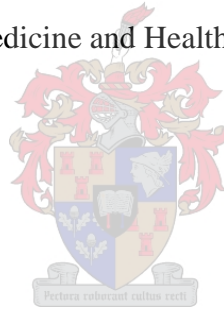


# **Disability and health care access in an isolated quarter of the Karoo**

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Dissertation presented for the degree of Doctor of Philosophy (Health Sciences  
Rehabilitation) in the Faculty of Medicine and Health Sciences at Stellenbosch University



Promoter: Dr L. Swartz

March 2015

## **Declaration**

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## Abstract

**Introduction:** High quality comprehensive health care services contribute to community integration and participation of persons with disability. However, persons with disabilities often experience barriers with regard to health care access. Neither these barriers nor the concept of disability have been sufficiently explored in rural Global South settings. This study describes the experience of living with a disability in a remote, rural setting with a specific focus on barriers and facilitators to health care access.

**Method:** A qualitative design utilising case study methodology and interpretative phenomenological analysis was used. The study population consisted of 283 persons with moderate or severe activity limitations, who lived in a rural town in the Northern Cape Province of South Africa. Eight of them were purposively sampled as anchor participants in eight case studies. Their significant others completed each case study. In addition data were collected from six service providers to the study community. Data were collected through 19 in-depth interviews and one focus group discussion, between March and October 2012. The principles of interpretative phenomenological analysis were used to analyse data and identify themes. Similar themes were clustered under superordinate themes. Cases were analysed separately after which patterns across cases were identified.

**Results:** Participants conceptualised disability as an individual problem according to the moral or medical approaches and often interpreted disability as physical in nature. Participants' level of participation and community integration varied from very little to being employed and well integrated. Self-belief and the attitude and support of significant others, community members and employers played an important role in the level of participation persons with disability achieved.

Participants' primarily utilised public, formal, health care services. These services were found to be mainly curative and preventative in nature. The provision of health promotion and rehabilitation were lacking. Users were not empowered to take control of their own health management and were not included in the health care team. Health system barriers identified included insufficient human and material resources, communication challenges,

and rigid protocols. The remoteness of the setting hampered health care service delivery. Free health care provision, high quality services at tertiary level, and outreach services to the community were identified as facilitators. A lack of products and technology, poverty, and low levels of education created further barriers to community integration and health care access.

**Implications:** Suboptimal health care together with personal and environmental barriers might have resulted in poor health, functional, community integration, and participation outcomes for participants. Health care was provided reactively to individual users and not according to the principles of primary health care. The little rehabilitation that was provided was not enough to ensure improved functioning or community integration and participation.

**Recommendations:** Since this was an inductive study with few participants recommendations centre on hypotheses for further study. The focus of these theories is on ways to provide health care according to the philosophy of primary health care and on introducing specific rehabilitation programmes in the community.

**Key terms:**

Disability, Health care access, rural

## Abstrak

**Inleiding:** Persone met gestremdhede mag omvattende gesondheidsorg van hoë gehalte benodig om gemeenskapsintegrasie te verseker. Ongelukkig ervaar hulle meermale probleme met toegang tot gesondheidsorg. Kennis oor die aard van hierdie probleme asook in verband met die ervaring van gestremdheid in die globale suide is onvoldoende. Hierdie studie het ten doel om vas te stel hoe persone met gestremdhede in 'n afgeleë, landelike omgewing die konsep van 'gestremdheid' ervaar en watter faktore toegang tot gesondheidsorg beïnvloed.

**Metodes:** Hierdie kwalitatiewe studie het gebruik gemaak van gevallestudies en interpreterende fenomenologiese analise. Die studiepopulasie het bestaan uit 283 individue met matige of ernstige aktiwiteitsbeperkings wat woonagtig was in 'n landelike dorp in die Noord Kaap provinsie van Suid Afrika. Ag van hulle is doelbewus geselekteer as anker deelnemers in ag gevallestudies. Persone wat 'n belangrike rol in die lewe van hierdie deelnemers gespeel het, het elke gevallestudie voltooi. Verdere data is ingesamel deur onderhoude met ses diensverskaffers. Data is tussen Maart en Oktober 2012, deur middel van 19 in diepte onderhoude en een fokusgroep bespreking ingesamel. Die beginsels van interpreterende fenomenologiese analise is gebruik om temas uit die data te identifiseer. Soortgelyke temas is saam gevoeg onder 'n beskrywende tema. Data van elke gevallestudie is eers afsonderlik geanaliseer waarna patrone tussen gevalle geïdentifiseer is.

**Resultate:** Deelnemers het gestremdheid as 'n individuele probleem beskou, dit uit 'n morele of mediese hoek benader, en dikwels as fisies van aard vertolk. Sommige deelnemers was geïntegreer in die gemeenskap en het gewerk. Andere daarenteen was glad nie geïntegreer nie. Die resultate dui daarop dat 'n geloof in eiewaarde en die houding van familie, die gemeenskap en werkgewers 'n belangrike rol gespeel het in suksesvolle gemeenskapsintegrasie en werk.

Deelnemers het meestal van staatsgesubsidieerde, formele, gesondheidsorg gebruik gemaak. Hulle het hoofsaaklik voorkomende en genesende dienste ontvang. Die bevordering van gesondheid en rehabilitasie dienste was onvoldoende. Deelnemers was nie bemagtig om beheer oor hulle eie gesondheid te neem nie en was nie ingesluit in die gesondheidsorgspan nie. Toegang tot gesondheidsorg is belemmer deur 'n tekort aan menslike en materiële hulpbronne, kommunikasie probleme en rigiede protokolle. Die afgesonderdheid van die

area het gesondheidsorg verder nadelig beïnvloed. Gemeenskapsintegrasie en toegang tot gesondheidsorg is ook bemoeilik deur `n tekort aan tegnologie en produkte, armoede en beperkte formele skool opleiding. Gratis voorsiening van gesondheidsorg, dienste van hoë gehalte op tersiêre vlak en uitreikdienste na die gemeenskap het toegang tot gesondheidsorg bevorder.

**Implikasies:** Sub optimale gesondheidsorg tesame met persoonlike en omgewingsbeperkinge het moontlik daartoe bygedra dat deelnemers nie optimale vlakke van gesondheid, funksie, en gemeenskapsintegrasie bereik het nie. Gesondheidsorg is reaktief aan individuele gebruikers voorsien in plaas van volgens die beginsels van primêre gesondheidsorg. Die rehabilitasie wat gedoen is, was te min om verbetering in funksie en gemeenskapsintegrasie te verseker.

**Aanbevelings:** Dit was `n induktiewe studie met min deelnemers. Daarom fokus die aanbevelings op die ontwikkeling van hipotesisse vir verdere studie. Hierdie hipotesisse hou meestal verband met die verwesenliking van die filosofie van primêre gesondheidsorg en die ontwikkeling van rehabilitasie programme in die studie gemeenskap.

# **Disability and health care access in an isolated quarter of the Karoo**

The experience of Disability and Health Care Access as portrayed by case studies in a remote South African setting

## **Dedication**

I dedicate this work to Brenda whose story has come to epitomise for me the experience of disability and health care access in the community of Fraserburg.

## Acknowledgments

- God Almighty  
Lord, I praise you for your blessings in my life, for each of the people mentioned below and for providing me with the ability and opportunity to carry out this study.
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## **Glossary of Terms**

### **Acceptability**

The extent to which health care systems match the social and cultural needs of users (Gilson & Schneider, 2008).

### **Activity limitations**

“...are difficulties an individual may have in executing tasks” (WHO, 2001. p. 10).

### **Affordability**

“Degree of fit between the cost of health care and individual’s ability to pay” (Gilson & Schneider, 2008. p. 028).

### **Availability**

An available service delivers appropriate assistance at the right time and place (Gilson & Schneider, 2008).

### **Community Based Rehabilitation**

. . . a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services. To ensure that people with disabilities are able to maximize their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large. To activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation. (WHO, 2004. p. 2-3)

## **Community integration**

Community integration is multidimensional and includes three common features, i.e., social activities and relationships, residential integration and productive activity (Parvaneh & Cocks, 2012; Sander, Clark & Pappadis, 2010).

## **Curative care**

. . . can be defined as the identification, assessment and treatment of health conditions and/or resulting impairments. Medical care can: provide a cure (e.g., treatment of leprosy or malaria), reduce the impact (e.g., treatment of epilepsy), and prevent avoidable impairments (e.g., treatment of diabetes to prevent blindness). (WHO, 2010a. p. 33)

## **Disability**

Disability “serves as an umbrella term for impairments, activity limitations or participation restrictions” (WHO, 2001. p. 3).

## **Equity in health**

Equity in health implies an unbiased, accountable service that addresses the needs of all members of society and provides everyone with a fair opportunity to attain their full health potential (Balarajan, Selvaraj, & Subramanian, 2011).

## **Environmental factors**

“. . . make up the physical, social and attitudinal environment in which people live” (WHO, 2001, p. 10).

## **Formal health care**

Health care services regulated by Governments (Kleinman, 1980).

## **Global South**

The [Global] South . . . is denoted here as a space that exists not only physically but also ontologically as something separate to the Global North. This is space where the bulk of the world's population resides, and where poverty is largely concentrated.

The term clearly delineates a divide with the Global North, and hence with rich and powerful countries, where wealth is largely concentrated and controlled, and which exert influence and power over the South, a power that is a function of and manifest in history (e.g. in colonial appropriations), ideologies, economics and politics among others. The term does not refer only to geography, but economic, political and social disadvantage and disparities, with the implication that the existence of a poor Global South is reflected in and maintained by the existence of the rich North and vice-versa. (Goodley, Hughes, & Davis, 2012. p. 324)

## **Health**

Health “is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity” (Alma-Ata Declaration, 1987. p. 1).

## **Health care access**

Access in the current study refers to both opportunity to use and actual use of health care services, since in the words of Donabedian (1972): “The proof of access is use of service, not simply the presence of a facility” (p. 111).

## **Health promotion**

Health promotion focuses on addressing those determinants of health that can potentially be modified, such as individual health behaviours and lifestyles, income and social status, education, employment and working conditions, access to appropriate health services and the physical environment. Health promotion does not require expensive drugs or elaborate technology; instead it uses social interventions, which, at the most basic level, require a personal investment of time and energy. (WHO, 2010a. p. 10)

## **Impairments**

“...are problems in the physiological functions of anatomical parts of the body such as organs, limbs and their components” (WHO, 2001. p. 10).

## **Participation**

“...involvement in life situations” (WHO, 2001. p. 10).

## **Participation restrictions**

“Problems an individual might experience in involvement in life situations” (WHO, 2001. p. 10).

## **Personal factors**

...are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health status. These factors may include gender, race, age . . . , lifestyle, coping styles, social background, education, profession, past and current experience . . . (WHO, 2001. p. 17)

## **Poverty**

For the purpose of this study poverty will be defined according to the basic needs approach i.e., “poverty is characterized by the deprivation of basic needs, including food, safe drinking water, sanitation facilities, health, shelter, education, and information.” (Palmer, 2011. p. 211).

## **Primary prevention**

“...interventions aimed at healthy individuals or groups in order to reduce the [incidence of health conditions]. Measures taken to promote optimum health or provide specific protection of target groups against disease and injury” (Katzenellenbogen & Hoffman, 2007. p. 18).

## **Primary Health Care (PHC)**

While Primary Health Care refers to a level of service delivery and entrance into the health care system the term as used in the study is more complex and refers to the philosophy of PHC as defined here:

...essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain. . . . It forms an integral part of the country's health system of which it is the central function and main focus, and of the social and economic development of the community. It is the first level of contact with individuals, the family and community . . . bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process. (Alma-Ata Declaration, 1978. p. VI)

## **Rehabilitation**

. . . a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning [in all walks of life] in interaction with their environments. . . . Typically rehabilitation occurs for a specific period of time . . . involve single or multiple interventions delivered by an individual or a team of rehabilitation workers . . . can be needed from the acute or initial phase immediately following recognition of a health condition through to post-acute and maintenance phases. (WHO, 2011. p. 96)

It includes all measures aimed at reducing the impact of disability at an individual and societal level and should enable the person to achieve social integration, participation, good quality of life and self-actualisation (DoH, 2000a; UN, 2006). In this dissertation rehabilitation refers to both “habilitation which aims to help those who acquire disabilities congenitally or early in life to develop maximal functioning; and rehabilitation, where those who have experienced a loss in function are assisted to regain maximal functioning” (WHO, 2011. p. 96).

### **Remote areas**

Characterised by: “. . . small populations dispersed over vast areas” (Wakerman et al., 2008)  
“. . . with relatively high health needs . . . a physical environment of climatic extremes. . . .”  
(Wakerman, 2004. p. 213).

### **Rural**

“. . . while the defining characteristic of rural health remains its geography . . . rural . . . is also sociologically, culturally, economically and spiritually different from metropolitan areas, as well as internally diverse” (Bourke et al., 2004. p. 181).

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## List of acronyms

CBR	Community Based Rehabilitation
CHCC	Community Health Care Centre
CP	Cerebral Palsy
DG	Disability Grant
DoH	Department of Health
DWCPD	Department of Women, Children and People with Disabilities
EquitAble	Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa
FAS	Foetal Alcohol Syndrome
HIV	Human Immunodeficiency Virus
HIV/AIDS	Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome
ICF	International Classification of Functioning, Disability and Health
IPA	Interpretative Phenomenological Analysis
MS	Multiple Sclerosis
PHC	Primary Health Care
RSA	Republic of South Africa
SCI	Spinal Cord Injury
Stats SA	Statistics South Africa
TB	Tuberculosis
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
USA	United States of America
WGQ	Washington Group Questions
WHO	World Health Organization
WHS	World Health Survey



# Chapter 1

## Introduction to the Study

### 1.1 Study Background

Community integration and equality of persons with disabilities are central to international and South African policy (DoH, 2000a; UN, 2006). Community integration of persons with disabilities is impacted by a variety of interrelated factors. Three of these, namely the conceptualisation of disability, health care access, and living in a rural area, were explored in this study, located in a rural South African context.

Disability is complex, heterogeneous and at its core a uniquely personal experience. It is influenced by impairments, personal attributes, life roles, the environment, religion, culture and societal perceptions. Thus the experience of disability may differ considerably over time as well as between and within countries, communities and individual people (Barile, 2003; Braithwaite & Mont, 2009; Grech, 2009, 2012; Iezzoni, 2000; Iezzoni, McCarthy, Davis, & Siebens, 2000; McKenzie, McConkey, & Adnams, 2013; Shakespeare, 2014; WHO, 2001, 2011). An understanding of these varying experiences is required to develop appropriate policy and services (Ingstad, 2007; Kalyanpur, 2011). According to Barile (2003) and Grech (2009, 2012) there is a lack of information on the experience of disability by persons with disabilities from rural Global South communities.

People living in rural Global South communities are often dependent on physical labour to ensure a livelihood. Thus access to high quality health care to address impairments which might impede physical ability is essential (Grech, 2009, 2012). However, persons with disabilities often experience challenges with regard to accessing health care both globally (Fouts, Andersen, & Hagglund, 2000; Gulley & Altman, 2008; Iezzoni, 2009; Iezzoni, Davis, Soukup, & O`Day, 2002; Iezzoni, Frakt, & Pizer, 2011; Iezzoni, Killeen, & O`Day, 2006; Iezzoni & Long-Bellil, 2012; Parish & Ellison-Martin, 2007; Parish & Huh, 2006; Shakespeare, 2012, 2014) and in Global South countries (Ahmad, 2013; Bateman, 2012; Eide, Loeb et al., 2011; Fisher & Shang, 2013; Grech, 2009, 2012; Grut, Mji, Braathen, & Ingstad, 2012; Maart & Jelsma, 2013; Mlenzana, Frantz, Rhoda, & Eide, 2013; Van Rooy et al., 2012). It is thus not surprising that Mannan and MacLachlan (2013) identified research

on barriers and facilitators to health care access for persons with disabilities as one of the key research challenges for disability and health. Health care access is influenced by multifaceted determinants such as policy, resources, user characteristics and the context (Gilson & Schneider, 2008; Levesque, Harris, & Russell, 2013; Obrist et al., 2007; Peters et al., 2008; UN, 2000).

Rural health care services are often of poorer quality and less accessible than urban services (Balarajan et al., 2011; Cooke, Couper, & Versteeg, 2011; Fisher & Shang, 2013; Gaede & Versteeg, 2011; Hossen & Westhues, 2011; Jian, Chan, Tang, & Reidpath, 2012; Kiadaliri, Najafi, & Haghparast-Bidgoli, 2011; Trani & Barbou-des-Courieres, 2012; Versteeg, Du Toit, & Couper, 2013) due to challenges like spatial isolation, poor infrastructure, underdevelopment, less training and employment opportunities, poverty, higher cost burden and fewer services (Bourke, Humphreys, Wakerman, & Taylor, 2012; Fitzgerald, Pearson, & McCutcheon, 2001; Gaede & Versteeg, 2011; Khan, Hotchkiss, Berruti, & Hutchinson, 2006; Leight 2003; Matsoso & Strachan, 2011; McPhedran, 2011; Mechanic & Tanner, 2007). Consequently the health status of people in rural communities is often poorer than that of their urban counterparts, and they often have more complex health care needs (Cooke et al., 2011; Lourenço, 2012; Russel et al., 2013; Turner-Goins, Williams, Carter, Spencer, & Solovieva, 2005).

Rural South Africans with disabilities experience bigger challenges to access services such as health care than persons with disabilities living in urban areas (Department of Women, Children and People with Disabilities (DWCPD), 2013; Schneider, Dasappa, Khan, & Khan, 2009). Furthermore rural areas are not homogenous, thus disability experiences and health care access may differ between various rural settings between and within countries (Fitzgerald et al., 2001; Hart, Larson, & Lishner, 2005; Lourenço, 2012; Philo, Parr, & Burns, 2003; Russel et al., 2013; Smith, Humphreys, & Wilson, 2008).

## **1.2 Problem Statement**

There is insufficient knowledge on the experience of disability and the perceptions of persons with disabilities regarding barriers and facilitators to health care access in isolated, rural South African settings.

### **1.3 Aim**

The aim of the study was to describe the experience of living with a disability in a remote, rural setting with a specific focus on barriers and facilitators to health care access.

### **1.4 Objectives**

- To explore participants'<sup>1</sup> experiences and conceptualization of disability.
- To describe participants' community integration and participation levels.
- To describe health care systems used by participants with a specific focus on formal health care systems.
- To explore the experiences and perceptions of participants with regard to access to formal health care services.
- To explore the impact of systems, context, community and personal barriers and facilitators on access to formal health care services for persons with disabilities in the setting.

### **1.5 Evolution of the Study**

I am a qualified physiotherapist, with a keen interest in disability and rehabilitation. I have worked clinically and academically in this field for three decades. In 2003 my family and I relocated to a sheep farm in the Fraserburg district in the Northern Cape Province of South Africa. While not actively practising as a physiotherapist I was often approached by members of the community with requests for treatment or advice. One such an encounter happened in 2008. A man whom I did not know approached me in the Fraserburg town library. He asked me whether I was “the woman who gives exercises”. When I affirmed this he introduced himself and asked if I would please come and assess his wife. I went to their home and learned that she had fallen some time previously, accessed health care, but received in their opinion little assistance and no therapy. Thus they approached me in hope of help.

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<sup>1</sup> Eight purposively sampled persons with disabilities who live in a remote, rural South African setting. See Chapter 6 for details.

This encounter strengthened my perception that persons with impairments in Fraserburg might not be receiving optimal health care intervention. An opportunity to investigate my perceptions presented itself when I became involved as a researcher in an international research project titled “Enabling universal and equitable access to healthcare for vulnerable people in resource poor settings in Africa” (EquitAble, 2008).

The primary objectives of the EquitAble study were to:

1. [Assess] “international, European Union and African country-level policies on universal and equitable access to health care with particular reference to people with activity limitations.
2. Undertake research into users’ and providers’ perceptions of the facilitators and barriers to equitable and universal access to health care in Sudan, Namibia, Malawi and South Africa.
3. Examine the relationship between access to health care services and activity limitations, and other mediating or interacting variables, in Sudan, Namibia, Malawi and South Africa.
4. Provide test sites for forthcoming measures of activity limitations that have been developed through extensive international consultation.
5. Make recommendations and create guidelines in support of effective and coherent health policy, at both country and international level, that promotes equitable and universal access to health care for people with activity limitations.
6. Explore and address barriers to implementing recommendations and guidelines across the four project countries and of scaling up the impact of our findings in other resource poor settings (EquitAble, 2008, p. 3).

During the EquitAble study data were collected in 17 sites in four countries, of which Fraserburg was one. Qualitative data were gathered to inform survey development and enhance quantitative findings. However, the predominant focus of EquitAble was on quantitative information. Thus EquitAble findings could be enhanced through adding nuanced, contextualized information on individual experiences (Yin, 2013). For this reason I decided to explore in-depth a small number of cases focusing on disability and health issues in the Fraserburg area, in this study.

