it.

8) Information

If you have any questions concerning this study, you should contact Desmond Mathye on 073 489 0911(C) or 015 812 4057 (H).

9) Confidentiality

All records obtained whilst in this study will be regarded as confidential. The results of this study will be published or presented in such a fashion that you and the child remain unidentifiable.

B: INFORMED CONSENT FORMS

Written informed consent form

I can confirm that I have read or the researcher and associates had read to me in a language that I understand the nature, process, risks, discomforts and benefits of the study before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

……………………………………....	……………………………
Participant's signature	Date
....	....
Person obtaining informed consent	Date
……………………………………….	………………..............
Witness	Date

Verbal informed consent form

I, the undersigned have read and have explained fully to the participant, named below the participant information leaflet, which has indicated the nature and purpose of the study in which I have asked the participant to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The patient indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without any consequences.
I hereby certify that the patient has agreed to participate in this study.

…………………………………….
Participant's Name (print)

…………………………………….
Investigator's Name print)

…………………………………….	……………………………..
Investigator's Signature	Date
…………………………………….	……………………………...
Witness's Name & Signature	Date

APPENDIX G: Rehabilitation professionals' information leaflet and informed consent form

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

A: INFORMATION LEAFLET

Development of a Model for the rehabilitation of children with disabilities in the Greater Giyani Municipality in Limpopo Province, South Africa

Dear Participant

1) Introduction

My name is Desmond Mathye and I am a doctoral (PhD) student in the Department of Physiotherapy at the University of Pretoria. You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) The nature and purpose of this study

Families of children with disabilities in rural areas face many challenges when seeking treatment for their children. Health-care workers are not sure on how to best address the needs of children with disabilities considering the limited resources in rural communities. The main aim of this study is to develop a guide that will be used by health-care workers on how to best address the health-care needs of children with disabilities in rural communities.

In order to address the problem mentioned above, the following should be done first:

a) Identify and describe the role of caregivers of children with disabilities during the rehabilitation process as perceived by the rehabilitation professionals.
b) Identify and describe services that are available in the Greater Giyani area for children with disabilities and their caregivers.
c) Identify and describe the knowledge, skills, competencies and experience of therapists working in a rural hospital's rehabilitation clinic for children with disabilities.
d) Identify and describe factors that affect or influence therapist's commitment to the rehabilitation clinic.

3) Explanation of procedures to be followed

I would like you to participate in an interview where you will be asked questions with regard to the above listed questions. This interview will be scheduled to last for about 30-45 minutes. Should we not get enough information during the first interview, we will schedule other interviews until we get enough information.

4) Risk and discomfort involved.

There is no risk and discomfort involved when participating in this study.

5) Possible benefits of this study.

The study has no therapeutic benefits but the outcome can be used in improving the quality of services that physiotherapist, occupational therapist and other therapists working in rehabilitation centres are offering to the children with disabilities and their families

6) Your rights as participant

Your participation in this study is voluntary. You can refuse to participate or stop at any time without giving reason and this will not affect you in any way.

7) Has the study received ethical approval?

This research study was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki which deals with the recommendations guiding doctors and other health professionals in research involving human subjects. A copy of the Declaration may be obtained from me should you wish to review it.

8) Information

If you have any questions concerning this study, you should contact Desmond Mathye on 073 489 0911(C) or 015 812 4057 (H).

9) Confidentiality

All records obtained whilst in this study will be regarded as confidential. The results of this study will be published or presented in such a fashion that you and the child remain unidentifiable.

B: INFORMED CONSENT FORMS

Written informed consent form

I can confirm that I have read or the researcher and associates had read to me in a language that I understand the nature, process, risks, discomforts and benefits of the study before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

……………………………………....	……………………………
Participant's signature	Date
....	....
Person obtaining informed consent	Date
……………………………………….	………………................
Witness	Date

APPENDIX H: Community rehabilitation workers’ information leaflet and informed consent form

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

A: INFORMATION LEAFLET

Development of a Model for the rehabilitation of children with disabilities in the Greater Giyani Municipality in Limpopo Province, South Africa

Dear Participant

1) Introduction

My name is Desmond Mathye and I am a doctoral (PhD) student in the Department of Physiotherapy at the University of Pretoria. You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) The nature and purpose of this study

Families of children with disabilities in rural areas face many challenges when seeking treatment for their children. Health-care workers are not sure on how to best address the needs of children with disabilities considering the limited resources in rural communities. The main aim of this study is to develop a guide that will be used by health-care workers on how to best address the health-care needs of children with disabilities in rural communities.