I found the study challenging. First I do not have a disability and in the eyes of some that would disqualify me from doing research of this nature (Goodley, 2011). Secondly I am a health professional, trained in Western Biomedicine. I practised in the field of acute medical rehabilitation for more than 10 years before I even became aware of the extent of academic dissent and debate around disability, and before I gradually came to realise that there are people with disabilities who regard professional health care providers with distrust; or even as a threat to their very existence (Goodley, 2011). This realisation left me with ambivalent feelings. I am not unaware of stories like the one of Terry Schaefer<sup>2</sup> (Gibbs, 2006), and of practices such as abortion, genetic manipulation and the move to legalise euthanasia and the threat these may hold to persons with disabilities (Shakespeare, 2014). Similarly, I cannot ignore the threat that poor or no access to skilled health care and rehabilitation intervention holds for persons with disabilities (Grech, 2009; Shakespeare, 2014). Both the medicalisation of disability and poor health care might lead to the exclusion and abuse of persons with disabilities. I agree with Shakespeare (2014) that even in a universally accessible society, life would be easier if as many body structures and systems functioned as well as possible. One can accomplish much more sitting well balanced in an appropriate wheelchair, than lying in bed. Therefore I believe health care and rehabilitation have an important role to play in the lives of some persons with disabilities. And I do have some experience in client centred health care and rehabilitation. Thus I continued with the study but remained acutely aware of my limitations. My aim was to enhance my own understanding as much as to inform and create awareness amongst health care service providers and the broader community on the negative consequences that poor access to health care might have for persons with disabilities.

## **1.6 Contribution**

The study explored the experiences of a small number of persons with disabilities and their families in the Fraserburg area with regard to disability and health care access through a series of case studies. It focused on the views and perspectives of persons with disabilities, as Shakespeare (2014) indicated studies on disability should. The value of collecting small

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<sup>2</sup> Terry Schaefer was a young American woman with a severe disability. A legal battle between her husband and parents on the quality of her life led to a court verdict to withhold nutrition, until she died.

scale in-depth information, against the background of broader information from a larger project, is that this contextual information gives a human face to statistical data. Thus information generated in this study can play a role in constructing a more comprehensive picture of health care access for persons with disabilities in this setting and in developing contextually relevant patient centred solutions (Iezzoni et al., 2006; Priestley, 2006). This study should enhance recommendations and contributions from the EquitAble study.

The context and socio-cultural background of users play important roles in the successful implementation of health care services. Contextual information, in conjunction with epidemiological data, are required to ensure effective intervention (Fitzgerald et al., 2001). It is especially important to gather nuanced data on the impact of context, culture and social systems in rural, Global South communities who seldom have a voice in the development of national and international policies and whose day-to-day existence, experiences and struggles might revolve around basic necessities and be far removed from those of city dwellers and Global North populations (Barile, 2003; Grech, 2009, 2012; Heap, Lorenzo, & Thomas, 2009). In addition, sparsely populated rural areas may not have the population figures to produce contextually meaningful statistics or even to allow meaningful statistical analysis on certain issues and health conditions (McPhedran, 2011). Qualitative exploration allows researchers and policy developers to include the opinions of people living in these communities and thus to contribute to a process to make policy and services more appropriate (Fitzgerald et al., 2001; Iezzoni et al., 2006; Ingstad, 2007; Kalyanpur, 2011).

Studies that focused on health care access for persons with disabilities or subgroups such as stroke survivors or persons with chronic diseases have been done in various South African provinces, including the Western Cape (Kahonde, Mlenzana, & Rhoda, 2010; Kritzinger, Schneider, Swartz, & Hellum-Braathen, 2014; Maart & Jelsma, 2013), Eastern Cape (Bateman, 2012; Grut et al., 2012; Ntamo, Buso, & Longo-Mbenza, 2013), Mpumalanga (Bateman, 2012; Goudge, Gilson, Russell, Gumede, & Mills 2009a, 2009b), Gauteng (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007) and KwaZulu Natal (Bateman, 2012; Wasserman, De Villiers, & Bryer, 2009). However, despite the fact that statistically the Northern Cape Province has the highest provincial disability rate (Stats SA, 2012) no research on health care access for persons with disabilities could be found for the Northern

Cape Province. Thus the study setting is in a province where research of this nature has to my knowledge not been done previously.

The study takes place against a background in which there are some encouraging signs. South African literature indicates positive changes with regard to health care service delivery such as increasing budgets and a decrease in mortality figures (Mayosi et al., 2012; Naledi, Barron, & Schneider, 2011). However, according to Gaede and Versteeg (2011) and Matsoso and Strachan (2011) these advances have not reached rural settings and it is not clear to what extent it has impacted positively on vulnerable populations such as persons with disabilities. This study should give some indication of that.

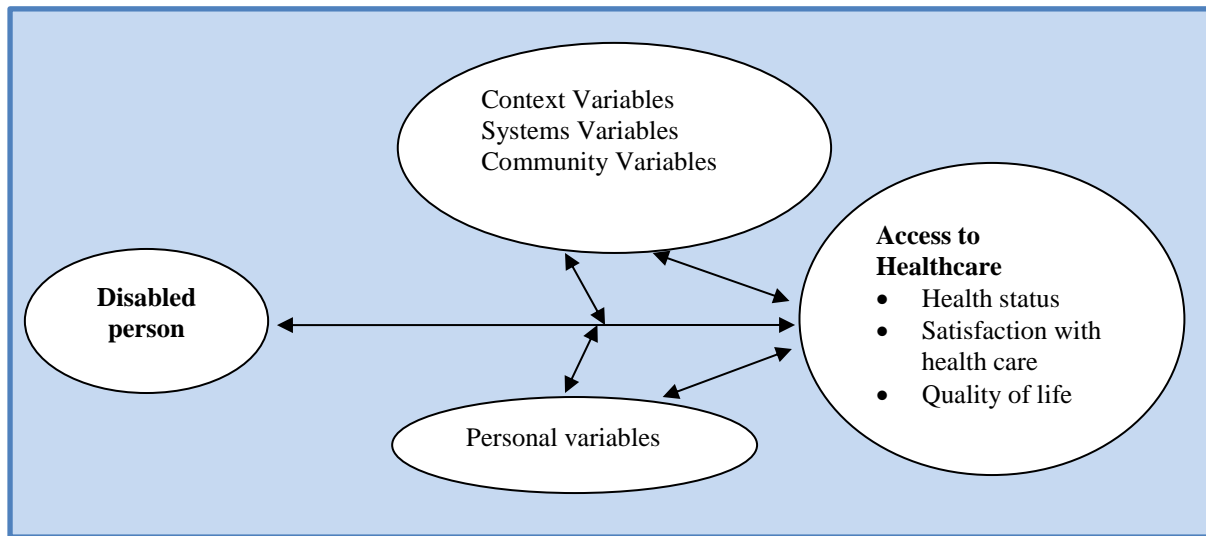
## **1.7 Theoretical Frameworks**

Two frameworks were used in this study, one to explore disability and the other for exploring health care access. With regard to disability, the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) was used to provide a definition for disability and a framework against which to explore the conceptualisation of disability. The reasoning that led me to this choice and a discussion on the ICF is presented in Chapter 2.

With regard to health care access many options were available, as presented in Chapter 4. Of these I found the Health Access Livelihood framework (Obrist et al., 2007), the framework presented by Levesque et al. (2013) and the EquitAble (2008) theoretical framework for access to health care the most comprehensive. All three incorporate policy, service characteristics, user characteristics, use, health status and client satisfaction. Since, the EquitAble framework (Figure 1.1) is used in the larger body of work related to this study I chose it as a health care access framework for the current study.

As shown in Figure 1.1 the EquitAble framework hypothesises that systems, context, community and personal variables have a reciprocal relationship with health care access, health status, satisfaction with care and quality of life. Context variables relate to characteristics of the setting such as economic situation, infrastructure and population density. Systems variables focus on the delivery of formal health care services. Community variables refer to the social fabric and cultural context of the setting that might impact health care access and include issues like violence (Trani & Barbou-des-Courieres, 2012), cultural

understandings of health, availability of caregivers, and social support (Grut et al., 2012; Ntamo et al., 2013; Zheng et al., 2014).



*Figure 1.1.* Theoretical framework for access to health care (Adapted from EquitAble, 2008)

Education, employment, income, age, gender as well as the severity and type of impairment are some of the personal variables that have an impact on health care access (Balarajan et al., 2011; Butler, Petterson, Phillips & Bazemore, 2013; Furumoto-Dawson, Gehlert, Sohmer, Olopade, & Sacks, 2007; Grut et al., 2012; Khan et al., 2006; Lee et al., 2010; Levesque et al., 2013; McGibbon, Etowa, & McPherson, 2008; Mechanic & Tanner, 2007; Ntamo et al., 2013; Peters et al., 2008; Tonoyan & Muradyan, 2012). Harris, Eyles, Penn-Kekana, Thomas, and Goudge (2014) expose the complex interaction between these variables by showing how unemployment, social isolation, poverty, a lack of proper nutrition, transport challenges, conflicting health beliefs, unsatisfying interactions with providers as well as staff and equipment shortages can independently, together or in various combinations lead to poorer health outcomes, dissatisfaction with services and non-compliance.

## 1.8 Summary

Both health care access and disability are complex phenomena, influenced by services, individual experiences, context, culture and community. In addition, health care provision in rural contexts is often more challenging than in urban areas. It is unknown how these factors impact the experience of disability and health care access for the disabled members of a rural,



Northern Cape, community. Quantitative data on these issues were gathered in the community through a household survey (EquitAble, 2008). This study evolved to add to the quantitative data through in-depth descriptions of individual experiences of persons with disabilities with regard to accessing health care services in this remote, rural town. This should provide background information against which the quantitative data can be interpreted.

## **1.9 Study Outline**

The study revolved around the concepts of disability, health care access and rural locality. In Chapter 1 the reader was introduced to the study and these concepts through a background sketch. The study problem, aim, objectives, and the theoretical frameworks to be used in the study were presented. Finally the evolution and possible contribution of the study was discussed. In the next four chapters the theories and research underpinning the study are presented. I start with an exploration of the complexities of disability in Chapter 2. Health and health care service delivery in South Africa is presented in Chapter 3. In Chapter 4 the impact of systems, community, context, and personal variables on health care access are explored. Chapter 5 concludes the review of the literature with an exploration of literature on health care access for persons with disabilities.

The choice of a multiple case study design and interpretative phenomenological analysis are explained in Chapter 6, as are other methodological issues such as population, sampling, data collection and data analysis procedures. In the next nine chapters (7 -15) results from individual case studies and a focus group discussion are presented. The reader is introduced to the eight primary participants and key role players in their lives as well as their experiences and opinions on the issues under study. Emerging themes are identified in each case and these are explored through narrative examples, researcher reflections and literature.

In Chapter 16 patterns across cases are developed and discussed. This is followed by study conclusions, recommendations, limitations, suggestions for future study and personal reflections in Chapter 17, the final chapter.

## Chapter 2

### Theoretical Perspectives on Disability

#### 2.1 Introduction

There are many opinions on the definition of disability and how to approach the issue, and more than a whole dissertation could be devoted to disability definitions and controversies. In this chapter, I explore some disability issues pertinent to this study, and I also make an argument for the use of the ICF as a conceptual framework on disability for purposes of the study. The discussion then moves to the questions of disability prevalence and the inclusion of persons with disabilities in mainstream society.

#### 2.2 Disability Defined

Disability is an interaction between impaired bodies and excluding environments. Yet even to speak of ‘disabled people’ as a category is problematic, given the differences between types and causes of impairments, and the interrelation of impairment and disability with other social divisions and identities. (Shakespeare, 2005, p. 147)

As can be deduced from the above quote, disability is complex and difficult to define (Altman, 2001; Goodley, 2011; Grech, 2009, 2012; Iezzoni, 2000; Iezzoni et al., 2000; Iezzoni & Freedman, 2008; Parnes et al., 2009; Schneider & Nkoli, 2011; Shakespeare, 2014; WHO, 2011). It is impacted on by a multitude of factors of which the impairment itself is only one. The impact of impairments differ due to the body function or structure involved, its severity, the way a particular impairment is interpreted in various cultures, and the financial and other means to mediate it (Grech, 2012; Shakespeare, 2005, 2014; WHO, 2011). Some people have been born with impairments; other impairments happened suddenly through an injury, for others disablement is a slow evolving process as a disease takes its course or as a result of ageing (Shakespeare, 2014). Impairments can regress over time, be static, improve or vary from day to day (Barile, 2003; Braithwaite & Mont, 2009; Iezzoni, 2000; Iezzoni et al., 2000; Shakespeare, 2014; WHO, 2011). While already complex the impairment constitutes but one dimension in the experience of disability.

Other variables that can impact the experience of disability are:

- Environmental factors. For example, hot weather can exacerbate fatigue, and inaccessible buildings may lead to limited function for wheelchair users (Barile, 2003; Braithwaite & Mont, 2009; Iezzoni, 2000; Iezzoni et al., 2000; Schneider, Hurst, Miller, Ustun, 2003; Shakespeare, 2014; WHO, 2011).
- Individual personalities (Geyh et al., 2011; Shakespeare, 2014; Smith, 2009).
- Life roles, expectations, income generating practices, and socio economic factors (Grech, 2012; Shakespeare, 2014; WHO, 2001; Yeo & Moore, 2003).
- Geographic isolation (Grech, 2012).
- The services one has access to (Grech, 2009, 2012; Shakespeare, 2014; WHO, 2011).
- Societal, cultural and religious perspectives on disability (Bickenbach, 2009; Grech, 2012; McKenzie et al., 2013; Meekosha, 2011; Schneider et al., 2003; Schuelka, 2013; Shakespeare, 2014; WHO, 2011).

Although rooted in a social context, disability is shaped against the loss or change of individual roles and functions and best understood by engaging with individual people (Barile, 2003; Grech, 2009, 2012; Iezzoni, 2000; Iezzoni et al., 2000; WHO, 2011).

Disability is so multifaceted that attempts to develop a single all-purpose brief definition of disability are bound to fail (Altman, 2001; Grech, 2012; Iezzoni, 2000; Iezzoni et al., 2000; Iezzoni & Freedman, 2008; Parnes et al., 2009; WHO, 2011).

It is, however, important to have working definitions of disability for different purposes. There is a need, for example, to define disability for the purpose of services, policy and legislation as well as from an epidemiological and research perspective (Altman, 2001; Heap et al., 2009; McDermott & Turk, 2011). In many countries, including South Africa, people must be identified as disabled according to some definition in order to access support services available only to people with disabilities. Without a medical form stating that they have a disability, South Africans cannot access a Disability Grant (DG)<sup>3</sup> or free health care or ask

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<sup>3</sup> A disability grant (DG) is provided by the South African Department of Social Development (2005) to an adult between the ages of 18 and 59 (female) or 64 (male) “who cannot support or maintain herself financially or by some other means, because her daily functioning is severely compromised as the result of a health condition” (p. 5).

for reasonable accommodations at work. The disability definitions used for these purposes are often contextual in nature and developed out of a specific approach to disability, with a specific purpose in mind (Goodley, 2011; Mitra, 2006; Schneider & Nkoli, 2011). For instance, definitions like those found in South African legislation such as the Employment Equity Act (RSA, 1998) or the Social Assistance Act (RSA, 2004a) have the purpose of identifying individuals with disabilities for reaching equity targets or implementing disability-specific social assistance. There is a real dilemma here. It is important for a democratic government to provide supports which appear equitable and applicable to a wide range of people with different impairments and in vastly differing circumstances. In South Africa, this must be achieved in a context of few resources for tailoring benefits, social assistance or other mechanisms aimed at achieving equity. The system therefore, despite policy positions to the contrary, ends up focusing on individual impairments and activity limitations with little or no basis for taking into account a range of environmental and personal factors (Gathiram, 2008; Schneider & Nkoli, 2011). It would be ideal, for example, to provide different levels of social assistance in the form of grants depending on whether a person needs a personal assistant. It would be helpful to take environmental factors into account such as access to good roads and transport, and to monitor whether these environmental factors change, and if so to adjust assistance accordingly. This level of differentiation would be true of the best models of disability, but would in practice be extremely expensive and difficult to implement, so what is essentially a “one size fits all” approach is used.

The complexity of disability has led to a variety of disability approaches. It is important to have an understanding of the leading approaches as they provide the backdrop against which I chose a disability framework and definition for this study.

### **2.3 Disability Approaches**

Approaches to disability have developed and changed through the years. However, while changes have occurred, as poignantly described by Shakespeare (2008a) in a personal account of his family’s experience of disability through generations, much seems to have stayed the same for many persons with disabilities. For instance, Goodley (2011) argues that the moral approach (the oldest and arguably most oppressive approach to disability, see Table 2.1) is still the most prevalent approach to disability throughout the world. Goodley’s

argument is supported by recent studies, from Thailand (Rukwong, 2008), Zimbabwe (Munsaka & Charnley, 2013) and Uganda (Mulumba et al., 2014) where participants often ascribe their impairments to misfortune, karma, ancestral punishment, witchcraft or bad luck and describe being ostracised from society, all features of the moral approach.

Shakespeare's (2008a) account also expressed a duality: on the one side there is a move from shame and shock to tolerance and acceptance; on the other, advances in medical technology exert pressure to choose against having a child with a disability. This duality seems to encompass the wider disability experience today. Despite the fact that globally the rights of persons with disabilities are protected by policy and international conventions with a focus on an inclusive, tolerant society, practices like surgery, eugenics, abortion and euthanasia are increasingly used to "normalise" and to ensure that only those who are "normal" are born (Garland-Thomson, 2005; Gibbs, 2006; Goodley, 2011).

As in many other countries, disability policy and legislation in South Africa has historically been built on a medical approach to disability. With the transition to democracy in 1994 and the entrenchment of disability rights in the Constitution of 1996, social and human rights approaches have been adopted, as can be seen in the Integrated National Disability Strategy White Paper of 1997 (Office of the deputy president, 1997). As in other areas of South African life, legislation has not caught up with newer approaches to social issues, and for this and other reasons, including reasons of practicality, it is still the case that health care and other services for persons with disabilities are mainly provided according to the medical approach (Mji et al., 2013). While the medical approach to disability has challenges, high quality medical intervention for persons with disabilities is important. Health care and rehabilitation are prerequisites to accessing equal opportunities. Thus Shakespeare (2008b) rightly warns that it is not medical intervention that should be criticised, but rather the form of the intervention and especially the relationship between medical professionals and persons with disabilities.

Table 2.1

*Disability approaches (Sources: Brown, 2009; Goodley, 2011; Mackelprang, 2010; Mitra, 2006; Oliver, 2006; Schuelka, 2013; Thomas, 2004).*

	<b>Conceptualisation of disability</b>	<b>Causes</b>	<b>Focus of intervention</b>	<b>Advantages</b>	<b>Challenges/ Criticism/ Results in</b>	<b>Role of body/ impairment</b>	<b>Role of environment</b>
<b>Moral Approach</b>	Defect to endure or overcome; Test of faith	Supernatural; Punishment for sin or moral lapse; Sorcery	Divine healing; Address sins or immoral nature; Appease spirits	?	Shame; Ostracism; Charity Hiding the disability symptoms or person with disability	Defective body	No role
<b>Medical Approach</b>	An individual medical problem caused by impairments; Personal tragedy	Individual actions; Lifestyle choices; Random occurrence	Cure; “Normalise”; Fit into society	Medical management of the impairment	Lack of attention to social exclusion; Power imbalance between professionals and persons with disabilities; Doing away with the “disabled” body	Cause disability	Acknowledged, but not addressed
<b>Social Approach</b>	Social Oppression & Barriers	Societal exclusion	Remove societal barriers	Address environmental barriers	Too little focus on the role of the impairment; Might devalue medical intervention; Prevalence numbers not important	Present but do not cause disability	Cause disability
<b>Human rights Approach</b>	Persons with disability are a minority group	Denied civil rights, equal access and protection	Broad societal and system changes to ensure equal rights	Inclusion of persons with disabilities in policy and laws	People need to be identified and labelled as disabled; Focus on political lobbying instead of basic development	Present but do not cause disability	Deny persons with disabilities opportunities to access their rights

As indicated in Table 2.1, according to the medical approach disability is caused by individual impairments. Its' supporters may acknowledge that societal barriers can have an impact on disability, but generally fail to address these (Goodley, 2011; Oliver, 2006; Thomas, 2004). Where this model is adhered to, the focus of disability management is on addressing individual impairments through medical intervention and therapy with the objective to cure or "normalise" so that the person can "fit into society" (Goodley, 2011; Mackelprang, 2010; Mitra, 2006). If these measures are unsuccessful the person with the disability is often marginalised. "Able bodied" service providers and communities decide on intervention strategies, control organisations for persons with disabilities, pass judgement on the quality of life of persons with disabilities, the meaning of suffering, and how suffering should be relieved. They might even decide on life or death for persons with disabilities (Brown, 2009; Edwards, 2009; Garland-Thomson, 2005; Gibbs, 2006; Goodley, 2011; Iezzoni, 2006a, 2006c; Shakespeare, Iezzoni, & Groce, 2009). The opinion of the person with the disability is not sought and service providers and communities fail to realise that some persons with disabilities might perceive their impairment as an integral part of who they are. They do not want to be cured, they want to be accepted and included (Hahn & Belt, 2004; Smith, 2009).

In the context of disability activism of the 1960s and 1970s, persons with disabilities rallied against the medical approach. They wanted control of their lives and destinies and were instrumental in developing the social approach to disability (Table 2.1) as a counter. Supporters of the social approach argue that disability stems from the inability of organised society to meet the needs and ambitions of citizens with disabilities, and to include them in all aspects of life. According to them disability is a social construct caused by oppression, stigma and societal barriers. Social approach supporters acknowledge impairments and their impact on a person's life, but argue that impairments do not cause disability (Goodley, 2011; Oliver, 2006; Thomas, 2004). In the words of Thomas (2004):

. . . disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed, that is, when they are wholly social in origin . . . it is entirely possible to acknowledge that impairments and chronic illness directly cause

some restrictions of activity. The point is that such non-socially imposed restrictions of activity do not constitute disability. (p. 580)

The focus of management is on universal access to be achieved through broad societal changes that allow inclusion, equal access to all community and societal systems, and promoting positive images of disability (Goodley, 2011; Mackelprang, 2010; Mitra, 2006; Oliver, 2006). The social model has been invaluable in exposing and confronting the oppression faced by many persons with disabilities, but disability encompasses more than oppression (Shakespeare, 2014). In addition, there are particular challenges in applying this model in the Global South.

Grech (2009, 2012), Heap et al. (2009), Ingstad (2007) and Meekosha (2011) note that the social approach was to a large extent developed in Global North countries and “exported” to Global South settings. The approach may not fully encompass the experience of disability in culturally different Global South settings, or against a backdrop of social deprivation, as often experienced in the Global South. Autonomy and individualism, core values of the social model, may be less relevant in communities where members are interdependent on each other sometimes for their very existence. Grech (2012) argues that disability is met with a variety of attitudes and behaviour in the Global South which range from positive to negative, and is dependent on socio-economic, cultural, political, personal and contextual variables.

Finally and of importance to this study, the social approach has a tenuous relationship with health care and health care service providers. Supporters of the social approach acknowledge impairments and the necessity of medical interventions to reduce or alleviate them (Oliver, 2006; Parnes et al., 2009). However, this acknowledgement may not be enough to prevent one from forgetting the important role of medical intervention when faced with the criticism health care service providers receive from social approach supporters (Grech, 2009; Shakespeare, 2014). In circumstances where health care provision is fragmented or absent, as can be found in the Global South, one should take care that societal approaches to disability do not fail to acknowledge medical problems that require treatment. Such failure may leave persons with disabilities without the necessary health care to ensure biological stability and optimal functional restoration



(Grech, 2009, 2012; Shakespeare, 2012, 2014). In addition, medical intervention has an important role to play in the prevention of impairments that can lead to disability.

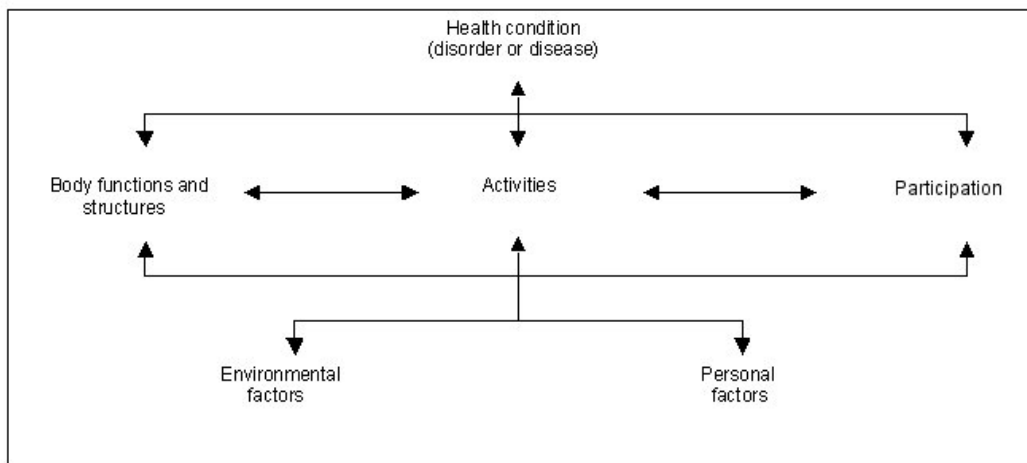
The role of the impairment is as real as the effects of social oppression in the experience of disability (Goodley, 2011; Grech, 2009; Shakespeare 2008b, 2014; Smith 2009; Taylor, 2005). Thus neither impairment and medical intervention nor societal oppression and creating a barrier free society should be neglected if one wants to ensure inclusion of persons with disabilities (Shakespeare, 2014). Impairments may be a source of strength and personal development but may also be a burden, source of suffering and cause of death (Grech, 2009; Hahn & Belt, 2004; Shakespeare, 2014; Smith, 2009; Taylor, 2005; Thomas, 2004).

Differences in the experience of impairment are illustrated by the findings of two studies. In a study that “investigates the assumption that disabled people want improvements in their functional abilities, or complete cures”, Hahn and Belt (2004, p. 453) found that study participants regard being disabled as a positive and enriching life experience, embrace their impairments and will not seek a cure even if it is available. On the other hand, in a study that “examined the adequacy of the social model for explaining the disability experience of persons with Chronic Fatigue Syndrome”, Taylor (2005, p. 497) found that study participants experience their impairment as a negative force in their lives. They want a cure and put a lot of effort into searching for it. Methodological differences might explain the difference in findings. The 47 participants in the qualitative study by Taylor (2005) experienced symptoms that made them feel constantly sick. Hahn and Belt (2004) did not provide information on medical diagnosis or impairments of the 165 disability activists that participated in their quantitative survey. It is possible that they experienced more varied impairments that caused less symptoms of ill health. In addition their role as disability activists might have led to a pre-determined attitude about the role of impairments. In my opinion the role of the impairment is well summarized by Shakespeare (2014) and Smith (2009) who argue that while the presence of an impairment does not automatically imply a tragedy, one cannot deny the very real experience of pain and suffering of some persons with impairments.

The individual person and the way that a person responds to circumstances also impact the experience of disability (Shakespeare, 2014; Smith, 2009). I argue that one should not ignore or place a lesser value on the impairment, the environment, or the person in conceptualizing disability. Therefore I want to conclude and agree with Bickenbach (2009) and Shakespeare (2014) that disability is the result of a complex interaction between the impairment, the environment and the individual person. For this reason, I use the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as a disability framework in this study.

## 2.4 The International Classification of Functioning, Disability and Health

According to the ICF, disability exists on a continuum with function (Kostanjsek, 2011; Schneider et al., 2003) and is the result of a multifaceted non-linear interaction between health conditions, impairments, activities, participation and contextual factors, as shown in Figure 2.1. Disability is a complex, multi-dimensional, universal experience that most people will encounter during their lifetime, instead of being limited to the few who were traditionally labelled disabled (Kostanjsek, 2011; Schneider et al., 2003; WHO, 2001).



*Figure 2.1.* Diagrammatic presentation of the interaction between the components of the ICF (Source: WHO, 2001)

The experience might be temporary, for example, while convalescing after surgery, waiting for a fracture to heal, or waiting for an assistive device like spectacles to be replaced. Conversely an injury or health condition might cause permanent impairments and disability like in the case of a Spinal Cord Injury (SCI) or might be a lifelong experience if born with an impairment.

Environmental factors might aggravate the impairment and/or decrease activity and participation and thus determine the presence and/or severity of a disability. For example, a fracture can become a permanent disability if health care systems fail to provide the necessary curative care. For a person with paralysis of the legs the severity of the disability is influenced by environmental factors such as having or not having a wheelchair, or living in a second floor flat without a lift (Schneider et al., 2003; WHO, 2001).

The impact of personal factors like age, education, socio-economic status, religion, coping mechanisms and personality traits on disability are acknowledged by the ICF (Geyh et al., 2011; Kostanjsek, 2011; Schneider et al., 2003; WHO, 2001). However, they are not classified or scored and might thus be interpreted as of lesser importance and neglected (Barile, 2003; Conti-Becker, 2009; Geyh et al., 2011). Further research on the role of personal factors in determining disability, and the development of a classification strategy for personal factors within the ICF is necessary (Geyh et al., 2011).

As a disability framework the ICF provides a model for measuring disability prevalence.

## **2.5 Disability Prevalence**

Disability prevalence rates vary and are influenced by varying disability definitions and approaches, and the methodologies used in prevalence studies and surveys. The wording of questions, the extensiveness of questions and response options, and training of data collectors can all impact on prevalence findings (Schneider, 2009; Schneider et al., 2009; WHO, 2011). Questions that focus on impairments or ask if a person is disabled, as well as narrow “yes/no” response options can yield underestimates of disability prevalence. There are many people who have impairments but who do not self-identify as disabled. Some impairments, for example, are considered by many to be part of normal ageing, such as hearing loss – if an older person does not identify as disabled but has substantial hearing loss, this impairment will be missed on

surveys asking people if they are disabled. There may also be lower reporting of disability rates because of stigmatizing implications of being labelled disabled. Questions based on the ICF such as the Washington Group Questions (WGQ) (Schneider, 2009) tend to give higher prevalence estimates.

The WGQ seeks to identify the presence of functional difficulties in one of six common activity sets (seeing, hearing, walking, remembering, communication and self-care) in an effort to identify individuals with activity limitations.

Scoring options range from:

- 0 - no difficulty.
- 1 - some difficulty.
- 2 - a lot of difficulty.
- 3 - cannot do.

The more detailed questions referring to difficulties as well as the range of response options should increase the number of “yes” responses (Braithwaite & Mont, 2009; Washington Group on Disability Statistics, 2010).

South Africa used an approach based on the WGQ in the 2011 census survey (Stats SA, 2011). An overall disability figure of 5.2% of South Africans five years and older was found. These figures were determined by defining disability as follows: “If an individual has ‘Some difficulty’ with two or more of the 6 categories then they are disabled. If an individual has ‘A lot of difficulty’ or is ‘Unable to do’ for one or more category they are classified as disabled” (Stats SA, 2012, p51).

Additional disability prevalence data for South Africa come from Mitra & Samboorthi (2013) and Schneider et al. (2009). Mitra & Samboorthi (2013) found a disability prevalence figure of 30% for South Africa, based on the World Health Survey (WHS) data. They found higher prevalence of disability than Stats SA (2011) in every functional area. Similarly Schneider et al. (2009), also using the WGQ, reported higher figures. They found an overall disability rate of 33% with 3% “cannot do”, 10% “a lot of difficulty” and 20% “some difficulty” in one domain.

Their population consisted of persons 15 years and older, as opposed to persons five years and older in the 2011 census. This difference in age might to some extent account for the differences in findings since disability prevalence increases with age (Graham et al., 2014).

Schneider et al. (2009) found that percentage-wise more persons living in rural areas reported a lot of difficulty or an inability to do an activity than in urban areas, as shown in Table 2.2. The authors attributed the increased percentage of persons with severe activity limitations in rural areas to a lack of services in these areas.

Table 2.2

*Percentage of persons with difficulties in rural and urban areas (Schneider et al., 2009)*

	Some difficulty	A lot of difficulty / cannot do
Rural	19.57%	15%
Urban	20.35%	10%

Thus, persons with disabilities are a large minority group that must be considered in policy and service delivery.

## 2.6 Disability Policy and Inclusion of Persons with Disability in South Africa

Internationally the focus on disability rights culminated in the United Nations Convention on the Rights of Persons with disabilities (UNCRPD), which were adopted in 2006. The UNCRPD's purpose is: "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN, 2006). The principles of the UNCRPD focus on autonomy, dignity, freedom, non-discrimination, equality, respect, acceptance, accessibility, inclusion and participation. South Africa ratified and signed the UNCRPD in 2008, thereby committing the country to dealing with disability as a human rights issue and the inclusion of persons with disabilities in all walks of life (DWCPD, 2013; Lang, Kett, Groce, & Trani, 2011; UN, 2006).

The first country report from the South African government on the implementation of the UNCRPD highlights progress towards political self-representation of persons with disabilities with 16 members of parliament, of whom one is a deputy minister. In addition, the report refers to various Reasonable Accommodations that ensure greater inclusion of persons with disabilities, tax benefits for, the success of the South African Paralympics team, social assistance through financial aid to persons with disabilities and the inclusion of persons with disabilities in higher education, adult literacy and learnership programmes. On the other hand the report pointed out challenges in the areas of public transport, early childhood development, inclusive education and the implementation of the UNCRPD in rural areas. Challenges to implementation in rural areas include isolation, poverty, low literacy levels, harmful traditional beliefs, a lack of transport and physical access, a lack of services, a shortage of health professionals, little support to educators of children with special needs, oppression and marginalisation (DWCPD, 2013).

On the whole it seems as if the UNCRPD policies and laws did not lead to much change in the lives of ordinary persons with disabilities in South Africa. Disability is often still perceived as an individual problem caused by impairment/s and persons with disabilities often exist at the fringes of society due to social exclusion and environmental barriers (Adnams, 2010; Schneider & Nkoli, 2011).

## **2.7 Summary**

Due to its complexity and the myriad of factors which impact on disability it is difficult to define disability. One has to take into consideration the impairment, the environment and the person. The ICF was chosen as a disability framework for this study since it combines these factors in an inclusive approach to disability. Determining disability prevalence is similarly difficult and figures for South Africa vary, but it seems as if at least 5% of the country's population has activity limitations that might lead to disability. These individuals must be afforded their rights and inclusivity in society in accordance with the UNCRPD. However, inclusion in South Africa is limited, especially in rural areas. One of the many essential components of inclusion is access to health care. Health and health care service delivery in South Africa is explored in the next chapter and health care access in the one thereafter.

## Chapter 3

### Health, Health Care Systems and Services in South Africa

#### 3.1 Introduction

Health and illness are integral components of being human. No person stays healthy all the time; death, the ultimate outcome of ill health, is inevitable (Davies, 2007). In addition neither health nor illness is static; they interact on a continuum from severe illness to exceptionally good health (Davies, 2007; Nosek et al., 2004; WHO, 2001). This chapter looks at the role of health in disability as well as health care systems and services in South Africa.

#### 3.2 Health, Disease, Function, Disability and Quality of Life

One's state of health is dependent on ever-changing balances on the continuum of health and illness. These balances are influenced by disease, personal, cultural and environmental factors (Davies, 2007). In addition, health is interconnected to various socio-economic factors such as adequate nutrition, uncontaminated water, housing, sanitation, employment, safe and healthy working conditions, education, information and health care. It is impacted on by freedom of association, assembly and movement as well as freedom from degrading actions such as torture and medical treatment without consent (UN, 2000; WHO, 2010b). Thus any attempt to define health will be fraught with difficulties and any definition of health open to controversy. Such is the case with the WHO definition of health, provided in the glossary of terms and used in this study. An in-depth discussion of the issues is beyond the scope of this dissertation. One issue, i.e., the use of the word "infirmity" (which is similar to "impairment") needs mentioning. The definition appears to imply that a person with an impairment cannot be healthy (Swartz & Bantjes, in press). An impairment or disability does not automatically reflect a decrease in health status (Chevarley et al., 2006; Nosek, Fuhrer, & Potter, 1995; Putnam et al., 2003; Shakespeare, 2014; Shakespeare et al., 2009). People with disabilities can have long, healthy and productive lives (Iezzoni, 2006a). As shown in Table 3.1, good health is experienced by relatively similar percentages of persons with and without disabilities. With the exception of the

Korean (Park, 2014), Sierra Leonean (Trani et al., 2011) and South African (Graham et al., 2014) studies the difference was within 10%.

Table 3.1

*Comparison of findings from studies on self-reported health status of persons with and without disabilities*

	Set- ting	% experiencing excellent health		% experiencing good/fair health		% experiencing poor health	
		Persons with disabilities	Persons without disabilities	Persons with disabilities	Persons without disabilities	Persons with disabilities	Persons without disabilities
Chevarley et al., 2006	USA	22	65	29	27	49	8
Drum, Horner- Johnson, and Krahn, 2008	USA	23	60	32	30	45	10
Fouts et al., 2000	USA	9	29	56	65	35	6
Graham et al., 2014*	South Africa	31	66	48	32	21	3
Gulley & Altman , 2008	USA	-	-	-	-	74	5
Gulley & Altman, 2008	Canada	-	-	-	-	69	3
Horner-Johnson et al., 2010	USA	27	63	30	28	43	9
Jamoon et al., 2008	USA	-	-	-	-	44	9
Park, 2014	Korea	6.4	27.1	18.1	39.8	75.5	33.1
Trani et al., 2011	Sierra Leone	-	-	74	89	26	11

\*The sum of the percentages for persons without disabilities is 101%. The information was used as presented in the original source.



Trani et al. (2011) distinguished only between good and poor health. Not having a category for excellent and very good health as the other authors did means that people in that category are included in the good health category and this might explain the bigger difference in this instance. It is uncertain what causes the difference in the Korean study and the authors did not offer any explanations (Park, 2014). Graham et al. (2014) found - rather surprisingly - that 17% more South Africans with disabilities experienced good/fair health than their non-disabled peers.

However Table 3.1 also shows that larger percentages of persons with disabilities experience poor health, and smaller percentages of persons with disabilities experience excellent health, than persons without disability. This might be due to the often complex connection between disease, and especially chronic health conditions, and disability. Chronic conditions can lead to functional limitations and symptoms such as pain that can cause disability; on the other hand disability is a risk factor for chronic conditions such as obesity or depression (Harrison, 2006; Iezzoni, 2006b, 2010; Krahn et al., 2009; Park, 2014; Rimmer, 2002; Rukwong, 2008; Shakespeare, 2014). Furthermore, impairments might generate health challenges through secondary complications such as pressure ulcers (Putnam et al., 2003; Shakespeare, 2014).

The type of health condition that caused the impairment also plays a role in persons with disabilities' perceptions of health and can cause fluctuations in their experienced health (Nosek et al., 2004; Rukwong, 2008; Shakespeare, 2014). For example, individuals with static conditions such as a Spinal Cord Injury (SCI) often saw the functional limitations caused by the SCI as a part of who they are and not as being sick. They related illness to acute medical episodes of infection or fever. Conversely those with regressing conditions (e.g., Motor Neuron Disease) or conditions that are characterised by periods of remission (e.g., Multiple Sclerosis (MS)) often saw the disabling condition as a disease which impacts on their health negatively (Nosek et al., 2004; Shakespeare, 2014).

Numerous studies show that for persons with disabilities (Harrison, Umberson, Lin, & Cheng, 2010; Lindsay, 1996; Munsaka & Charnley, 2013; Nosek et al., 2004; Putnam et al., 2003; Rukwong, 2008), and for their non-disabled counterparts (Abdulrahim & Ajrouch, 2010; Bilinski, Duggleby, & Rennie, 2010; Dutta & Basu, 2007; Goins, Spencer, & Williams, 2011;

Hughner & Kleine, 2008; McCarthy, Ruiz, Gale, Karam, & Moore, 2004; Yehya & Dutta, 2010), health and wellbeing has spiritual, emotional, social and physical components. Spiritually, health and wellbeing is achieved by celebrating life, and transcending the physical body to attain a state of grace (Lindsay, 1996). On an emotional level, self-respect and self-love (Lindsay, 1996), positive mental attitudes (Nosek et al., 2004), despondency (Rukwong, 2008), stress, depression and frustration (Putnam et al., 2003) have been mentioned as factors that could influence health and wellbeing. Socially, persons with disabilities felt it important to connect with others (Lindsay, 1996) and have social support (Nosek et al., 2004, Putnam et al., 2003). Physically, functional ability and the absence of physical symptoms such as pain were related to being healthy (Nosek et al., 2004; Putnam et al., 2003; Rukwong, 2008).

Loss of function might decrease quality of life (Clarke & Black, 2005; Rukwong, 2008; Zheng et al., 2014). However, a range of other factors such as community inclusion, participation in life roles, personal and societal attitudes towards the disability, quality of care and support, and access to services, also increase or decrease the experienced quality of life (Becker, 2006; Clarke & Black, 2005; Cramm, Lorenzo, & Nieboer, 2013; Harrison et al., 2010; Krahn et al., 2009; Nosek et al., 1995, 2004; Putnam et al., 2003; Rukwong, 2008; Zheng et al., 2014). Nosek et al. (1995) found that participation restrictions had a statistically significant negative impact on satisfaction with life ( $p = 0.05$ ), while the inability to perform activities of daily living ( $p = 0.21$ ) did not have a significant impact on quality of life.

Lower levels of wellbeing were generally expressed by participants with disabilities in studies from Zimbabwe (Munsaka & Charnley, 2013), Uganda (Mulumba et al., 2014) and Thailand (Rukwong, 2008) than by those from the United States of America (USA) (Harrison et al., 2010; Lindsay, 1996; Nosek et al., 2004; Putnam et al., 2003). Some Thai participants saw themselves as sick and their lives as of little value: “My life is like a flame which is gone” (Rukwong, 2008, p. 63). Zimbabweans (Munsaka & Charnley, 2013) describe social exclusion, having lesser value and lower social status, being pitied and being hidden from sight. It seems as if context, lack of services and cultural interpretation linked disability to poor health in the two Global South settings.