In order to address the problem mentioned above, the following should be done first:

a) Identify and describe the role of caregivers of children with disabilities during the rehabilitation process as perceived by community rehabilitation workers.
b) Identify and describe the role of community rehabilitation workers in the rehabilitation of children with disabilities.
c) Identify and describe the role of rehabilitation professionals during the rehabilitation process of children with disabilities.

3) Explanation of procedures to be followed

I would like you to participate in an interview where you will be asked questions with regard to the above listed questions. This interview will be scheduled to last for about 30-45 minutes. Should we not get enough information during the first interview, we will schedule other interviews until we get enough information.

4) Risk and discomfort involved.

There is no risk and discomfort involved when participating in this study.

5) Possible benefits of this study.

The study has no therapeutic benefits but the outcome can be used in improving the quality of services that physiotherapist, occupational therapist and other therapists working in rehabilitation centres are offering to the children with disabilities and their families

6) Your rights as participant

Your participation in this study is voluntary. You can refuse to participate or stop at any time without giving reason and this will not affect you in any way.

7) Has the study received ethical approval?

This research study was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki which deals with the recommendations guiding doctors and other health professionals in research involving human subjects. A copy of the Declaration may be obtained from me should you wish to review it.

8) Information

If you have any questions concerning this study, you should contact Desmond Mathye on 073 489 0911(C) or 015 812 4057 (H).

9) Confidentiality

All records obtained whilst in this study will be regarded as confidential. The results of this study will be published or presented in such a fashion that you and the child remain unidentifiable.

B: INFORMED CONSENT FORMS

Written informed consent form

I can confirm that I have read or the researcher and associates had read to me in a language that I understand the nature, process, risks, discomforts and benefits of the study before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

…………………………………....	……………………………
Participant's signature	Date
....	....
Person obtaining informed consent	Date
…………………………………….	………………................
Witness	Date

APPENDIX I: Interview guiding questions for caregivers

- What can you tell me about this child?
- What is your role as a caregiver during the rehabilitation of the child?
- What are the available services for children with disabilities and caregivers in Giyani?
- What are the challenges that you experience as you try to seek rehabilitation for the child?
- What can you tell me about the role of community rehabilitation workers?
- How is your general level of satisfaction about health-care services that you have received?
- What are your expectations from the available services?
- How do you cope with the pressures of having a CWD?
- What are your sources of support?
- How are you and the child perceived in the community?

APPENDIX J: Letter of confidentiality

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

I, …………………………………………………………have been appointed as a research assistant (transcriber) by Desmond Mathye, do swear that I will not directly or indirectly communicate or reveal to any person any matter which I have seen or heard while exercising my duties as a research assistant.

……………………………………………………. ……………………………………….
Signature of the research assistant Date

…………………………………………………….. ………………………………………..
Signature of the researcher Date

…………………………………………………….. ……………………………………….
Witness Date

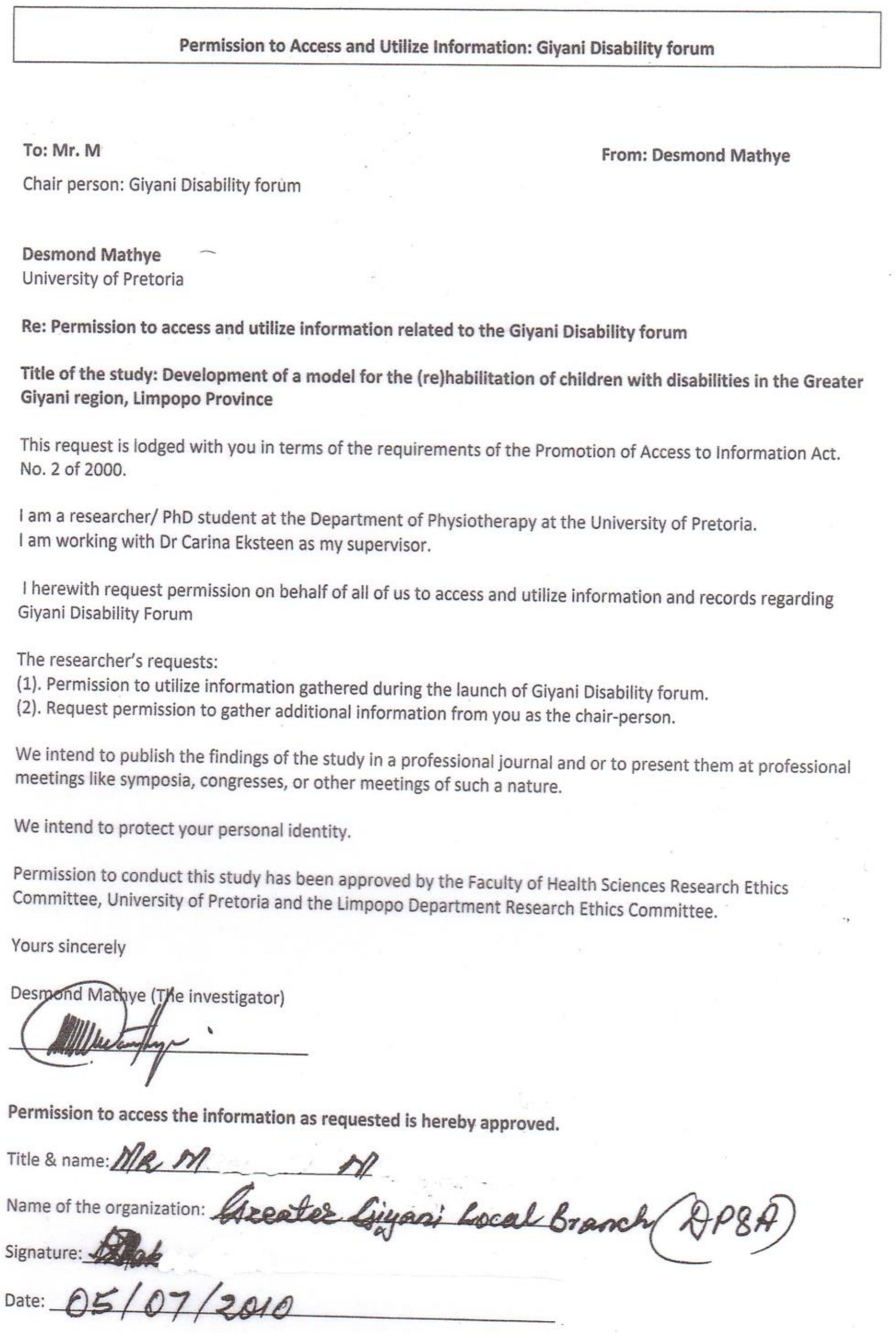
APPENDIX K: Interview guiding questions for rehabilitation professionals

- What is the role of caregivers during the rehabilitation of children with disabilities?
- What services are available for children with disabilities and their caregivers in Giyani?
- What are the challenges that caregivers and children with disabilities experience?
- What is your role as a rehabilitation professional during the rehabilitation of children with disability?
- What are the competencies of the rehabilitation professionals working in the rehabilitation clinic?
- What are the factors that affect or influence your commitment to your work in the clinic?

APPENDIX L: Interview guiding questions for community rehabilitation workers

- What is the role of caregivers during the rehabilitation of children with disabilities?
- What is the role of CRWs during the rehabilitation process of children with disabilities?
- What is the role of rehabilitation professionals during the rehabilitation process of children with disabilities?

APPENDIX M: Permission to access and utilise information: Giyani Disability Forum



Permission to Access and Utilize Information: Giyani Disability forum

To: Mr. M
Chair person: Giyani Disability forum

From: Desmond Mathye

Desmond Mathye
University of Pretoria

Re: Permission to access and utilize information related to the Giyani Disability forum

Title of the study: Development of a model for the (re)habilitation of children with disabilities in the Greater Giyani region, Limpopo Province

This request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a researcher/ PhD student at the Department of Physiotherapy at the University of Pretoria.
I am working with Dr Carina Eksteen as my supervisor.