A South African study by Jelsma, Maart, Eide, Ka Toni, & Loeb (2007) found that 305 Xhosa speaking participants with disabilities sampled conveniently from two urban districts in the Western Cape Province (n = 61) and 15 rural districts in the Eastern Cape Province (n = 244), reported low levels of health-related quality of life with mean scores of 66/100 for rural participants and 60/100 for urban participants (these figures were not compared to a control group of persons without disabilities). The participants indicated that pain, anxiety, depression and difficulty to perform their usual activities caused them decreased health-related quality of life.

By contrast, De Klerk and Ampousa (2003) found in a qualitative study, performed in Tshwane (urban Gauteng) with 47 women participants with physical disabilities, that study participants were happy with their lives. All participants in this study were involved in vocational rehabilitation programmes. In contrast only six per cent of participants in the study by Jelsma et al. (2007) were employed. This might account for the difference in findings, because being employed is associated with improved quality of life. Apart from the differences in design and setting just discussed different data collection methods might further account for the differences in findings. Jelsma et al. (2007) collected data through a standardised questionnaire; De Klerk and Ampousa (2003) collected data through semi-structured interviews. Participants also differed, in that those participating in the study by Jelsma et al. (2007) were from both genders and all Xhosa speaking, while those in the study by De Klerk and Ampousa (2003) were women from all the population groups in South Africa.

Cramm et al. (2013) found in a matched case, cross sectional study amongst South African youths (18–35 years old; 120 with disabilities and 117 without disabilities) from the Northern and Eastern Cape provinces that disability impacts wellbeing negatively. However wellbeing of participants in this study improved with access to education, employment and social support services (Cramm et al., 2013). These findings show the importance of access to services, in improving quality of life for persons with disabilities, an aspect that is often lacking in Global South communities (Grech, 2012; Heap et al., 2009; Meekosha, 2011). The focus of this study is on access to one type of service: health care.

### **3.3 Health Care Systems: Formal and Informal**

The focus of the current study is on the formal health sector. However, it cannot be studied without acknowledging the other sectors since it does not operate in a vacuum and is often used in conjunction with other sectors (Helman, 2007).

People have various ways of dealing with a perceived health problem (Dahlberg & Trygger, 2009; Hughner & Kleine, 2008). They can choose to ignore it or try to control it through their attitude, behaviour and lifestyle (Hughner & Kleine, 2008). They may use popular health care through treating themselves with home remedies or off the shelf medication, or consulting family, friends or a lay health expert in the community. They may consult a traditional health care provider, faith healer or alternative medicine practitioner such as a homeopath or reflexologist (Gqaleni, Moodley, Kruger, Ntuli, & McLeod, 2007; Hughner & Kleine, 2008; Yehya & Dutta, 2010) or consult a formal health care provider such as a doctor (Dahlberg & Trygger, 2009; Helman, 2007; Hughner & Kleine, 2008). People might explore any one or a combination of options consecutively or simultaneously, depending on their views of the cause of the disease or for reasons like affordability and access (Dahlberg & Trygger, 2009; Germond & Cochrane, 2010; Hughner & Kleine, 2008; Peltzer, 2009).

#### **3.3.1 The popular sector**

The popular sector refers to the home and community where ill health is commonly first identified and where health care often starts. It is the biggest of the three sectors. Treatment in this sector comprises all the actions people take to address ill health that does not include visiting a traditional health care provider, faith healer, alternative medicine practitioner or professional health care provider (Cocks & Moller, 2002; Helman, 2007; Hughner & Kleine, 2004; Kleinman, 1980). Health care is provided within the family. Knowledge on treatment is gained from sources such as the media, folklore and home doctor books. Cultural differences between provider and user are negligible and misunderstandings about the meaning of health, illness and treatment seldom occur (Helman, 2007; Kleinman, 1980).

### **3.3.2 The folk sector**

The folk sector comprises healers who work for money or are paid in kind, but are often not recognised as formal health care providers in a country and are not legalised by laws and governing bodies. In South Africa various types of folk practitioners, such as reflexologists, homeopaths, faith healers, diviners, herbalists, African chemists, traditional surgeons and traditional birth attendants are found (Dhalberg & Trygger, 2009; Peltzer, 2009). South Africa has begun a process of including the folk sector into national health care delivery, as shown by initiatives such as the Directorate for traditional medicine in the Department of Health and a traditional medicine research institute (Peltzer, 2009). Folk healers usually belong to the same culture as the user and often involve the family in treatment. This helps them to explain diseases and their causes in culturally acceptable terms (Helman, 2007; Kleinman, 1980). Folk, or indigenous health care as it is called in South Africa, is especially frequented by members of the Black population groups who use it side by side with formal health care. However, indigenous care is often expensive and poor people might not be able to afford it (Dhalberg & Trygger, 2009; Peltzer, 2009).

### **3.3.3 The formal sector**

The formal sector consists of the legally organised health care providers in a country and in South Africa refers to what is traditionally known as Western, scientific medicine. This group includes doctors and various medical specialists and professions allied to medicine such as nurses and therapists. Practitioners in the formal health sector often enjoy a higher status and income, and have more rights and obligations than those in the other health care sectors. The formal sector often provides only a small percentage of the health care in a country (Helman, 2007; Kleinman, 1980).

## **3.4 Formal Health Care Service Provision in South Africa**

Formal health care in South Africa is provided by a public and private sector that run parallel to each other. Due to poverty and high levels of unemployment, approximately 80% of the population access public formal health care (Blecher, Kollipara, De Jager, & Zulu, 2011). Public

health care services are provided at primary, secondary and tertiary level. The levels are linked through a referral system. Primary level services are provided through clinics and community health centres. It is the point of entrance into health care services and should involve health promotion, prevention, management of uncomplicated acute conditions, routine management of chronic conditions and basic rehabilitation. Services at secondary level are usually provided in district and regional hospitals and manage conditions that cannot be dealt with at primary level. Tertiary level health care is highly specialised, deals with complex conditions, involves the use of specialised professionals and technology, and is provided at provincial level in large city hospitals (WHO, 2010b; UN, 2000).

Formal health care services in South Africa are governed by the National Health Act of 2003 (RSA, 2004b). Various subordinate acts, policies and position papers such as the White Paper on the Transformation of the Health System of 1997 (DoH, 1997) and more recently the Green Paper on National Health Insurance (Minister of Health, 2011) and the Negotiated Service Delivery Agreement (DoH, 2011) guide the implementation of the National Health Act. According to these documents health care in South Africa should be provided according to the philosophy of PHC (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Kautzky & Tollman, 2008; Naledi et al., 2011).

The definition of primary health care (PHC), as presented in the glossary of terms, was formalised at the Alma-Ata Conference in 1978. While still a fundamental document on PHC the Alma Ata declaration is becoming dated and other authors have built on it. This review describe PHC based on the principles of Alma Ata and two more recent publications i.e. the WHO's "World Health Report: Primary health care now more than ever" (WHO, 2008a), and Kringos and colleagues literature review on the core dimensions of PHC (Kringos, Boerma, Hutchinson, van der Zee & Groenewegen, 2010).

Universal cover and access to health care services according to need (equity) forms the basis of PHC. Communities and individuals must be empowered to participate in health care service management and in the planning and execution of personal health care strategies. It "relies . . . on health workers . . . suitably trained socially and technically to work as a health team". PHC

“should be sustained by integrated, functional and mutually supportive referral systems”. Implementing PHC means changes to the health care system as well as recognising and “addressing the underlying social, economic and political determinants of poor health” in communities (Alma-Ata Declaration, 1987, p. 1-2). Thus the implementation of PHC requires a coordinated effort from various sectors such as health, agriculture, education, employment, and housing. According to the Alma-Ata Declaration (1987) PHC:

. . . includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition; an adequate supply of safe water and basic sanitation; maternal and child health care, including family planning; immunization against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common diseases and injuries; and provision of essential drugs. (p. 2)

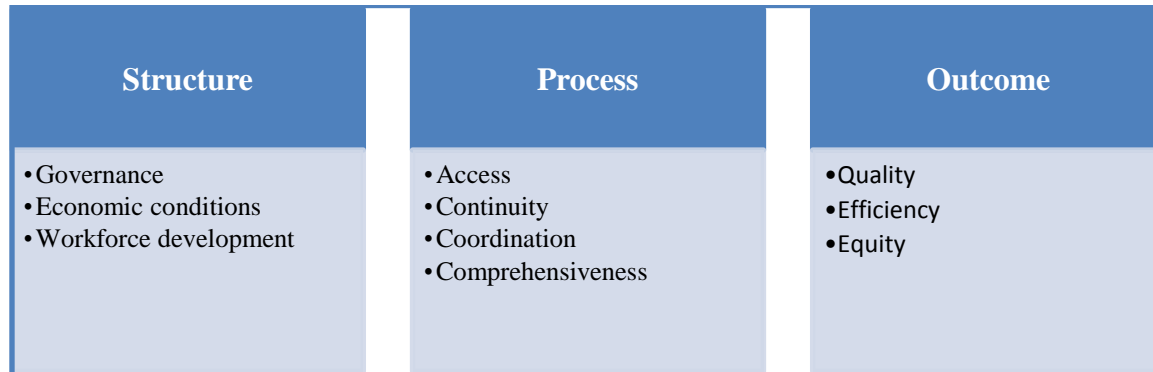
PHC is not a low resource solution to the health care problems of the poor or isolated. It is an ambitious, comprehensive service as is shown in Table 3.2 (WHO, 2008a).

Table 3.2

*Primary health care (WHO, 2008a)*

Primary health care is...	Primary health care is not...
Addressing a diverse range of health needs	Dealing only with priority diseases
The point from which users are guided through the health system	An isolated service in a community
An ongoing relationship between user and provider	A lack of continuity
Patient centred health care	The provision of one directional interventions
An opportunity for prevention of diseases and health promotion	Only treating common ailments
Provided “by teams of health professionals with specific and sophisticated biomedical and social skills”	Low technology, non-professional rural health care for poor users
Supported by adequate resources and investment to provide better value for money	Cheap

According to Kringos et al. (2010) PHC is dependent on three levels i.e. structure, process and outcome as presented in figure 3.1. Of special importance to this study is the process dimension of access which includes components like availability, geographic access, accommodation, affordability, acceptability, use and equality. These components are discussed in more depth in chapter 4. Furthermore continuity, coordination and comprehensiveness of care as well as quality and equity are important to the current study.



*Figure 3.1.* Dimensions of PHC according to Kringos et al. (2010)

Fragmented, inequitable service delivery, vertical, uncoordinated, disease specific programmes, separation between facility, community and home based functions, a curative focus and challenges with regard to referral systems hamper the implementation of PHC in South Africa (Blecher et al., 2011; Naledi et al., 2011). Until relatively recently health indicators showed negative trends with life expectancy rates dropping and child mortality rates rising (Kautzky & Tollamn, 2008). South Africa was not set to reach Millennium Development Goals four to six (Mayosi et al., 2012). However, positive changes, such as an increase in the number of service providers, compulsory community service, ward based outreach teams and community health workers, a specialised PHC nurse and environmental health specialist, school health services, district clinical specialist teams, policies targeting specific health conditions and curbing overspending, have been seen more recently (Blecher et al., 2011; Mayosi et al., 2012; Naledi et al., 2011). The result of these efforts are perhaps best illustrated by the fact that life expectancy, which dropped after 1994, improved and reached the 1994 rates of 54 years for men in 2010 and 59 years for women in 2011 (Blecher et al., 2011; Naledi et al., 2011). Figures also show a



change from no progress or regression in Millennium Development Goals four to six to a point where none of the indicators showed regression and some showed slight progress (Mayosi et al., 2012).

Despite these positive changes South Africa's current health outcomes are still below what one would expect from the health expenditure. On the whole the health care system is inefficient and a gap exists between policy and policy implementation (Mayosi et al., 2012; Naledi et al., 2011). Health care workers are not sufficiently equipped to implement PHC. They have too little training on the impact of social determinants of ill health and health outcomes and the advocacy role they have in this regard. In-service training is weak and often provided in silos instead of holistically (Naledi et al., 2011). South Africa has failed to establish a strong district system and especially to develop management capacity at district level (Mayosi et al., 2012; Naledi et al., 2011). Workload has been decentralized, but not resources. Provincial governments still maintain decision making power and control much of the financial resources. This top down management results in role uncertainty, a lack of authority and accountability of district managers and leaves them with little power to solve problems. In addition the institutional environment makes it difficult to act innovatively and implement new strategies (Naledi et al., 2011). These challenges are especially pronounced in rural provinces (Gaede & Versteeg, 2011; Matsoso & Strachan, 2011; Versteeg et al., 2013).

### **3.5 Summary**

Health and disease affect disability, function and quality of life. However, a relationship cannot be simplistically assumed nor be explained in a linear way, because quality of life is dependent on physical, emotional, spiritual, social and structural factors. Even so the physical component plays an important role and can be addressed through popular, folk or professional health care. In South Africa professional health care should be delivered according to the principles of PHC, but, this does not always occur. The next chapter explores health care access and might provide reasons why the implementation of the philosophy of PHC is challenging in South Africa.

## Chapter 4

### Theoretical Perspectives on Formal Health Care Access

#### 4.1 Introduction

Persons with disabilities access the same health care systems as their non-disabled counterparts. Thus this chapter explore variables that impact on health care access in general according to the EquitAble framework for health care access, i.e., systems, contextual, personal and community variables. Systems variables are discussed under accessibility, acceptability, affordability and equity of services. The specific contextual challenges of living in a rural area are explored under contextual variables. As is the impact of living in an agrarian community since the study population come from a community of farm workers. The chapter ends with a brief look at the role of relevant personal factors such as poverty, education and employment. While the variables that impact health care are presented in sequence it is important to remember that they are interrelated in complex ways, for instance disability and poverty are linked and both are in turn individually and together linked to health care access (Parnes et al., 2009).

#### 4.2 Global Health Care Access Figures

Wagner et al. (2011) and Wagner et al. (2013) used data gathered by the WHO in 2002 and 2003 as part of the WHS to analyse various aspects of health care access globally. They found that between 93% and 100% of households could access acute care as needed (Wagner et al., 2011). The findings on access to medication showed slightly lower figures with between 29% and 15% of households reporting not receiving all or most medicines in the previous 12 months (Wagner et al., 2011, 2013). Access for care of chronic conditions were lower, especially in poorer households, with 73% of poorer households in low-income countries and 49% of poorer households in high-income countries reporting a paucity in treatment for all or some chronic conditions (Wagner et al., 2011). Findings on access to preventative services showed that 39% of children received at least one measles and one diphtheria, tetanus and whooping cough vaccine and 55% of children received at least one vitamin A capsule in the 12 months prior to data collection (Wagner et al., 2013).

### 4.3 Formal Health Care Access

Formal health care access involves a dynamic interaction between service provision (supply) and the service user (demand). In order to demand health care users must identify a need for it. Various factors like knowledge, education, information, health literacy, health beliefs, trust, expectations, perceptions of health and illness, as well as sociocultural factors, such as gender, religion, and cultural beliefs play a role in whether an individual might identify a need for and seek health care. For example, some people might see lower back pain as part of their life's, and live with it, while others might see it as a disease and seek health care for it. Should a person identify a need for and seek health care they must be able to reach, afford and receive appropriate services; aspects that are influenced by variables like location, infrastructure, transport, quality, quantity, organisation, cost, attitudes and cultural sensitivity, many of which are determined by national, provincial and institutional policies and processes (Aday & Andersen, 1974; Balarajan et al., 2011; Gilson & Schneider, 2008; Levesque et al., 2013; Obrist et al., 2007; Peters et al., 2008; Russel et al., 2013).

Various frameworks, as summarised in Box 4.1, have been developed to illustrate the multifaceted nature of health care access. As indicated in Chapter 1 I used the EquitAble framework in this study. Thus health care access will be discussed under systems, contextual, personal and community variables.

**Health Access Livelihood framework (Obrist et al., 2007)**

According to this framework health care access, use and quality depends on policy, service availability, acceptability, affordability, adequacy and accessibility as well as user assets and vulnerabilities.

**Andersen's Behaviour Model of Health Services Use (Aday & Andersen, 1974)**

Health policy, health system characteristics, population characteristics, utilisation of health, service delivery and consumer satisfaction determine access.

**EquitAble framework (2008)**

Access depends on system, community, context and personal variables, and are determined by health status, quality and user satisfaction.

**Frenk's Domains of Access (Ricketts & Goldsmith, 2005)**

Access depends on availability and accessibility of services.

**Gilson & Schneider (2008)**

Access depends on availability, acceptability and affordability of services.

**Index of Rural Access (McGrail & Humphreys, 2009)**

Access depends on availability of, and proximity to, services, health needs and mobility.

**Institute of Medicine model (IOM) of access to personal health services (Brewer, 2005)**

Access depends on user barriers, utilization barriers, effectiveness and outcomes, as determined by equitability, efficiency and quality.

**Levesque et al. (2013)**

Access has five service (supply) dimensions, i.e., Approachability, Acceptability, Availability and accommodation, Affordability, Appropriateness; and five user (demand) dimensions, i.e., Ability to perceive a need, to seek, to reach, to pay and to engage health care.

**Penchansky's Elements of Access (Penchansky & Thomas, 1981)**

Access is the fit between user needs and the system's ability to meet their needs. "The specific dimensions are availability, accessibility, accommodation, affordability and acceptability" (p. 127)

**Peters et al. (2008)**

Access depends on policy, user characteristics, geographic access, acceptability, financial access, availability and quality of services.

**Russel et al. (2013)**

Access depends on availability, affordability, acceptability, geographic access, accommodation, timeliness and awareness.

**United Nations (2000)**

Access depends on availability, affordability, non-discrimination and equity.

*Box 4.1. Health care access frameworks*

Appendix 3 presents summaries of the methodologies used in the studies to which I refer in the discussion on access.

#### **4.4 Systems Variables that Impact Health Care Access**

I have identified availability, acceptability, affordability and equity as key health system dimensions, common to most frameworks, which impact health care access. These four dimensions were also used by Harris et al. (2011) in a South African study on health care access.

##### **4.4.1 Availability**

For the purpose of this study availability refers to all physical aspects of the service. An available service is of adequate quantity, quality, range and type. Numbers and skills of service providers are adequate; as is hours, location, medication, equipment and infrastructure (Balarajan et al., 2011; Gilson & Schneider, 2008; Levesque et al., 2013; McGrail & Humphreys, 2009; Obrist et al., 2007; Penchansky & Thomas, 1981; Peters et al., 2008; Ricketts & Goldsmith 2005; Russel et al., 2013; UN, 2000). Accommodations for persons with disabilities must be in place. This includes physical access to facilities and equipment, access to information in an understandable form, and staff knowledge about assisting and providing health care to persons with disabilities (UN, 2000).

While some access frameworks (Box 4.1) presents location as a separate dimension under accessibility (Obrist et al., 2007; Penchansky & Thomas, 1981) or geographic access (Peters et al., 2008; Russel et al., 2013) others included it under availability (Gilson & Schneider, 2008; Levesque et al., 2008; UN, 2000) as I did in this study since one can only use a service if you can reach it. Obrist et al. (2007) called organisation of care adequacy, while Penchansky and Thomas (1981) and Russel et al. (2013) refer to it as accommodation. Levesque et al. (2013) and Russel et al. (2013) organised information on services under approachability and awareness respectively. Other frameworks (Gilson & Schneider, 2008; Peters et al., 2008; UN, 2000) include these issues under availability as I have done in this study.

### *Human resources*

Health care systems are dependent on people to implement them. A service can only fulfil its obligations to users if staff are available in sufficient numbers, have adequate training and skills and are motivated (Balarajan et al., 2011). Staff shortages can have negative consequences for users, individual service providers and the organisation. Users might experience long waiting times and short consultations. Individual service providers have to deal with bigger workloads and might be forced to accept that they are unable to deliver services according to their personal standards. This can cause dissatisfaction and poor morale. The organisation might face problems like suboptimal patient care, poor staff retention and challenges with recruitment (Harris et al., 2014; Newman & Maylor, 2002). In addition to being adequate in numbers, service providers must be adequately skilled and have clinically sound knowledge as illustrated by the ability to provide a variety of clinical services, accurate diagnoses and effective treatments (Balarajan et al., 2011; Mosadeghrad, 2013; Sofaer & Firminger, 2005).

Various authors of the South African Health Review of 2011 identified insufficient numbers of health care workers as one of the key reasons for the poor performance of health care services in South Africa (Balarajan et al., 2011; Blecher et al., 2011; Cooke et al., 2011; Matsoso & Strachan, 2011). A participant in a study by Harris et al. (2014) describes the staffing dilemma in South African health care aptly: “the clinic is growing, it’s not frozen [unlike staff posts]” (p. 8). Shortages occur amongst all professional groups (Cooke et al., 2011; DWCPD, 2013; Harris et al., 2014; Tshitangano, 2013). Furthermore a lack of skills amongst service providers was identified as a challenge in South Africa by Mills et al. (2012). Users in the study by Harris et al. (2014) described the occurrence of misdiagnosis and Harris et al. (2011) found through a national household survey (n =4668) that 17.5% of South African study participants felt the medication they received at primary level did not improve their condition. The reasons for this were not explored and it might be related to issues like unavailability of drugs or a lack of clinical skills amongst providers.

According to Cooke et al. (2011), Gaede and Versteeg (2011), and Matsoso and Strachan (2011), staff shortages are more pronounced in rural South Africa than in urban parts of the country.

Studies performed in rural areas highlighted the following issues pertaining to human resources:

- Two qualitative studies performed in the North West Province identified staff shortages as themes from the data (Couper et al., 2007; Van Deventer et al., 2008).
- Staff shortages was seen as a challenge by 83% of participants in a rural Eastern Cape and KwaZulu Natal study (Schoeman et al., 2010).
- Eygelaar & Stellenberg (2012) identified a shortage of staff (indicated by 97% of nurse participants) in the West coast Winelands region (rural Western Cape) and a lack of skills amongst staff (indicated by 96% of participants).
- According to Van Deventer et al. (2008) inexperience and a lack of skills amongst rural staff limit service provision.
- In addition to general staff shortages, Eygelaar and Stellenberg (2012) and Van Deventer et al. (2008) identified shortages amongst doctors. In the study by Eygelaar and Stellenberg (2012) 72% of participants indicated a shortage of doctors.

Providers might be less enthusiastic to work in rural areas due to social isolation, less support and less access to training opportunities due to distances, time and staffing limitations (Brems et al., 2006; Cooke et al., 2011; Eygelaar & Stellenberg, 2012; Van Deventer et al., 2008). Fewer health care professionals limit the user's choice between service providers (Elliot-Schmidt & Strong, 1997; Fitzgerald et al., 2001; Iezzoni et al., 2006; Philo et al., 2003; Turner-Goins et al., 2005) and can thus negatively impact the acceptability of the service (Russel et al., 2013). Small teams, as often found in rural areas, are vulnerable since the loss of one team member can have a huge impact on service delivery (Gaede & Versteeg, 2011). International authors indicated that a shortage of providers, high provider turnover, a lack of skills, incorrect diagnosis and under treatment hampers rural health care service delivery (Arcury, Gessler et al., 2005; Brems et al., 2006; Chipp et al., 2011; Lourenço, 2012; Russel et al., 2013; Turner-Goins et al., 2005).

## *Medication*

Timely provision of medication is essential as delays in treatment can cause poorer health outcomes and disability in some instances (Ingstad et al., 2012). While South Africa has a National Essential Drug List, access to these drugs remains inadequate and stock outs in the public health care sector are reported on in reviews (Gaede & Versteeg, 2011; Naledi et al., 2011; Pharasi & Miot, 2013) and urban and rural research:

- Hasumi & Jacobsen (2014) found that 14% of South Africans reported unavailability of drugs.
- Walker & Gilson (2004) found in a survey of seven urban, primary health care facilities that 80% of responding primary health care nurses (n = 113) felt that essential drugs were not always readily available.
- Couper et al. (2007), Goudge et al. (2009a) and Mashia & Van Wyk (2004) indicated shortages of medication as a problem, but provided no figures.

Naledi et al. (2011) ascribes the challenges with regard to availability of drugs to weak procurement, warehousing and distribution systems.

Unavailability of medication is found throughout Sub Saharan Africa (Cameron et al., 2009; Kiwanuka et al., 2008; Mills et al., 2012; Obrist et al., 2007; Streefland, 2005; Toda et al., 2012). Cameron et al. (2009) used WHO survey data from 10 African countries, and found the mean availability of a basket of 15 generic medicines to be 29.4%, in the public health sector in Africa. Thus while public health care services in some countries might provide medicine free of charge unavailability might leave users with no alternative but to buy it from private sector suppliers. In addition, Patel et al. (2010) found that urban South African users believed that, since public service drugs were free of charge and/or generic brands, they are less effective and of lower quality.



### ***Equipment and consumables***

Eighty five percent of professional nurses identified shortages of consumables and equipment in the study by Walker & Gilson (2004). Mills et al. (2012) found a lack of diagnostic equipment in the public health care sectors of South Africa, Tanzania and Ghana. Challenges related to equipment are compounded by a shortage of staff with the technical skills to operate specialised equipment, poor maintenance of equipment, arbitrary procurement practices, a lack of guidelines on operation and repair as well as long waiting times for servicing and repairs (Bhagwandin, 2011; Naledi et al., 2011).

With regard to rural areas specifically, more than 70% of participants in the study by Eygelaar and Stellenberg (2012) identified a shortage of consumables and equipment as well as challenges with maintaining equipment. These figures are higher than the 43% of participants that identified a shortage of equipment and the 35% that identified a shortage of supplies in the Eastern Cape and KwaZulu Natal provinces (Schoeman et al., 2010). The difference might be due to a difference in study population. Eygelaar and Stellenberg (2012) interviewed all nursing staff while Schoeman et al. (2010) collected data from clinic managers only. Couper et al. (2007) also found shortages and poor maintenance of equipment as challenges in their qualitative study in the North West province.

### ***Hours and waiting times***

Inconvenient hours and long waiting times have been identified as a challenge during PHC visits in urban and rural South Africa (Day & Gray, 2008; Gilson et al., 2004; Harris et al., 2011; Hasumi & Jacobsen, 2014; Mashiri et al., 2008; Van Deventer et al., 2008). Furthermore users might wait months to be seen by a specialist and years to receive treatment of a more advance nature such as joint replacement surgery. Reasons for long waiting times include the large number of patients, lengthy administration procedures, a shortage of medical personnel, inefficiency, poor coordination of care between various service providers and levels of service and between private and public service providers (Goudge et al., 2009a).

### ***Infrastructure***

Old, small and dilapidated buildings, as well as a shortage of water, electricity and communication systems cause infrastructure challenges in rural South Africa (Couper et al., 2007; Gaede & Versteeg, 2011; Schoeman et al., 2010). Schoeman et al. (2010) found in a study in four rural districts of the Eastern Cape and KwaZulu Natal that 43% of clinic buildings in both provinces were in a poor condition. In addition 75% of clinics in the Eastern Cape and 50% in KwaZulu Natal had insufficient water supplies. Energy was a challenge in 65% of Eastern Cape clinics and 25 % of KwaZulu Natal facilities. These problems exist despite the building 1300 new clinics and upgrading a further 252 since 1994. According to Blecher et al. (2011) there is ongoing under-expenditure of money earmarked for infrastructure development in South Africa due to a lack of capacity and supervision.

### ***Range of services***

According to Gaede and Versteeg (2011) limited service packages in rural areas give rural users fewer options than their urban counterparts. In addition rural emergency services are less resourced than urban emergency services (Gaede & Versteeg, 2011).

In summary, the availability of health care services in South Africa is hampered by a lack of resources such as service providers, medication, and equipment. In addition the skills of service providers are not always adequate. The lack of resources, in combination with organisational and infrastructure challenges, can impact negatively on acceptability of services.

#### **4.4.2 Acceptability**

Box 4.1 shows that most of the health care access frameworks included acceptability as a dimension of health care access. An acceptable service is ethical, respectful, confidential, culturally appropriate and, sensitive to gender and life-cycle requirements (Gilson & Schneider, 2008; Levesque et al., 2013; Obrist et al., 2007; Penchansky & Thomas, 1981; Peters et al., 2008; Russel et al., 2013; UN, 2000). Acceptability of services is dependent on:

- Cultural sensitivity to users' beliefs on and construction of health and healing (Dillip et al., 2012; Gilson & Schneider, 2008; Mosadeghrad, 2013; Obrist et al., 2007).
- Treating users as persons not diseases (Brugge et al., 2009; Mosadeghrad, 2013).
- Communication between user and provider (Atinga et al., 2011; Gilson & Schneider, 2008; Goudge et al., 2009a; Hussey, 2013; Tonoyan & Muradyan, 2012). The importance of communication is asserted by Bensing, Verhaak, van Dulmen and Visser (2000, p. 3) who call communication "the royal pathway to patient centred medicine". Attentive listening and the ability to explain complex medical terms, conditions, tests results, prognosis, management strategies and procedures in an understandable way are valued by users (Bensing et al., 2000; Brugge et al., 2009; Goudge et al., 2009a; Mosadeghrad, 2013; Sofaer & Firminger, 2005).
- Education that empowers users to make autonomous decisions about their health and its management (Bensing et al., 2000; Brugge et al., 2009; Goudge et al., 2009a; Mosadeghrad, 2013; Sofaer & Firminger, 2005).
- Patient centred care. Health care users should participate in goal setting and management planning. They must be empowered through communication, sharing of information and education on their condition and alternative management strategies to enable them to make informed choices about their management. Patient centred care has been associated with advantages like a decrease in symptoms, increased function, improved physical and mental health status, improved patient satisfaction with services, and better compliance with and acceptance of management strategies (Zimmermann, Konrad, Muller, Rundel, Korner, 2014; WHO, 2011).
- The absence of prejudice and stereotyping (Gilson & Schneider, 2008).

Health worker attitudes and behaviour play an important role in creating an acceptable service. Users stressed the importance of behavioural aspects like eye contact, empathy, listening to them, sensitivity, kindness, friendliness, courtesy, respect, compassion, dependability, and emotional support. In addition service acceptability is impacted by clinical factors. This include spending enough time with users, doing comprehensive clinical examinations, trust in the skills of service providers, explaining the condition and treatment, involving users in clinical decision

making, and respecting the privacy of users (Brugge et al., 2009; Gilson et al., 2004; Mills et al., 2012; Mosadeghrad, 2013; Sofaer & Firminger, 2005; Tonoyan & Muradyan, 2012).

In South Africa acceptable and respectful service delivery as encompassed by the Batho Pele principles are expected from every civil servant. The term Batho Pele means “people first” and advocates improved public service delivery. Batho Pele is based on eight principles of which at least four, i.e., user consultation, courtesy, providing information to users, and redress, have a direct connection to service acceptability (South African Department of Public Service and Administration, 1997). In spite of the Batho Pele principles, unacceptable practices by health care service providers are documented (Day & Gray, 2008; Gilson et al., 2004; Harris et al., 2011; Hasumi & Jacobsen, 2014). Challenges in both rural and urban areas related to:

- Communication difficulties because of poor proficiency in a mutual language. South Africa has 11 official languages. Thus it is not unusual for users and providers to have no common language in which both are proficient (Hussey, 2013).
- Negative, uncaring attitudes, rudeness and disrespect (Cleary et al., 2012; Couper et al., 2007; Day & Gray, 2008; Gaede & Versteeg, 2011; Gilson et al., 2004; Gilson & Schneider, 2008; Harris et al., 2011, 2014; Hasumi & Jacobsen, 2014; Kautzky & Tollman, 2008; Versteeg et al., 2013). Harris et al. (2014) described how shaming and humiliation of users lead to user passivity and a reluctance amongst users to ask questions.
- A lack of confidentiality (Couper et al., 2007; Harris et al., 2011).
- Inadequate explanations (Harris et al., 2014; Patel et al., 2010).
- Allowing paperwork to take precedence over users (Peltzer, 2000).
- A lack of privacy (Harris et al., 2011; Westaway et al., 2003).
- A lack of individualised care (Patel et al., 2010).
- Taking long breaks (Gilson et al., 2004).
- Users turned away (Hasumi & Jacobsen, 2014).
- Not using a triage system (Gilson et al., 2004).
- Dirty facilities (Hasumi & Jacobsen, 2014).

- Incorrect or no diagnosis (Hasumi & Jacobsen, 2014).
- Lost results and inadequate or absent records (Gilson et al., 2004; Gilson & Schneider, 2008; Hasumi & Jacobsen, 2014; Kautzky & Tollman, 2008; Van Deventer et al., 2008).
- Poor continuity and seeing a different member of staff at every visit (Van Deventer et al., 2008).
- Confusing processes and bureaucratic systems with regard to levels of care, referral pathways and access requirements hamper user access to the system and cause users to be lost to follow up (Bateman, 2012; Cooke et al., 2011; Gaede & Versteeg, 2011; Van Deventer et al., 2008).
- Irregular and inadequate follow up (Van Deventer et al., 2008).

Staff satisfaction, attitudes, morale and behaviour are shaped by a variety of factors including the demands of their jobs, availability of resources, working conditions, decision making power, workloads, the standard of training, training opportunities, respect and support from managers and users, safety, remuneration (Gilson et al., 2004; Gilson & Schneider, 2008; Graber et al., 2008; Kautzky & Tollman, 2008; Newman & Maylor, 2002; Tshitangano, 2013), the hardships experienced by the communities they serve (Gilson et al., 2004) and health care reform (Gilson et al., 2004). PHC professional nurses are especially exposed to the stressors related to patient care since they are often working at the interface between the public and the health system. In order to cope with the challenges they have developed practical strategies such as splitting and distancing. Splitting refers to the breakdown of patient care into tasks with different providers taking users histories, measuring vital signs, consulting and dispensing medication. Distancing include aspects such as referring to a user though his or her disease (the paraplegic from School street), not becoming involved with emotional issues and standardised routines. Splitting and distancing help to create a defence system that decreases personal involvement with users and the need to develop creative solutions for specific challenges faced by individual users, but might decrease service acceptability (Van der Walt & Swartz, 1999).

Acceptable services empower users to take appropriate action. In addition, the insights and knowledge gained on the disease empowered the user and family to become a community resource on that condition (Goudge et al., 2009a). Unacceptable services can lead to

inappropriate or lower rates of intervention relative to need, users not understanding the diagnosis and management strategies, users doubting the effectiveness of treatment, healer shopping, user unwillingness to reveal past medical history, lower referral rates to secondary and tertiary care, limited user compliance, failure to follow up, lower self-reported health status, and dissatisfaction with services (Gilson & Schneider, 2008; Goudge et al., 2009a).

In summary South African health care workers do not always provide an acceptable service. Communication, behaviour, attitudinal and process challenges have been identified. Where users find services unacceptable they might incur expenses in order to access a different service.

#### **4.4.3 Affordability**

While definitions differ, affordability refers to a match between the cost of the service and the ability/willingness of users to pay for it (Gilson & Schneider, 2008; Levesque et al., 2013; Obrist et al., 2007; Penchansky & Thomas, 1981; Peters et al., 2008; Russel et al., 2013; UN, 2000). Cost of care can create barriers with regard to access and continuity of health care (Ansah et al., 2009; Balarajan et al., 2011; Falkingham, 2004; Kiwanuka et al., 2008; Obrist et al., 2007; Peters et al., 2008; Tonoyan & Muradyan, 2012; Trani & Barbou-des-Courieres, 2012; WHO, 2008a). However, receiving health care of good quality and services underlying good health like clean water should not depend on a person's ability to pay for it (Gilson & Schneider, 2008; Peters et al., 2008; UN, 2000). Accordingly the South African public sector provides health care based on a system that does not exclude anybody on grounds of not being able to pay and give particular support to vulnerable groups. This might be why Mills et al. (2012) found that 0.09% of South Africans incurred catastrophic health expenses versus 2.43% of Ghanaians and 1.52% of Tanzanians. Free health care policies have shown increased use of preventative, curative and promotive health care in South Africa and Uganda (Peters et al., 2008), while introduction of fees showed a drop in health care utilisation in Ghana (Ansah et al., 2009; Peters et al., 2008).

However affordability remains a problem for some South Africans, because exemption policies are not always applied (Goudge et al., 2009a, 2009b; Harris et al., 2011; Mills et al., 2012). A study done in two rural villages in Mpumalanga found that illness accounted for 4.5% of household spending. Visiting a clinic incurred a burden of 1.3%, while an out-patient visit to a

hospital incurred a burden of 8.2% (this is equal to the average cost of a month's supply of staple starch) and in-patient hospital costs caused a burden of 45% (Goudge et al., 2009b). Cleary et al. (2013) found that South Africans from rural settings incurred higher costs to access health care while they had less means to pay for it, than those from urban settings. A greater proportion of households in the rural settings of this study borrowed or sold assets to pay for health care. The authors pointed out that this practice is not sustainable in the case of chronic conditions such as tuberculosis (TB) or Human Immunodeficiency Virus (HIV). The same authors reported that 50% of users in an anti-retroviral therapy programme in a rural setting spent more than 10% of the household resources on health care (this is seen as catastrophic spending) and 36% borrowed money to cover the expense (Cleary et al., 2012).

The cost burden of health care is further exposed by data from the WHS where 22% of participants from low-income countries and 16% from low- to middle-income countries indicated that the burden of health care expenses was potentially catastrophic. Forty four percent of participants in low- income countries (data from 20 low-income countries were analysed) used savings, borrowed money or sold assets to pay for health care (Wagner et al., 2011). The main reason for the high expenses was indicated as the cost of medication (Balarajan et al., 2011; Blecher et al., 2011; Cameron et al., 2009; Mills et al., 2012; Wagner et al., 2011). In low-income countries medication was, after food, the biggest family expense (Cameron et al., 2009). In addition to direct costs, indirect costs such as transport, meals, accommodation and loss of income impacts negatively on affordability of health care (Ansah et al., 2009; Bakeera et al., 2009; Balarajan et al., 2011; Buchanan et al., 2006; Cleary et al., 2012, 2013; Elliot-Schmidt & Strong, 1997; Goudge et al., 2009b; Harris et al., 2011; Hjortsberg & Mwikisa, 2002; Ingstad et al., 2012; Kautzky & Tollman, 2008; Kiwanuka et al., 2008; Levesque et al., 2013; Matsoso & Strachan, 2011; Obrist et al., 2007; Peters et al., 2008; Philo et al., 2003; Russel et al., 2013). A study from rural Mpumalanga found that 42% of money spent on health care was spent on transport; this increased to 60% when hospital visits were considered (Goudge et al., 2009b).

When health care must be purchased at a price beyond the means of the person who needs it, the person might not seek care which might exacerbate the condition and require more expensive care at a later stage (Balarajan et al., 2011; Goudge et al., 2009b). Ill health can also impact

negatively on quality of life and the ability to earn. On the other hand should people access health care at a price that they cannot afford it will erode funds destined for basic necessities like food and long term investments in for example education. These can also have a negative effect on quality of life and health (Wagner et al., 2011; WHO, 2008a). Alternatively people might seek health care from unregulated and unlicensed providers, or other sources (Ansah et al., 2009). In this situation health promotion and prevention are seldom addressed and it might lead to financial exploitation, bad quality and unsafe care (Goudge et al., 2007; Peters et al., 2008; WHO 2008a).

In conclusion it seems as if health care costs can cause economic hardship for families even in South Africa where cost exemption policies exist. A considerable amount is expended on medication and indirect costs related to transport, loss of income and meals. Cost of care can lead to inequity in service delivery with the poor receiving fewer services than the rich.

#### **4.4.4 Equity**

Equity in health care refers to a moral commitment to ensure social justice in health care service provision (Fleurbaey & Schokkaert, 2011; Kawachi, Subramanian, & Almeida-Filho, 2002). Thus equitable health care services should enable everybody to reach an optimal level of wellbeing, and to be equitable services should be provided according to individual need (Ataguba & McIntyre 2013; UN, 2000). Equity is achieved when two persons with the same morbidity receive the same amount and quality of care. Health inequality is caused by injustice (Fleurbaey & Schokkaert, 2011; Kawachi et al., 2002), for example the disparities in health care service delivery to various South African population groups before 1994 (Coovadia et al., 2009).

Gilson & Schneider (2008) incorporate equity as a sub dimension of acceptability; arguing that it is usually marginalised groups which are discriminated against. On the other hand the United Nations (UN, 2000) Right to Health document incorporates equity under availability and affordability by stressing that service availability should not depend on a person's ability to pay for it. Obirst et al. (2007) and Brewer (2005) see equity as a health status outcome. However equity can be a determinant of health status, quality of services and user satisfaction as well.



Therefore and because of the challenges South Africa experience with providing equitable services equity has been included as a separate dimension in this study.

Ataguba et al. (2011) and Mills et al. (2012) indicate pro-rich health care service benefits in both the private and public sector of South Africa while the poor showed higher burden of disease. However, Ataguba and McIntyre (2013) found a pro poor benefit at public facilities such as clinics, community health care centres and district hospitals in South Africa and an equal distribution of benefits between rich and poor when all public service facilities are looked at in combination. Hasumi & Jacobsen (2014) found that health care service delivery in South Africa is inequitable with regard to race. Significantly more Black African households reported challenges when accessing health care than the other population groups (this was true after adjustment for provider type and socio-demographic factors).

Thus while the South African government is committed to equity in policy and legislation, inequities remain between population and socio-economic groups as well as between provinces, and within provinces between urban and rural areas (Cooke et al., 2011; Coovadia et al., 2009; Gaede & Versteeg, 2011; Sanders & Chopra, 2006). Examples include an infant mortality rate ranging from 71 per 1000 live births in rural areas to 43 in urban areas and TB cure rates that are 19.9% higher in Gauteng than in the North West Province (Gaede & Versteeg, 2011). While social and economic factors play a role in these figures, inequities in health care service provision between rural and urban areas and access challenges in rural areas are in part to blame (Balarajan et al., 2011; Blecher et al., 2011; Cooke et al., 2011; Gaede & Versteeg, 2011; Matsoso & Strachan, 2011). For instance more urban provinces have on average 30 general doctors and 30 specialists per 100 000 of the uninsured population, while more rural provinces have on average 13 general doctors (7690 people per general doctor) and two specialists per 100 000 of the uninsured population (Cooke et al., 2011).

Rural areas might require more money per capita than urban areas to ensure equitable services. Certain basic resources and crucial services must be available irrespective of how often they are utilised. Thus efficiency indicators should not be the only yardstick when allocating resources to rural services (Gaede & Versteeg, 2011; Matsoso & Strachan, 2011). For instance mobile

services may spend a lot of money and time on travel while providing services to only a few users and are therefore less efficient, but not less vital to the right to health of rural populations.