I herewith request permission on behalf of all of us to access and utilize information and records regarding Giyani Disability Forum

The researcher's requests:
(1). Permission to utilize information gathered during the launch of Giyani Disability forum.
(2). Request permission to gather additional information from you as the chair-person.

We intend to publish the findings of the study in a professional journal and or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect your personal identity.

Permission to conduct this study has been approved by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and the Limpopo Department Research Ethics Committee.

Yours sincerely

Desmond Mathye (The investigator)

Permission to access the information as requested is hereby approved.

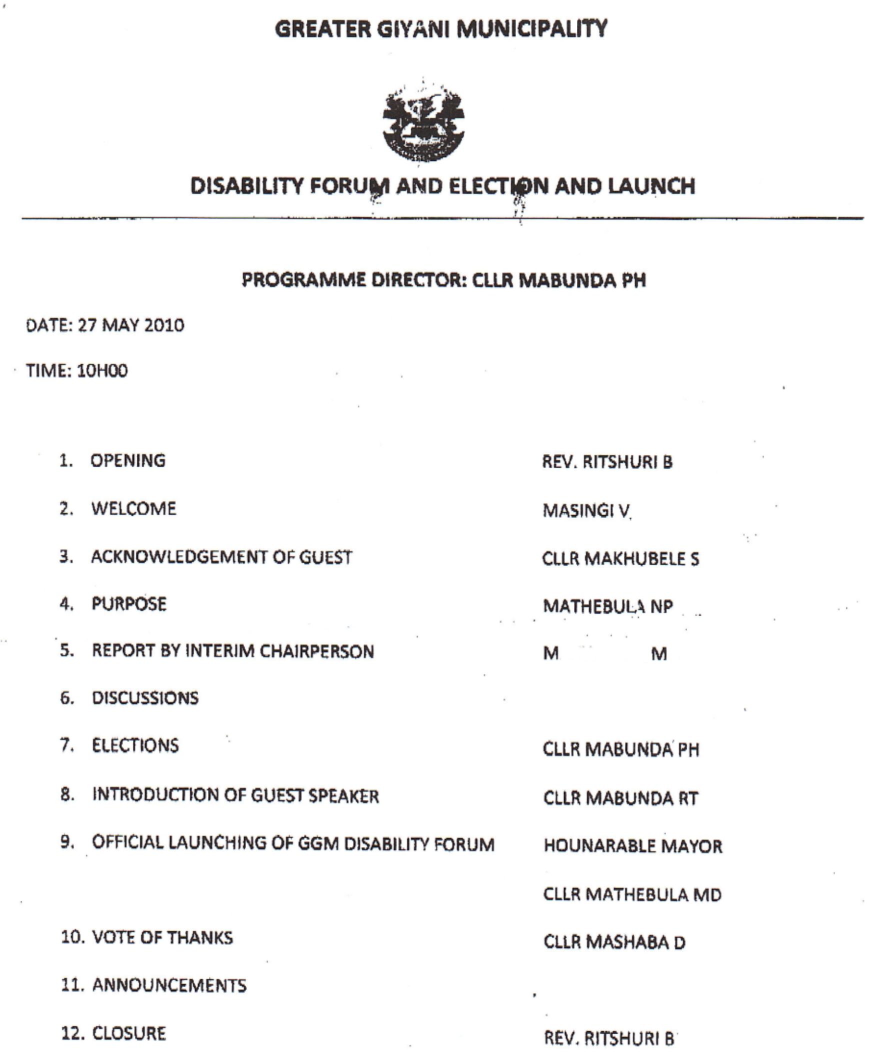
Title & name: Mr M ______ M

Name of the organization: Greater Giyani Local Branch (DPSA)

Signature:

Date: 05/07/2010

APPENDIX N: Programme of the launch of Greater Giyani Disability Forum



GREATER GIYANI MUNICIPALITY

DISABILITY FORUM AND ELECTION AND LAUNCH

PROGRAMME DIRECTOR: CLLR MABUNDA PH

DATE: 27 MAY 2010

TIME: 10H00

1. OPENING	REV. RITSHURI B
2. WELCOME	MASINGI V.
3. ACKNOWLEDGEMENT OF GUEST	CLLR MAKHUBELE S
4. PURPOSE	MATHEBULA NP
5. REPORT BY INTERIM CHAIRPERSON	M M
6. DISCUSSIONS	
7. ELECTIONS	CLLR MABUNDA PH
8. INTRODUCTION OF GUEST SPEAKER	CLLR MABUNDA RT
9. OFFICIAL LAUNCHING OF GGM DISABILITY FORUM	HOUNARABLE MAYOR CLLR MATHEBULA MD
10. VOTE OF THANKS	CLLR MASHABA D
11. ANNOUNCEMENTS	
12. CLOSURE	REV. RITSHURI B

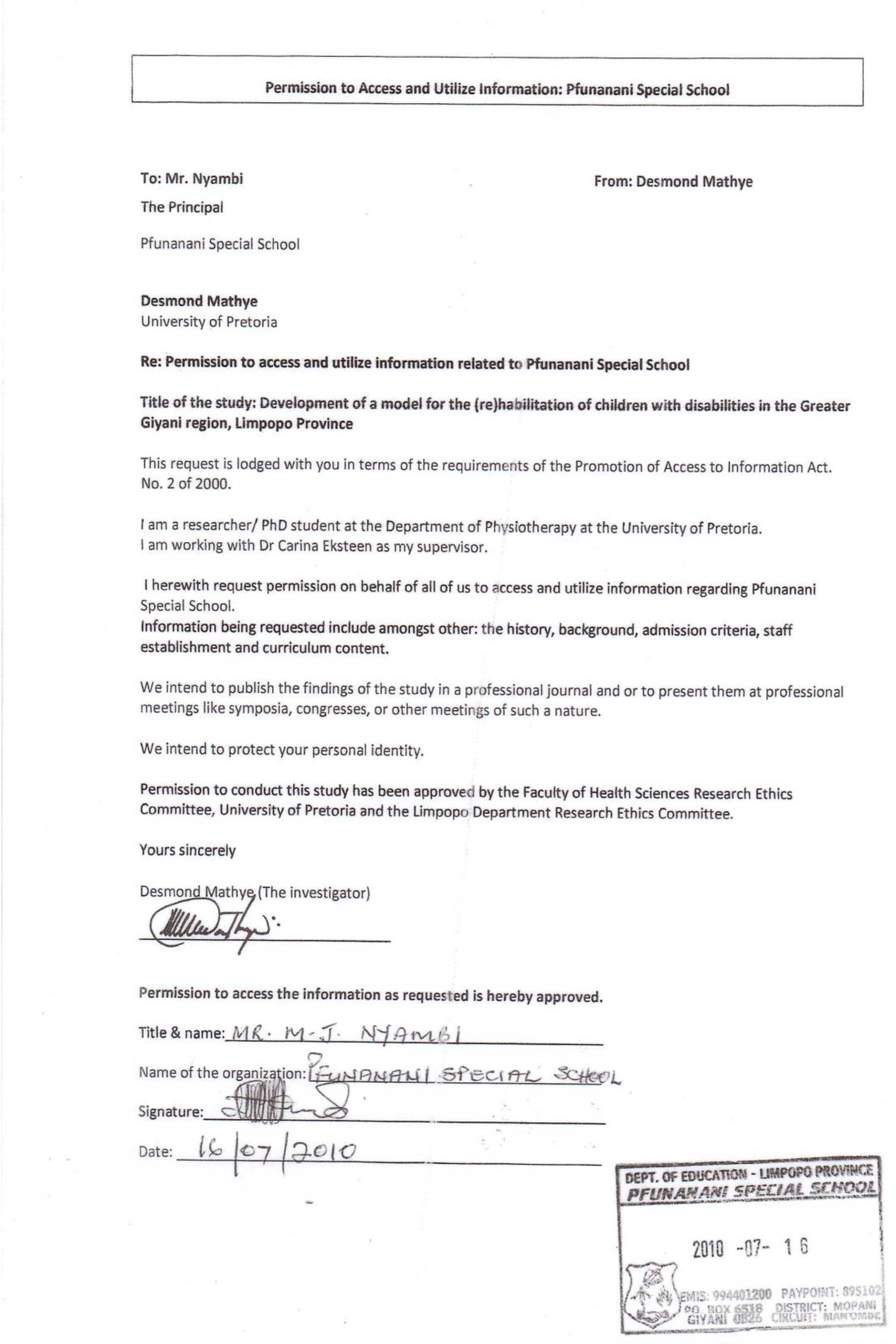
APPENDIX P: Focus group discussion guiding questions for caregivers