Strict scope of practice regulations might be inappropriate in rural contexts, especially in the light of staff shortages and limited transport to district hospitals. Service providers in rural areas may need to perform procedures that are not within their scope of practice and need to increase their capacity (Gaede & Versteeg, 2011; Gilson et al., 2004). An example is the catheterization of males, a procedure outside the scope of practice of the primary health care nurse, but one that can save a user severe discomfort in a rural setting with no immediate access to a doctor.

#### **4.5 Contextual Variables that Impact Health Care Access in Rural Areas**

The physical and demographic features of rural areas impact on health care access (Philo et al., 2003). Distances from services, the degree of harshness of the environment, climate extremes, landscape challenges, poor infrastructure, travelling time and availability or not of transport interact to create barriers to health care access in rural areas of all parts of the world (Arcury, Preisser et al., 2005; Arcury, Gesler., et al., 2005; Auchinloss & Hadden, 2002; Balarajan et al., 2011; Brems et al., 2006; Buchanan et al., 2006; Cummins, 2002; Elliot-Schmidt & Strong, 1997; Fitzgerald et al., 2001; Gaede & Versteeg, 2011; Goudge et al., 2009b; Hjortsberg & Mwikisa, 2002; Hossen & Westhues, 2011; Khan et al., 2006; Klemick, Leonard, & Masatu, 2009; Mamdani & Bangser, 2004; McGibbon et al., 2008; Mills et al., 2012; Peltzer et al., 2007; Russel et al., 2013; Tonoyan & Muradyan, 2012; Turner-Goins et al., 2005).

Arcury, Gesler et al. (2005) found in a quantitative study in rural North Carolina, USA that persons living farther from services have fewer regular check-up visits per year, but that distance did not impact the number of acute and chronic care visits. However, Hiscock et al. (2008) found that longer travel times decreased General Practitioner consultations and Pharmacy visits in New Zealand. In addition rural users have poorer access to specialists, who seldom practise in rural areas since the low population density makes it economically non-viable. Thus rural users have to travel long distances often at high cost to access specialist services in urban hospitals (Ansah et al., 2009; Bakeera et al., 2009; Brems et al., 2006; Buchanan et al., 2006; Chipp et al., 2011; Cooke et al., 2011; Elliot-Schmidt & Strong, 1997; Fitzgerald et al., 2001; Gaede &

Versteeg, 2011; Hjortsberg & Mwikisa, 2002; Khan et al., 2006; Kiwanuka et al., 2008; Mamdani & Bangser, 2004; Obrist et al., 2007; Peters et al., 2008; Russel et al., 2013; Schoeman et al., 2010; Turner-Goins et al., 2005; Van Deventer et al., 2008). In a qualitative study by Turner-Goins et al. (2005), 33% of 101 elderly Americans indicated that having to travel out of town for specialist care was a barrier to health care access. Participants suffering from chronic conditions, in a qualitative study from rural Australia, reported loss of time before a diagnosis was made. They ascribe the time loss to limited availability of doctors and especially specialists in rural areas (Fitzgerald et al., 2001). Staying in a city for specialist care may cause anxiety about family and work at home. The strangeness of the surrounds and lack of family support may be distressing and can impact negatively on healing (Elliot-Schmidt & Strong, 1997). Furthermore, distance impacts negatively on attending regular sessions such as therapy (Buchanan et al., 2006; Elliot-Schmidt & Strong, 1997) and on accessing timeous emergency care (Cummins, 2002; Gaede & Versteeg, 2011).

Travelling in rural areas in Global South countries is challenged by problems such as difficult terrain, flooding, poor quality of roads, expensive, inadequate or non-existent public transport (; Kiwanuka et al., 2008; Obrist et al., 2007; Schoeman et al., 2010) and unavailable or expensive private transport (Obrist et al., 2007). South Africa has 221 000 kms of rural roads, some of which are difficult to negotiate by motorised vehicle. This creates barriers to the provision of transport (DWCPD, 2013). In addition, in emergencies ambulances are not always available or when they are available it takes a long time for the ambulance to arrive (Couper et al., 2007; Gaede & Versteeg, 2011; Harris et al., 2014). Walking, often over difficult terrain, is the most common way of reaching health care services in rural Africa (Hjortsberg & Mwikisa, 2002; Khan et al., 2006; Kiwanuka et al., 2008; Mamdani & Bangser, 2004; Mashiri et al., 2008; Peters et al., 2008). In a nationwide South African study Harris et al. (2011) found that 45.2% of participants used public transport to access health care while 37% walked.

Finally distances and isolation decrease access to sources of information such as radio, television and internet (Eide, Loeb et al., 2011). This might negatively impact the knowledge of rural communities, lead to a lack of awareness of services (Turner-Goins et al., 2005) and of information on newly developed interventions (Chipp et al., 2011) and hamper health promotion,

prevention and management practices. Furthermore, agrarian communities face their own special circumstances.

#### **4.5.1 The agrarian context**

Farms and farming areas vary widely. Therefore there are no universal truths about the health of agrarian communities (Atkinson, 2007). However, farming might expose both employer and employee to a number of environmental, chemical, biological, mechanical and physical hazards that can lead to musculo-skeletal conditions, dermatitis, eye, and respiratory problems, traumatic injuries, hearing loss, chemical injuries and various cancers (Lovelock, 2012; Olowogbon & Fakayode, 2013; Smith et al., 2008). Furthermore criminal attacks, causing death or injury to owners and sometimes farm workers, are escalating and have become a health risk in farming communities in South Africa (Lemke, 2005).

Elliot-Schmidt & Strong (1997) found in Australia that people living on farms often postponed seeking health care until a trip to town was scheduled. These trips have multiple purposes such as stocking up on food and attending community meetings. Thus seeking health care might not always be a priority. This can cause delayed treatment and result in increased complexities or permanent impairments in conditions that could have been cured (Elliot-Schmidt & Strong, 1997).

In South Africa many rural dwellers work on commercial farms for wages (Hall et al., 2013). Historically farmer farmworker relations have been hallmarked by social paternalism, unequal social relationships and “rigid gridlines of racial stratification” (Atkinson, 2007, p. 2; Levine, 2013). An increase in professionalism, changing relationships between farmers and farmworkers, and laws that protect farmworkers against exploitation are beginning to bring about change (Atkinson, 2007). However the changes are slow. For instance, Levine (2013) argues that, in many instances, policies and laws meant to improve the situation of farmworkers have an adverse effect and lead to even deeper poverty, hunger and social depravation, because there is

no social structure to support those disadvantaged by generations of adverse practices such as the “dop”<sup>4</sup> system.

Thus farmworkers are amongst the most vulnerable South Africans in terms of income, health and education (Atkinson, 2007; Hall et al., 2013; Lemke, 2005). They experience structural inequalities caused by the history of the country, gender inequality, dysfunctional families and a lack of social and organisational skills (Atkinson, 2007; Hall et al., 2013). They are often faceless and powerless; difficult to reach due to the remoteness of where they live, a lack of basic communication services and a lack of transport (Atkinson, 2007). Farm workers are often dependent on farmers for transport (Atkinson, 2007; Botes, 2011), since less than 3% of farmworkers own a vehicle and there is little or no public transport available to them (Cummins, 2002). Visits to town might be as infrequent as once per month (Atkinson, 2007). Lemke (2005) describes farmworkers as “trapped” without the skills to participate in the wider economy and without the opportunity for progress on the farm; a scenario made all too real by Levine’s ethnographic studies on child labour in the Cape winelands (Levine, 2013) and by this quote from (Atkinson, 2007, p. 1–2):

Conditions are poor on many farms, so many farmworkers are losing their jobs and moving to towns and cities. But deep poverty already characterises the towns and cities, those who have migrated to the towns . . . will simply swell the numbers of the . . . poor . . . and those farmworkers who remain on the farms are unlikely to be able to make their needs known.

Thus it is not surprising that, according to Hall et al. (2013), dependence on social security payments are increasing in rural towns.

The health of farmworkers is negatively affected by occupational hazards, poor access to health care, migrancy, social discrimination, poor living conditions, poverty and coercive labour relations (Lemke, 2005). In addition high levels of smoking, alcohol abuse, domestic violence

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<sup>4</sup> “. . . farmers providing alcohol as a method of partial payment to workers” (Atkinson, 2007, p. 138).

and malnutrition is found amongst farm workers (Atkinson, 2007; Botes, 2011; Lemke, 2005). Alcohol related trauma, Fetal Alcohol Syndrome (FAS)<sup>5</sup>, and diseases in which smoking and alcohol abuse are risk factors, are common (Atkinson, 2007). On the whole farmworkers face adverse socio-economic circumstances.

#### **4.6 Personal Socio-economic Variables that Impact Health and Health Care Access**

There is a well-documented negative association between health care access, good health outcomes and aspects of social deprivation such as:

- Poverty (Butler et al., 2013; Gaede & Versteeg, 2011; Jatrana & Crampton, 2009; Khan et al., 2006; Ncho & Wright, 2013; Rukwong, 2008; Wagner et al., 2011).
- Lack of education (Balarajan et al., 2011; Butler et al., 2013; Gaede & Versteeg, 2011).
- Unemployment (Butler et al., 2013; Ncho & Wright, 2013).
- Substance abuse (Butler et al., 2013; Gaede & Versteeg, 2011).
- Food insecurity and poor nutrition (Butler et al., 2013; Gaede & Versteeg, 2011).

Mechanic and Tanner (2007) summarise the connection as follows:

The pathways through which education, income, wealth, and occupational status shape vulnerability and resilience are complex, but socio economic status indicators are associated with almost every measure of health and health care, including . . . morbidity, impairment and disability, health behavior, and less access to medical care of all kinds. (p. 1226)

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<sup>5</sup> “Fetal alcohol syndrome (FAS)/partial FAS (PFAS) are endemic in impoverished communities of the Western and the Northern Cape provinces of South Africa. . . . levels of FAS/PFAS ranging between 40.5 and 119.4 per 1 000 have been documented in several parts of these provinces. A recent study [May et al., 2013] examined the prevalence of FASD (which is a broader and less well defined group) in an area of the Western Cape, and estimated the prevalence at between 135.1 and 207.5 per 1 000 . . . FAS/PFAS is more common where mothers were resident in a rural area at the time of pregnancy” (Olivier, Urban, Chersich, Temmerman, Viljoen, 2013, p. 402).

In general, persons with disabilities experience higher incidence of these correlates of poor health than do their peers (Drum et al., 2008; Groce, Bailey, Lang, Trani & Kett, 2011 et al., 2011; Iezzoni, 2009; Ingstad & Eide, 2011; Mitra, Posarac, & Vick, 2012) and they are often the most vulnerable in situations of poverty or deprivation (Ingstad & Eide, 2011).

#### **4.6.1 Poverty**

Vladeck (2007) has argued that poverty is the biggest cause of vulnerability and persons with disabilities are overrepresented amongst the very poor of society (Ingstad & Eide, 2011; Mitra, Findley, & Sambamoorthi, 2009). This is true for South African society too, where Ataguba et al. (2011) have found that poor South Africans show significantly higher prevalence of disability than their more affluent country folk.

Poverty and disability relate to each other in a complex, often negative, spiral. Each is both a cause and an effect of the other. Poverty may lead to disablement through having to live in neighbourhoods with a higher incidence of social determinants of poor health, malnutrition and hazardous employment, as well as limited access to education, health care, land and shelter, and political and legal processes (Furumoto-Dawson et al., 2007; Graham et al., 2014; Ingstad & Eide, 2011; Lee et al., 2010; Leight, 2003; Mamdani & Bangser, 2004; Mechanic & Tanner 2007; Parnes et al., 2009; Peters et al., 2008; Vladeck, 2007; Yeo & Moore, 2003). Specifically with regard to health care poverty can cause late or no health care seeking, poor continuity of care, and difficulty in complying with disease management strategies, which can aggravate impairments and disability. This can lead to increased health care cost through higher rates of hospitalisation, a need for more complex management strategies and longer treatment times, which in turn aggravate poverty (Goudge et al., 2009a, 2009b; Goudge et al., 2007; Harris et al., 2014; Ingstad & Eide, 2011; Kiwanuka et al., 2008; McGibbon et al., 2008; Peters et al., 2008; Rukwong, 2008; WHO, 2008a).

Disability in turn may lead to poverty due to a reduction in income generating opportunities caused by the impairment, discrimination, social isolation, low expectations, exclusion from education, employment, political, and legal processes as well as decreased access to health care (Groce, Kembhayi et al., 2011; Yeo & Moore, 2003). The burden of disability increases the risk

of poverty for households through increased costs related to the disability, such as medical care, assistive devices, consumables and care giving (Palmer, 2011; Parnes et al., 2009; Yeo & Moore, 2003).

Thus in a continuous cycle poverty can cause or aggravate disease, ill health and disability; and disease, ill health and disability can cause or aggravate poverty (Braithwaite & Mont, 2009; Ingstad & Eide, 2011; Palmer, 2011; Parnes et al., 2009; Trani & Loeb, 2012; Yeo & Moore, 2003). In a case study from rural Eastern Cape, South Africa, Grut et al. (2012) provide an example of the negative interplay between poverty, social deprivation and a health condition; they show how poverty causes barriers to health care access on personal, communal and systems levels through societal norms, a lack of infrastructure, services, transport, money to afford what is available, knowledge and understanding as well as poor responsiveness from health care services. These factors led to increasing severity of impairments and disability, which in turn aggravated the challenges of accessing health care and deepened poverty.

#### **4.6.2 Education, knowledge and literacy**

A lack of knowledge and education has been linked to:

- Decreased health care access, health care use and compliance with care (Balarajan et al., 2011; Butler et al., 2013; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Gaede & Versteeg, 2011; Kiwanuka et al., 2008; Leight, 2003; Levesque et al., 2013; Obrist et al., 2007; Peters et al., 2008; Plug et al., 2012; Trani & Barbou-des-Courieres, 2012).
- Poorer ability to understand and deal with health conditions (Sofaer & Firminger, 2005).
- Being less able to demand health care services (Balarajan et al., 2011; Levesque et al., 2013; Trani & Barbou-des-Courieres, 2012).
- Decreased use of preventative health services including screening procedures and immunisations (Plug et al., 2012; Scudder, 2006).
- Less disease specific knowledge amongst those who suffer from chronic diseases such as Diabetes Mellitus and hypertension (DeWalt et al., 2004; Gazmararian, Williams, Peel, & Baker, 2003).
- Poor health outcomes (Bakeera et al., 2009; DeWalt et al., 2004; Mfenyana et al., 2006).



- A higher prevalence of negative health behaviour such as smoking, excessive use of alcohol and obesity (Plug et al., 2012).

Education of children with disabilities plays an important role in decreasing poverty among adults with disabilities (Groce, Kembhayi et al., 2011). However, persons with disabilities experience lower rates of education throughout the world (Drum et al., 2008; Eide, Loeb et al., 2011; Graham et al., 2014; Lang et al., 2011; Mitra et al., 2012; Park, 2014; Trani and Loeb, 2012; WHO, 2011; Yeo & Moore, 2003). In addition persons with disabilities from poorer countries have lower levels of education than from more affluent countries (WHO, 2011). An African study found that between 25% and 40% of people with disabilities in rural areas have not attended school while 15% to 30% of persons with disabilities in urban areas never attended school (Eide, Loeb et al., 2011).

Similarly educational levels are lower amongst South Africans with disabilities than their counterparts without disabilities (Cramm et al., 2013; Gathiram, 2008; Schneider et al., 2009; Schneider & Nkoli, 2011). The World Disability Report (WHO, 2011) indicates that 99% of South African children, aged six to 11, without disabilities are in school compared to 75% of those with disabilities. Loeb, Eide, Jelsma, Ka Toni, and Maart (2008) found that 12% of children with disabilities of school going age in the Eastern Cape have never been to school and 22% in the Western Cape, while 1% of children without disabilities in the Eastern Cape and 4% in the Western Cape have never attended school. The difference is statistically significant for both provinces ( $P = < .001$  Eastern Cape and  $0.003$  Western Cape). Cramm et al. (2013) found that 81.5% of youth with disabilities in the Northern and Eastern Cape provinces received formal education versus 98.3% of their peers.

Low levels of education have a negative impact on employment status (Groce, Kembhayi et al., 2011; Mechanic & Tanner, 2007), since it limits employment opportunities and often leaves people with no choice but to take on hazardous jobs, which in turn carry a high risk of injury and impairment (Ingstad & Eide, 2011).

### **4.6.3 Employment**

Persons with disabilities are more likely to be unemployed than those who are not disabled (Cramm et al., 2013; Drum et al., 2008; Graham et al., 2014; Lang et al., 2011; Mitra et al., 2012; Schneider et al., 2009; Schneider & Nkoli, 2011; Trani & Loeb, 2012; WHO, 2011). According to the World Disability report 12.4% of South Africans with disabilities are employed compared to 41.1% of their able bodied peers (WHO, 2011). Unemployment and unstable work histories increase vulnerability to disease and disability through poverty, lack of social status and lack of opportunities to gain knowledge and information (Mechanic & Tanner, 2007). With stable employment come advantages such as health insurance and sick leave. Both improve one's ability to access health care. In addition health insurance provides the user with choices with regard to service providers, points of service delivery and treatment options (Lee et al., 2010).

### **4.7 Community Variables that Impact Rural Health Care Access**

Rural communities often face bigger socio economic challenges than those in urban areas internationally (Arcury, Gesler et al., 2005; Brems et al., 2006) and in South Africa (Gaede & Versteeg, 2011; Neves & Du Toit, 2013). Furumoto-Dawson et al. (2007), Khan et al. (2006), Mechanic and Tanner (2007) and Ncho and Wright (2013) connected living in disadvantaged neighbourhoods to decreased health care access, increased health risks and poorer health outcomes. Reasons for this included underdeveloped infrastructure, crime, pollution, poor service delivery and fewer resources at health care service facilities. In addition, rural populations may show higher incidence of behaviour associated with poorer health outcomes such as smoking, high alcohol consumption, stress, poor nutrition and little exercise (Bourke et al., 2004; Smith et al., 2008). Rural residents are less likely to access preventative screening (Smith et al., 2008) and adhere to preventative practices (Lovelock, 2012; Smith et al., 2008).

On the positive side rural communities tend to be close knit with social networks that connect people in useful, supportive ways and provide practical, physical, financial and emotional assistance during stressful times. Strong social support networks can increase access to money, knowledge, information and somebody to accompany one, and thus improve people's ability to

access health care (Kiwanuka et al., 2008; Mechanic & Tanner, 2007; Obrist et al., 2007; Peters et al., 2008). However, social support depends on acceptance and people suffering from a health condition that carries a stigma might avoid seeking health care (Brems et al., 2006).

People in rural areas know each other well due to routine encounters and because most are involved in the same community institutions such as schools and churches; a situation that can impact privacy negatively (Bourke et al., 2012; Brems et al., 2006; Chipp et al., 2011; Smith et al., 2008). Seeking health care on a sensitive issue from someone one knows socially causes a lack of anonymity which may cause hesitance in disclosing all relevant information, distress and non-use of services (Bourke et al., 2004, 2012; Brems et al., 2006; Elliot-Schmidt & Strong, 1997; Fitzgerald et al., 2001; Philo et al., 2003). In addition it might become difficult for providers to separate social and professional roles (Brems et al., 2006; Chipp et al., 2011; Philo et al., 2003). Furthermore, new comers are seldom trusted immediately in close-knit rural communities. This can create a lack of trust in incoming health care providers (Chipp et al., 2011; Elliot-Schmidt & Strong, 1997).

#### **4.8 Summary**

This chapter focussed on systems, contextual, community and personal variables that impact health care access. Health systems variables were discussed according to four interdependent system dimensions, i.e., availability, affordability, acceptability and equity. South African health care services experience challenges in all four domains and with multiple aspects under each domain. The combined effect of these system challenges might be aggravated by personal, contextual and communal challenges.

The literature reviewed suggests that health care access challenges for rural populations are often the result of the complex interaction between a lower number of health care services, increased distances from services, infrastructure challenges, the natural environment, transportation challenges, hazardous employment circumstances and higher levels of risk taking behaviour. The complexities of rural health care access are illustrated through the theoretical framework for access to health care in Figure 4.1.



*Figure 4.1.* A summary of variables impacting rural health care access based on the theoretical framework for access to health care

The next chapter will explore availability, acceptability, affordability and equity of health care access for persons with disabilities.

## Chapter 5

### Health care access for persons with disabilities

#### 5.1 Introduction

Access to quality medical care, when and as often as needed, is critical for maintaining good health and functioning, particularly for people with disabilities who may experience poor levels of health. (WHO, 2010a, p. 33)

The causes and manifestations of disability are diverse, and persons with disabilities may have the same health needs as their non-disabled peers (Iezzoni, 2006a, 2009; Shakespeare et al., 2009; Shakespeare, 2014). However, impairments often leave persons with disabilities with increased health needs, a small health margin, and at higher risk to develop preventable complications (Graham et al., 2014; Iezzoni, 2009; Shakespeare, 2012, 2014). Their health is often precariously balanced and they might be highly susceptible to minute failings in health care systems (Iezzoni, 2013). Addressing the health needs of persons with disabilities in an adequate, timely manner through medical intervention is an essential step on the way to successful community integration. When optimal functioning of physiological systems are not achieved and maintained it is very difficult to successfully pursue life roles, education and or employment (Clarke & Black, 2005; Neri & Kroll, 2003; Shakespeare, 2012, 2014). This chapter explores persons with disabilities' satisfaction with health care services and the barriers they experience with regard to health care access.

#### 5.2 Satisfaction with Health Care Services

According to Article 25 of the UNCRPD (UN, 2006) persons with disabilities have a right to attain the highest possible standard of health, and states should:

- Provide persons with disabilities the same range and quality of care as their peers.
- Ensure disability specific health care interventions, for example, the prevention of secondary complications.

- Not discriminate or deny health care on the grounds of disability.

However, persons with disabilities are vulnerable with regard to health care access, often underserved and more often dissatisfied with services than their able bodied counterparts, as shown in Table 5.1.

Table 5.1

*Satisfaction with health care services*

	Country	Persons with severe disability	Persons with moderate disability	Persons without disability
% who are satisfied with health care				
Fouts et al., 2000	USA	87	-	92
Gulley & Altman, 2008	Canada	75	82	88
Gulley & Altman, 2008	USA	66	76	89
Parish & Huh, 2006	USA	85	-	92
Trani et al., 2011	Sierra Leone	81	84	94

Parish and Ellison-Martin (2007) found, in a national survey in the USA, that dissatisfaction with services caused late health care seeking amongst women with disabilities ( $p < .001$ ). Margaret Nosek (2010) argued that persons with disabilities suffer from second class health care services caused by a multitude of barriers. The World Report on Disability (WHO, 2011) concurs with this view when it states that persons with disabilities are more often denied care, treated badly or confronted with inadequate health care skills and equipment than general populations of countries. Barriers put users with disabilities at risk for injury, late diagnosis, inadequate health care management, poor health outcomes and psychological harm (Kirschner, Breslin, & Iezzoni, 2007).

Gulley and Altman (2008) found that 8% of Americans and Canadians with no disability indicated unmet health care needs versus 21% with non-severe disability and 25% with severe disability. Fisher and Shang (2013) found that in China only 26% of children with disabilities who needed medical services received it. Table 5.2 shows that between 8% and 39% of persons

with disabilities in various African countries felt they did not receive health care when needed. In addition the table shows that access to rehabilitation, assistive devices and disability specific counselling were limited.

Table 5.2

*Percentage of persons with disabilities who felt they needed services but did not receive it (Eide, Loeb et al., 2011)*

	<b>Namibia</b>	<b>Zimbabwe</b>	<b>Malawi</b>	<b>Zambia</b>
Health care	27.1	8	39	20.7
Family disability counselling	58.3	54.6	80.5	78.1
Counselling for persons with the disability	84.8	59.2	89.3	85.7
Assistive devices	82.7	63.4	82.1	81.6
Rehabilitation	73.7	45.2	76.2	62.5

Systems barriers account for many of the challenges persons with disabilities experience with regard to health care access.

### **5.3 Systems Barriers to Health Care Access Experienced by Persons with Disabilities**

The systems barriers that persons with disabilities face with regard to health care access are discussed under availability, affordability, acceptability and equity. The methodologies of the studies that are referred to in the discussion are presented in Appendix 4.

#### **5.3.1 Availability**

In instances where persons with disabilities received health care services availability was hampered by challenges with regard to physical access, provider knowledge and skills, silos of care, poor continuity of care as well as limited access to medication, doctors, specialist care, rehabilitation, assistive devices, preventative care and health promotion.

***Physical access***

A number of studies in a range of countries (see appendix 4 for details) have found provider offices to be inaccessible due to the physical characteristics of the building and surrounds.

Specific challenges included:

- Inadequate parking (Buchanan et al., 2006; Kroll et al., 2006; Scheer et al., 2003).
- A lack of ramps (Ahmad, 2013; Kroll et al., 2006) and/or curb cuts (Scheer et al., 2003).
- Swing doors and/or narrow doorways (Kroll et al., 2006; Scheer et al., 2003).
- High thresholds (Scheer et al., 2003).
- Small waiting and examination rooms (Ahmad, 2013; Kroll et al., 2006).
- Inaccessible (Ahmad, 2013; Kahonde et al., 2010; Scheer et al., 2003) or unavailable (Van Rooy et al., 2012) rest rooms.

Inaccessible buildings and equipment limits health care access and can lead to the infringement of rights such as privacy (Iezzoni et al., 2006). According to Scheer et al. (2003) USA users found these challenges stressful enough to risk their health though postponing health care visits. Due to a lack of transport parking might not be a big issue in the study community. The other barriers indicated above might all hamper access to health care in rural South Africa and the study community.

***Equipment related barriers***

Persons with disabilities from various settings around the world experienced a variety of equipment related barriers. These included narrow, high, hard, and slippery examination tables, no sitting scales, and inaccessible diagnostic equipment such as mammography machines, Magnetic Resonance Image scanners, and chairs for eye testing (Buchanan et al., 2006; Drainoni et al., 2006; Iezzoni et al., 2000; Kroll et al., 2006; Nosek, 2010; Pharr, 2014; Scheer et al., 2003; Story et al., 2009; Van Rooy et al., 2012) as well as difficulty in manoeuvring nurse call buttons and bed adjustment controls (Drainoni et al., 2006). Persons using wheelchairs participating in a regional USA study by Kroll et al. (2006) indicated that they have not been weighed for years, which make it very difficult for them to know if they are maintaining their ideal weight, a very



important health promotion activity for them (Hughes et al., 2003; Rimmer & Rowland, 2008). Harrington et al. (2009) found that 59% of wheelchair users in their USA study were examined in the wheelchair because they could not transfer to the examining table. Findings from Pharr (2014) concurred and indicated that some procedures were skipped or users were assessed in their wheelchairs.

### ***Provider knowledge, skills and understanding***

Health care service providers often have limited training and experience in dealing with the complex needs of persons with disabilities (Drainoni et al., 2006; Harrington et al., 2009; Iezzoni, 2006b, 2006c; Iezzoni et al., 2006; Iezzoni, McCarthy, Davis, Harris-David, & O`Day, 2001; Iezzoni & Long-Bellil, 2012; Neri & Kroll, 2003; Scheer et al., 2003; Van Rooy et al., 2012; WHO, 2011). Service providers may lack knowledge in managing the person`s clinical needs and/or disability specific aspects such as understanding the underlying impairment, the impact of the disability on the person`s life and/or identifying the contributors and risk factors to the disability. The service provider may ignore the disability or focus exclusively on the disability and not discern when a condition arises from the disability and when it is caused by a different health condition (Iezonni, 2006b, 2006c; Iezzoni et al., 2001; Iezzoni & Long-Bellil, 2012; Mlenzana et al., 2013; Neri & Kroll, 2003; Scheer et al., 2003; Shakespeare, 2014; WHO, 2011). Inadequate knowledge and understanding of disability can negatively affect the quality of health care provided, cause misdiagnosis, delays in treatment, incorrect or unsafe care and wasting of resources (Fisher & Shang, 2013; WHO, 2011).

In addition, service providers may have limited knowledge of referral pathways for persons with disabilities, assistive devices, alternative ways of performing activities, and the impact of environmental barriers and how to deal with these. Thus they may not be able to advise the person on functioning and fulfilling their life roles or they might give unfeasible recommendations and management strategies (such as advising a wheelchair user to rest the shoulder muscles), both of which will impact quality of life negatively (Iezzoni, 2006b; Scheer et al., 2003). Health care users with disabilities that participated in the regional, USA study by Drainoni et al. (2006) felt that insufficient knowledge on disability caused providers to follow set

management routines instead of identifying more suitable alternatives depending on the impairment and the individual person.

Furthermore users with disabilities felt insufficient knowledge caused misconceptions and pre-conceived ideas on the side of providers that could impact negatively on holistic health care provision (Neri & Kroll, 2003; Mlenzana et al., 2013; Scheer et al., 2003). Examples of misconceptions included:

- A person with physical impairments is also cognitively impaired (Drainoni et al., 2006).
- Persons with disabilities are sexually inactive (Iezzoni, 2009; Scheer et al., 2003).
- Persons with intellectual impairments do not feel pain (Drainoni et al., 2006).

Users struggled to find a provider knowledgeable enough to assist them (Iezzoni et al., 2006; Scheer et al., 2003). They painted a picture of trying out doctors until they found one that they were happy with. Once found they continue to seek care from that person. According to Iezzoni et al. (2006), finding a preferred provider in a rural area is especially challenging since providers are fewer in numbers. In addition continuity is often lower in rural areas due to providers moving out of the area. In public health care in South Africa users with and without disabilities have little choice and often have to consult the provider they are allocated to or who is on duty (Van Deventer et al., 2008; Visagie & Schneider, 2014).

### *Silos of care*

Health care service providers often think of illness from the perspective of specialised knowledge of particular disorders or difficulties. They may thus not assess and treat users in a holistic way (Nosek, 2010). Therefore medical management for people suffering from multiple chronic conditions and/or disability may be fragmented, leaving the user to interpret information and management strategies prescribed by various service providers which can be confusing or even conflicting at times (Iezzoni, 2010; Nosek, 2010). Comprehensive health care for persons with disabilities calls for interdisciplinary teams of health care professionals since no one profession can address the diverse needs caused by many of the impairments. Historically

various team members were seldom exposed to the roles of other team members and integrated care across disciplines (Iezzoni & Long-Bellil, 2012). While this was the case in health care service provision in general, the impact might be bigger on persons with disabilities that often require input from a range of medical professionals due to complex health conditions and impairments.

### *Time*

Persons with disabilities in the studies by Drainoni et al. (2006), Iezzoni, Davis, Soukup, and O'Day (2003), Mlenzana and Mwansa (2012), and Neri and Kroll (2003) indicated that the length of consultations with service providers were often too short. Non-disabled health care users might also experience challenges with regard to the length of consultations. However, shorter consultations might be more problematic for users with disabilities because of the complexity of the impairment/s, the time needed for physical activities such as transfers and undressing, communication challenges and conflicting perceptions between user and service providers on the experience of disability (Iezzoni et al., 2003; Iezzoni et al., 2006).

### *Loss of time*

Time is spent waiting for appointments at primary level, which in turn lengthens the time before a specialist is consulted or management started. Problems are further exacerbated when referral systems are varied and confusing (Scheer et al., 2003). Winitzer et al. (2012) found that some American children with special needs waited longer than a year for a specialist appointment.

Participants in studies from Pakistan (Ahmad, 2013) and Namibia (Van Rooy et al., 2012) complained about time being wasted because they could not make an appointment, but had to queue for services, a process that might take an entire day. In similar vein 37% of participants in the Zambian study by Mlenzana and Mwansa (2012) were dissatisfied with the length of waiting times.

### ***Continuity of care***

Drainoni et al. (2006) found poor continuity of care due to high staff turnover and a lack of effective communication between service providers.

### ***No doctors***

Fifty-four percent of Zambians with disabilities were dissatisfied with the availability of doctors (Mlenzana & Mwansa, 2012) and Ahmad (2013) found poorer PHC service delivery for persons with disabilities in rural Pakistan when there were no doctors at facilities. Users in this study felt that service providers other than doctors did not have enough knowledge to assist them adequately. No information could be found on South Africans with disabilities satisfaction with the availability of doctors. However, a general shortage of doctors and other service providers have been described under 4.4.1 and one can assume that persons with disabilities will experience this shortage as well.

### ***Specific and specialist services***

Persons with disabilities experience challenges to accessing specialist medical consultants such as orthopaedic surgeons and neurologists, mental health care services, dental care and speech therapy (Drainoni et al., 2006; Mlenzana et al., 2013; Mlenzana & Mwansa, 2012; Scheer et al., 2003; Smith, 2008; Winitzer et al., 2012).

### ***Medication***

Two studies from Global North settings found access to medication to be a bigger barrier for persons with disabilities than for the general public. Gulley and Altman (2008) found that 11% of participants with non-severe disabilities in USA and Canada and 15% of participants with severe disabilities needed medication which they could not afford versus 4% of persons without disabilities. Similarly Iezzoni et al. (2011) found that 30% of uninsured persons with disabilities could not access the medication they required versus 5% of uninsured individuals without disabilities. Participants in the Namibian study by Van Rooy et al. (2012) also indicated that a

shortage of drugs hamper health care service delivery. No data from South Africa could be found on this.

### ***Rehabilitation***

According to Article 26 of the UNCRPD, states should ensure access to high quality rehabilitation, as defined in the glossary of terms, to persons with disabilities (UN, 2006).

Rehabilitation is in many instances essential to ensure community integration of persons with disabilities (Olaogun, Nyante, & Ajediran, 2009; Shakespeare & Officer, 2011; WHO, 2011).

Rehabilitation includes:

- Modification of the impairment through therapeutic, medical and surgical methods.
- Compensation for loss of function through assistive devices and compensatory techniques.
- Modification of the environment (WHO, 2011).

Both the person's home environment as well as the bigger community may need modification to ensure community integration. Thus rehabilitation should have a dual focus, i.e., the individual and the impairment as well as society and the elimination of physical and attitudinal barriers, equalisation of opportunities, and promotion and protection of human rights. As such rehabilitation should be provided through combined and co-ordinated service provision of medical, social, educational and vocational services and not solely by medical services (DoH, 2000a; UN, 2006; WHO, 2010a, 2011).

South African national policy places rehabilitation in the realm of primary health care with the use of institutions as referral centres. Thus rehabilitation should to a large extent be provided at clinics and district hospitals (DoH, 2000b; Chappel & Johannsmeier, 2009). Rehabilitation at clinic level should include prevention of disabling conditions, early detection and management of conditions that can lead to disability, a basic assessment, a client centred management programme, provision of and training in use of assistive devices and consumables and assessment for social support grants (DoH, 2000b).

The South African National Rehabilitation Policy proposes community based rehabilitation (CBR) as the strategy to ensure rehabilitation as part of PHC in South Africa (DoH, 2000a). CBR is multisectoral and focuses on improved quality of life as well as inclusion and participation of persons with disabilities in five areas, i.e., health, education, livelihood, social and empowerment. In 2010 the WHO published a series of booklets that provide practical guidelines for the development and strengthening of CBR programmes in each of these areas (WHO, 2010c). The booklet for health states: “CBR programmes support people with disabilities in attaining their highest possible level of health, working across five key areas: health promotion, prevention, medical care, rehabilitation and assistive devices” (WHO, 2010a, p1).

Specific suggestions from these guidelines regarding the role of CBR in rehabilitation include:

- Identification of rehabilitation needs.
- Facilitating referral and follow-up.
- Early intervention and childhood development activities.
- Encouraging functional independence.
- Facilitating environmental modifications to ensure universal access.
- Linking persons with disabilities with self-help groups.
- Developing and distributing resource materials.
- Providing training to CBR staff and to health care service providers.

Drainoni et al. (2006) and Scheer et al. (2003) have indicated that while available access to rehabilitation is challenging for some persons with disabilities in Global North countries. In Global South countries rehabilitation services were often unavailable:

- Sixty three percent of Chinese children received no government services including medical care and therapy (Fisher & Shang, 2013).
- More than 70% of Namibians and Malawians who required rehabilitation reported not receiving rehabilitation. Figures for Zimbabwe (45%) and Zambia (63%) are slightly better, though still high (Table 5.2) (Eide, Loeb et al., 2011).

- “In almost all of the rural clinics and regardless of type of disability, people living with disabilities complained of lack of rehabilitation” (Van Rooy et al., 2012, p772).
- In South Africa:
  - Thirty percent of participants in the Western Cape Province study by Maart and Jelsma (2013) needed, but did not receive rehabilitation.
  - Seventy-four percent of the children who needed rehabilitation, in the study from Orange farm, Gauteng, did not receive rehabilitation (Saloojee et al., 2007).
  - Wasserman et al. (2009) found that no stroke survivors received rehabilitation post hospital discharge in a rural KwaZulu-Natal setting.
  - Bateman (2012) painted a bleak picture with regard to rehabilitation service delivery in the Eastern Cape, Mpumalanga and KwaZulu Natal.

A shortage of service providers and other resources challenges rehabilitation service delivery in the South African public service (Bateman, 2012; DWCPD, 2013; Maart & Jelsma, 2013; Ntamo et al., 2013; Rhoda et al., 2009; Wasserman et al., 2009). Additional system challenges include insufficient budgets, and transport, crippling policies such as short length of stay in acute hospitals, red tape, breakdown in communication, challenges with referral to secondary and tertiary services (Bateman, 2012) and language barriers (Maart & Jelsma, 2013).

No studies that report on rehabilitation service delivery in the Northern Cape Province could be found. Furthermore, there is no reference to rehabilitation programmes or planning, CBR, physio-, occupational-, or speech therapy in the Northern Cape’s Department of Health 10 year vision which culminates in 2014 (NCDoH, 2006).

### ***Assistive devices and consumables***

Unhampered access to an ongoing supply of consumables and durable, suitable assistive devices are essential to ensure an active productive life and quality of life for some persons with disabilities. If they cannot access these it can have negative health and functional consequences and higher levels of morbidity and mortality can be experienced (Greer, Brasure, & Wilt, 2012; Iezzoni, 2006a; Shakespeare, 2012; UN, 2006; WHO, 2008b, 2011). Inadequate supplies of

consumables can force users to rely on unhygienic practices such as reusing disposable catheters (Drainoni et al., 2006).

It seems as if challenges with regard to assistive devices in Global North countries revolve around type, timely replacement, repairs and out of pocket payments (Drainoni et al., 2006; Scheer et al., 2003). Drainoni et al. (2006) found unsafe home repairs, poor positioning, secondary complications and injuries due to inadequate replacement policies. Participants in the study by Scheer et al. (2003) indicated that devices recommended by the physician were not covered by their insurance which covered less expensive and often less durable models. In addition support equipment like batteries for motorised wheelchairs was not covered. In my experience similar challenges are encountered in South Africa.

Furthermore persons with disabilities in Global South countries often received no assistive devices. Fisher and Shang (2013) found only 10% of Chinese children with disabilities received the assistive devices they needed. African countries showed similar challenges (Table 5.2) with 82% of Namibians, Malawians and Zambians, and 63% of Zimbabweans reporting not receiving the assistive devices they needed (Eide, Loeb et al., 2011). In South Africa 34.5% of participants in the Western Cape Province study by Maart and Jelsma (2013) did not receive the required assistive devices and 72% of the children with disabilities in the Gauteng study did not receive assistive devices (Saloojee et al., 2007).

### ***Health promotion***

Persons with disabilities can experience the same conditions as the general public. In addition, persons with disabilities might experience associated conditions (e.g., spasticity) secondary complications (e.g., pressure ulcers) and comorbidities (Harrison, 2006; Rimmer, 2002; Rimmer & Rowland, 2008; Shakespeare, 2012; WHO, 2010a). Furthermore, persons with disabilities are at higher risk for obesity, social isolation, fatigue, pain, depression, smoking and substance abuse (Brucker, 2007; Chevarley et al., 2006; Hughes et al., 2003; Rimmer & Rowland, 2008; Smedema & Ebener, 2010). Thus persons with disabilities should be an important target group of health promotion activities (Harrison, 2006; Rimmer, 2002; Rimmer & Rowland, 2008;



Shakespeare, 2012; WHO, 2010a) as behavioural and lifestyle changes can assist them to improve their health status (Ravesloot et al., 2005; Rimmer & Rowland, 2008; WHO, 2010a).

The CBR practical guidelines on health provide the following guidance on inclusion of persons with disabilities in health promotion programmes (WHO, 2010a):

- Include persons with disabilities in existing community health promotion programmes.
- Provide persons with disabilities with knowledge and skills to make healthy choices and maintain a healthy lifestyle.
- Connect persons with disabilities to self-help groups.
- Educate health care service providers on the inclusion of persons with disabilities in health promotion programmes.
- Create enabling environments.
- Focus on health promotion within the CBR organisation or programme.

Persons with disabilities require supportive environments such as accessible buildings and exercise equipment, positive attitudes, and knowledgeable service providers. Furthermore personal factors like fatigue, pain, spasticity, seizures, depression and obesity can hinder persons with disabilities' participation in health promotion programmes. Therefore intervention with the aim to include persons with disabilities in health promotion activities should be multipronged and focus on the person and the environment (Harrison, 2006; Rimmer, 2002; Rimmer & Rowland, 2008).

### ***Primary prevention***

Many persons with disabilities can expect to lead long and productive lives and should thus receive similar preventative care to their non-disabled counterparts (Iezzoni et al., 2001; WHO, 2010a). Studies found persons with disabilities to be less likely to receive preventative and screening procedures such as pap tests, mammograms, prostate specific antigen tests (Chevarley et al., 2006; Harrison, 2006; Iezzoni, et al., 2000, 2001; Ramirez et al., 2005) and tetanus injections (Harrison, 2006). On the other hand, Iezzoni et al. (2000) found persons with mobility

impairments were as likely as the general USA population to receive pneumonia and influenza immunisations. Harrington et al. (2009) found in a study from the USA that more than 70% of participants with disabilities received various screening procedures and preventative procedures such as cholesterol tests (91%), pap smear (83%), mammogram (77%), tetanus booster (73%) and influenza vaccination (86%).