- What can you tell me about this child?
- What is the role of caregivers during the rehabilitation of children with disabilities?
- What are the available services for children with disabilities and their caregivers in Giyani?
- What are the challenges that you experience as you to seek rehabilitation for the child?
- What can you tell me about the role of community rehabilitation workers?
- How is your general satisfaction with the health-care services you have received?
- What are your expectations from the available services?
- How do you cope with the pressures of having a child with disabilities?
- What are your sources of support?
- How are you and the child perceived in the community?

APPENDIX Q: Focus group discussion guiding questions for rehabilitation professionals

- What do you know about the genetic clinic?
- What are the challenges that caregivers and children with disabilities experience?
- What is your plan of action to correct the challenges that you have identified?

APPENDIX R: Permission to conduct the study (Principal: Pfunanani Special School)



Permission to Access and Utilize Information: Pfunanani Special School

To: Mr. Nyambi
The Principal
Pfunanani Special School

From: Desmond Mathye

Desmond Mathye
University of Pretoria

Re: Permission to access and utilize information related to Pfunanani Special School

Title of the study: Development of a model for the (re)habilitation of children with disabilities in the Greater Giyani region, Limpopo Province

This request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a researcher/ PhD student at the Department of Physiotherapy at the University of Pretoria.
I am working with Dr Carina Eksteen as my supervisor.

I herewith request permission on behalf of all of us to access and utilize information regarding Pfunanani Special School.
Information being requested include amongst other: the history, background, admission criteria, staff establishment and curriculum content.

We intend to publish the findings of the study in a professional journal and or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect your personal identity.

Permission to conduct this study has been approved by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and the Limpopo Department Research Ethics Committee.

Yours sincerely

Desmond Mathye (The investigator)

Permission to access the information as requested is hereby approved.

Title & name: MR. M.J. NYAMBI
Name of the organization: PFUNANANI SPECIAL SCHOOL
Signature:
Date: 16/07/2010

DEPT. OF EDUCATION - LIMPOPO PROVINCE
PFUNANANI SPECIAL SCHOOL
2010 -07- 16
EMIS: 994401200 PAYPOINT: 895102
PO. BOX 6518 DISTRICT: MOPANI
GIYANI 0826 CIRCUIT: MANOMBE

APPENDIX S: Demographic data collection sheet for caregivers

CAREGIVERS' DETAILS

Name ……………………………………………………………………………

Gender ……………………………………………………………………………

Date of birth ……………………………………………………………………………

Age ……………………………………………………………………………

Contact number ……………………………………………………………………………

Relationship with the child ……………………………………………………………………………

Number of dependents (including the CWDs) ……………………………………………………………

Marital status ……………………………………………………………………………

Educational background ……………………………………………………………………………

Employment status ……………………………………………………………………………

Electricity ……………………………………………………………………………

Water ……………………………………………………………………………

Sanitation/toilet ……………………………………………………………………………

Nearest health-care facility ……………………………………………………………………………

CHILD'S DETAILS

Name ……………………………………………………………………………

Gender ……………………………………………………………………………

Date of birth ……………………………………………………………………………

Age ……………………………………………………………………………

Diagnosis ……………………………………………………………………………

APPENDIX T: Demographic data collection sheet for rehabilitation professionals

PERSONAL DETAILS

Name ……………………………………………………………………………………

Gender ……………………………………………………………………………………..

Age ……………………………………………………………………………………..

PROFESSIONAL BACKGROUND

Profession ……………………………………………………………………………………..

Rank ……………………………………………………………………………………..

Qualification ……………………………………………………………………………

Training institution ……………………………………………………………………………………..

Experience (years) ……………………………………………………………………………