Trani et al. (2011) found that persons with severe disabilities in Sierra Leone were less likely to receive immunisation than those without (74.6% versus 88.14%  $p = 0.003$ ). A South African study on the knowledge of persons with disabilities on HIV prevention found that 40% of participants received HIV testing and 56% received information on the prevention of HIV at health care institutions. The study used non probability sampling and was done in urban, peri-urban and rural settings in Gauteng, the Western Cape Province and KwaZulu Natal. No information on possible difference in findings for rural and urban dwellers was provided (Eide, Schür et al., 2011).

In addition to general health promotion activities persons with disabilities might require specific education, intervention and support to prevent secondary complications (Rimmer & Rowland, 2008; WHO, 2010a). WHO guidelines suggest the following general actions to increase access for persons with disabilities to primary prevention (WHO, 2010a):

- Access to existing prevention programmes.
- Encourage immunisation.
- Ensure proper nutrition.
- Facilitate access to maternal and child health care.
- Education in the prevention of secondary complications.

### ***Transport***

Unavailability of transport for persons with disabilities to access health care services has been widely reported on (Ahmad, 2013; Drainoni et al., 2006; Jezzoni et al., 2006; Kahonde et al., 2010; Maart & Jelsma, 2013; Scheer et al., 2003; Smith, 2008; Van Rooy et al., 2012).

Challenges occurred with private transport, public transport and specialised transport

programmes for persons with disabilities (Scheer et al., 2003). Public transport is often not an option due to unavailability (Heap et al., 2009), inaccessibility (Ahmad, 2013; Gaede & Versteeg, 2011; Heap et al., 2009), and distance between route stops and the person's home or provider's office (Scheer et al., 2003). In South Africa taxis sometimes do not stop for persons in wheelchairs or charge extra for the wheelchair (Kahonde et al., 2010; Ntamo et al., 2013).

Users of specialised transport programmes for persons with disabilities in the USA voiced frustrations with having to book transport up to a week in advance, eligibility criteria, schedules conflicting with caregiver schedules and nondependability causing them to be early or late for appointments or even missing appointments (Drainoni et al., 2006; Iezzoni et al., 2006; Oliver, 2006; Scheer et al., 2003). Challenges with regard to bookings and reliability of specialised transport for persons with disabilities in the few areas of South Africa where it is available is also widespread according to anecdotal information.

Van Rooy et al. (2012) report from Namibia that transport is provided by private car, donkey car or homemade sledge, but that the majority of people with disabilities walk to access health care. Hiring transport increases the cost of health care and may deter people from accessing services. In instances where the person is very sick an ambulance can be arranged, but it can take a long time for the ambulance to arrive (Van Rooy et al., 2012).

De Koker et al. (2006) found in a nationwide South African study that 59% of DG recipients walk to access health care facilities. Specific findings for the Northern Cape Province indicated that 71.8% of DG recipients walk to their closest health care facility. The majority (82.9%) stayed within 5km of the closest health care facility. It took 68.7% of them less than 30 minutes to reach the closest health facility and 5.5% more than an hour (De Koker et al., 2006).

### **5.3.2 Acceptability**

#### ***Communication***

Open communication and consultation is often lacking between health care service providers and users with disabilities (Iezzoni & Long-Bellil, 2012; Shakespeare et al., 2009; WHO, 2011).

Ineffective communication can create long lasting barriers, fear and anxiety, erode trust and lead to poor compliance and suboptimal health and functional outcomes for users with disabilities (Drainoni et al., 2006; Iezzoni, 2006b, 2009; Shakespeare et al., 2009). The reasons for ineffective communication are multifaceted and might be related to the service provider or the impairment (Drainoni et al., 2006; Iezzoni, 2006c). Mlenzana and Mwansa (2012) found in their Zambian study that persons with disabilities were dissatisfied with the doctors' listening to them (17%) and providing explanations to them (25%).

Communication challenges are especially evident in instances where users have hearing, speech, language, and/or cognitive impairments (Drainoni et al., 2006; Iezzoni, 2006c; Kritzinger et al., 2014; Van Rooy et al., 2012). The challenges experienced by these users started when they contacted providers by telephone to make appointments. Experiences of front office staff hanging up on persons with speech impairments have been documented (Drainoni et al., 2006). Deaf participants commented on the lack of sign language interpreters and indicated that writing was not a good substitute especially when providers used jargon (Drainoni et al., 2006).

Communication challenges can also be caused by language barriers, as found by Maart and Jelsma (2013) in the Western Cape, South Africa, and Van Rooy et al. (2012) in Namibia. In the study by Maart and Jelsma (2013), 48.3% of participants with disabilities indicate language barriers as an obstacle to access rehabilitation services.

Communication challenges can result in users not getting health information in a format accessible to them or they might not understand explanations given to them by health care service providers, leading to misunderstandings of treatment regimens (Drainoni et al., 2006; Kritzinger et al., 2014). However communication challenges have a much broader impact on health issues. Health promotion information is often provided through public communication sources such as the radio and television or sound systems in clinic and hospital waiting rooms. People who are deaf have little use for these sources and might not be exposed to health promotion and prevention information as needed. Finally the language in which information is available might not be the person's mother tongue and thus limit understanding.

### ***A lack of information sharing***

Eide, Loeb et al. (2011) (Table 3.3), Fisher and Shang (2013), Kahonde et al. (2010), Mlenzana et al. (2013), Mlenzana and Mwansa (2012) and Van Rooy et al. (2012) found that health care service providers did not always provide sufficient information and education to persons with disabilities and their families on the management of their condition.

### ***Patient centred care***

According to Mlenzana and Mwansa (2012), 26% of Zambians with disabilities were dissatisfied with the extent to which they were involved in decisions about their care. Kahonde et al. (2010) found that some users were involved in decisions about rehabilitation strategies while others were not. Some users indicated that they defer to therapists since they feel the therapists have more knowledge on their conditions.

### ***Provider perceptions about disability***

Personal beliefs on the part of some health care service providers that disability leads to poor quality of life can bias their clinical decisions and lead to delayed, suboptimal, less vigorous or no treatment (Ahmad, 2013; Brown, 2009; Drainoni et al., 2006; Iezzoni, 2006a, 2006c; Shakespeare et al., 2009; WHO, 2011). Clinicians must seek and respect the views of users and not make value judgements on the quality of the life of the user with a disability (Drainoni et al., 2006; Iezzoni, 2006c; Iezzoni & Long-Bellil, 2012; Mlenzana et al., 2013; Shakespeare et al., 2009; WHO, 2011).

### ***A power imbalance***

Traditionally health care service providers held a position of power as described under the medical approach to disability. In addition doctors are often the arbiters on who gets social support such as a disability grant and were party to forced procedures such as sterilization until recently (Iezzoni & Long-Bellil, 2012). Thus one can understand that persons with disabilities felt they must keep in favour with providers and not anger them in order to ensure that providers address their needs, as found by Harrison et al. (2010).

### ***Role uncertainty***

Traditionally the role of health care service providers was to relieve suffering and provide cure, aspects of health care that persons with disabilities might need. However, the impact of social and environmental factors on disability adds a public health dimension to disability management that asked for interventions different to the standard medical interventions (Iezzoni & Long-Bellil, 2012). In addition persons with disabilities want to make their own choices about care and treatment, as presented in the section on approaches to disability. Thus the role of health care service providers is complex and not only the traditional one of providing a cure.

### ***Attitudes***

Mlenzana et al. (2013) found in a review of the literature on barriers and facilitators to rehabilitation experienced by persons with disabilities that providers treated users with respect and empathy. These findings are supported by findings from Kahonde et al. (2010). However, other studies found attitudinal challenges like a lack of sensitivity, patience, courtesy and respect (Drainoni et al., 2006; Mlenzana & Mwansa, 2012; Neri & Kroll, 2003; Ntamo et al., 2013; Van Rooy et al., 2012). Drainoni et al. (2006) provided examples such as users being treated like a child, being yelled at, being seen as difficult and not being taken seriously. Drainoni et al. (2006) describes reluctance on the side of some providers to provide care to users with disabilities. This was especially true for users who are HIV positive, users with severe developmental disabilities and elderly users.

### **5.3.3 Affordability**

A lack of health insurance, financial problems and/poverty decreased access to health care and in instances led to poorer health outcomes for persons with disabilities in the USA (Cheverlay et al., 2006; Drainoni et al., 2006; Gulley & Altman, 2008; Iezzoni et al., 2006, 2011; Mitra et al., 2009; Winitzer et al., 2012). Van Rooy et al. (2012) found that in Namibia cost of health care prohibited persons with disabilities from accessing health care in some instances, but that payment was waived in other instances. Ahmad (2013) found that in Pakistan out of pocket

payment for things like transport, medication and tests increase cost of service and in some instances rendered services unaffordable for persons with disabilities.

In a South African study, Maart and Jelsma (2013) reported that 71% of study participants did not access rehabilitation services, because they could not pay for it, and Ntamo et al. (2013) found that 29% of stroke survivors did not access rehabilitation due to a lack of money. Ntamo et al. (2013) linked the findings to transport costs incurred by rural dwellers of which 32% lived more than 100km from the service they had to access. Maart and Jelsma (2013) did not discuss the findings further and it is possible that in this instance participants also referred to indirect costs such as transport since health care to persons with disabilities should, according to South African national policy, be free of charge.

Cost of care impacts health care access for persons with disabilities through a lack of access to:

- Specific providers and services (Cheverlay et al., 2006; Maart & Jelsma, 2013; Winitzer et al., 2012).
- Medication (Cheverlay et al., 2006; Drainoni et al., 2006; Gulley & Altman, 2008; Iezzoni et al., 2006; Iezzoni et al., 2011). According to Iezzoni et al. (2006) users went without medication or halved dosages when they could not afford it.
- Consumables, assistive devices and repairs (Cheverlay et al., 2006; Drainoni et al., 2006; Iezzoni et al., 2006).

#### **5.3.4 Equity**

Trani et al. (2011) found that in Sierra Leone persons with disabilities had poorer access to community and hospital health care than their non-disabled compatriots. When one considers the information on unmet health care needs, physical and information barriers, challenges with service provider knowledge and skills, time constraints, poorer access to medication, promotion and prevention as well as challenges with accessing rehabilitation and assistive devices, it seems as if persons with disabilities in other parts of the world similarly do not receive health care according to their needs.

## 5.4 Summary

Persons with disabilities often have greater health care needs than their peers, while experiencing greater barriers to health care access. Availability of health care services for persons with disabilities is negatively impacted by insufficient provider knowledge and skills in conjunction with negative provider attitudes and perceptions. Physical access and access to information creates barriers, as do inadequate provision of specialist and rehabilitation services. Costs, poor continuity of care, communication challenges, staff shortages and transport challenges further hamper access for persons with disabilities.

This chapter concludes the section on theoretical perspectives. In the next chapter the methodology used in the study is explored.



## Chapter 6

### Methodology

#### 6.1 Introduction

The aim of the study was to describe the experience of living with a disability in a remote, rural setting with a specific focus on barriers and facilitators to health care access. The exploration of experiences depends on people's stories as told through qualitative measures (Silverman, 2013). Therefore this study employed a multiple case study design, purposive sampling, and in-depth interviews and used interpretative phenomenological analysis (IPA) as an analytic framework. The reasons behind each of these choices are explored in this chapter. In addition the reader is introduced to the study setting and to health care service delivery in the study setting.

#### 6.2 Study Design

##### 6.2.1 Multiple case studies

Case studies are empirical enquiries that “investigate a contemporary phenomenon (the “case”) in depth and within its real-world context especially when the boundaries between phenomenon and context may not be clearly evident” (Yin, 2013, p. 16). Case studies can be used as an adjunct to surveys in order to explain “how” and “why”, because they are designed to produce detailed and nuanced information on a specific issue in a specific context. The method assists researchers to develop a deeper understanding of complex societal issues and processes that can inform action. Case studies are explorative and can open up analytical possibilities through expanding and generalising theory. The case study design does not only explore the perspective of single participants, but looks at the interaction amongst participants and groups to capture a holistic understanding of the phenomenon under study (Hodgetts & Stolte, 2012; McGloin, 2008; Silverman, 2013; Yin, 2013).

Case studies can have single or multiple case designs, with one or multiple units of analysis. Single case designs are used when the case being studied can be seen as critical, unique, extreme,

representative, revelatory or longitudinal. None of the cases in the current study could be seen as one of those. In addition it is improbable that a single case will capture all the different nuances with regard to health care access for persons with disabilities in the setting. Furthermore multiple cases make for a more robust design and can strengthen analytic conclusions (Yin, 2013). Thus a multiple case design was utilised. Yin (2013) advises that data from multiple cases are first analysed individually and then integrated across cases. In addition, Yin (2013) suggests that researchers find a method of data analysis that will ensure analyses of high quality and suit their style and requirements. I chose to analyse data according to IPA as described by Smith, Flowers, and Larkin (2009).

### **6.2.2 Interpretative phenomenological analysis**

Based on the earlier concepts of phenomenology and hermeneutics, IPA came to the fore in the nineties as a qualitative approach with the purpose of capturing the essence of lived experiences. IPA aims to comprehend phenomena from the perspective of the person experiencing them in order to enhance understanding of the phenomenon. Initially IPA was used mainly in health psychology research in the United Kingdom. However it has grown substantially and is now used in social and health sciences amongst other fields<sup>6</sup>. Due to its holistic nature IPA has extensive application possibilities in health and social sciences and is of particular use when the researcher wants to do a comprehensive, ideographic case study or is interested in exploring participants' experiences (Smith, 2004, 2011; Smith et al., 2009).

IPA's phenomenological component hinges around exploring and describing an individual's understanding or perception of an experience; rather than presenting an objective description of it. However, one can never completely understand the experience of another, thus in IPA the researcher has to focus on creating a coherent third person account of the participants experience, and make sense of another's world, through interpretation (Larkin, Watts, & Clifton, 2006; Smith, 2004, 2011; Smith et al., 2009). Smith (2004) describes the interpretation that occurs in IPA as follows:

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<sup>6</sup> See <http://www.ipa.bbk.ac.uk> for publications of research using IPA.

Broadly, one can say that most of the interpretive levels employed in IPA are more in keeping with a hermeneutics centred in empathy and meaning recollection. However, IPA also allows a hermeneutics of questioning, of critical engagement, as the reader may well ask questions and posit readings which the participants would be unlikely, unable or unwilling to see or acknowledge themselves. Both stances can be seen to contribute to a more complete understanding of the participant's lived experience. Within such an analysis, the empathic reading is likely to come first and may then be qualified by a more critical and speculative reflection. (p. 46)

IPA is idiographic, because each case is analysed separately. The researcher does not move to the next case before conclusion is reached. Only once all cases have been analysed, patterns across cases are identified through cross case analysis. In cross case presentation attention is given to converging and diverging findings, and the researcher should show how themes played out in the experiences of individual participants. Furthermore, results are not presented in isolation, but connected to wider social and cultural contexts as well as existing theory (Larkin et al., 2006; Smith, 2004; Smith et al., 2009).

Supporters of the social approach to disability have criticised phenomenology for locating disability with individuals and thus distracting attention from oppressive social practices (Scully, 2009). However, I have argued in the literature review that disability is about more than social oppression and that experiences might be affected deeply by living with an "impaired" body. Therefore understanding disability and experiences of persons with disabilities from the personal perspective is a necessary part of the whole required to understand disability (Scully, 2009). Thus I aim to add the voices of a group of disadvantaged persons with disabilities from a rural setting to the dialogue on health care access in South Africa through the combined use of case studies and IPA.

### **6.3 Study Setting**

The study was performed in Fraserburg, a rural town in the Northern Cape Province of South Africa (Figure 6.1). South Africa covers 1 220 800 km<sup>2</sup> and has a population of 51 million people of whom 40% live in rural areas. The Northern Cape Province is the largest province in

South Africa and covers 30.5% of the country, but has the smallest population of the nine provinces and 2.2% of the total South African population. Roughly 30% of the population of the Northern Cape Province lives in rural areas. The Northern Cape Province has, at 10.2%, the highest provincial disability prevalence rate in South Africa (Stats SA, 2012).



*Figure 6.1.* Map of South Africa with the Northern Cape Province to the left (The star indicates the location of Fraserburg)

Within this province the town of Fraserburg (Figure 6.2) is home to a rural, small livestock farming community. Fraserburg was purposively sampled as an Equitable study site because it is an example of a semi-arid rural area with low population density, poor infrastructure, high levels of poverty, and inequities between various social groups in the community (Karoo Hoogland Municipality, 2009). There are many similar rural settings in South Africa. The entire

Northern Cape Province, as well as parts of the North West, Free State, Eastern Cape and Western Cape provinces are arid or semi-arid. These settings are often dependent on small livestock farming, are geographically isolated, and have poor infrastructure like roads and communication systems (Atkinson, 2007; Botes, 2011).



*Figure 6.2.* Fraserburg and surrounds

Members of the Fraserburg community live as far as 80kms from town. Farms are connected to each other and the town through a series of dirt roads with one tar road leading out of town towards the Western Cape border. The shortest routes to all other towns, including those that provide secondary and tertiary health care, involve some driving on dirt roads. These roads are not kept in good repair, as Figure 6.3 shows.



*Figure 6.3.* A dirt road in the Fraserburg district

Demographic data on Fraserburg`s community came from two sources: Statistics South Africa (Stats SA, nd), which provides data for the Karoo Hoogland Municipal area (Fraserburg, Sutherland, Williston and surrounds), and a Fraserburg municipal community survey<sup>7</sup>. The municipal area has a total population of 12 588, with a population density of 0.4 people/km<sup>2</sup>. The Coloured group is in the majority at 79% followed by 15% Whites, 5% Africans and 1% Asians. Afrikaans is the first language of 90% of the population. An expanded unemployment rate of 14.6% is reported for the area. The main sources of employment are agriculture, tourism, financial services, private households, community and social services. The general income in the area is low and 39% of the community lives in poverty (Stats SA, nd). Figure 6.4 presents the needs in the community as identified through the municipal survey in 2009. Services referred mainly to a need for sanitation services. This need as well as the need for housing might have

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<sup>7</sup> A municipal community survey was performed in 2009 in Fraserburg. The raw data were never analysed, but were made available to me by the Community Development Officer, Mr V. Opperman. I entered the data onto an Excel spreadsheet and from there collated the information used in this document. 559 persons participated in the survey. Sampling was convenient and only persons from the Coloured community living in the town of Fraserburg participated in the survey. Thus information cannot be extrapolated to the other groups in the community such as White town dwellers, farmers or farm labourers. However, the data provided some compelling information about the largest subgroup in this community i.e. the Coloured town dwellers.



been addressed to a large extent by the building of 200 government subsidised houses with flush toilets in 2011.

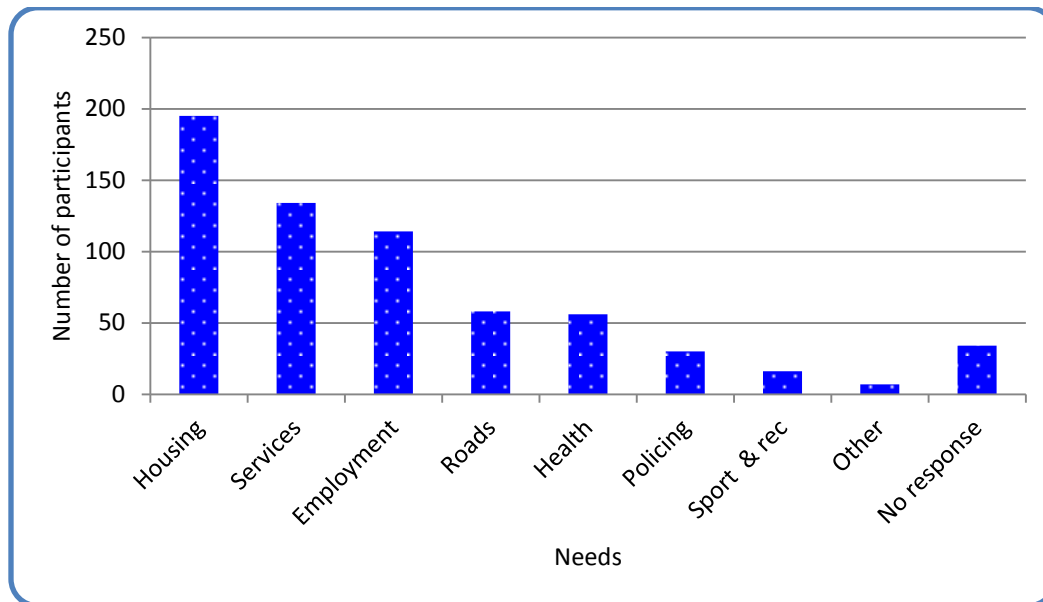


Figure 6.4. Needs of the community of Fraserburg (N = 559; Source: Fraserburg community survey)<sup>8</sup>

In addition to above information the EquitAble study gathered information that is important to this study. This information and a short description of the methodology followed in the EquitAble study is presented here.

### 6.3.1 EquitAble methodology

The EquitAble study was undertaken between 2010 and 2013 and focused on health care access for vulnerable groups in Africa. Figure 6.5, which illustrates the study design, shows that data collection and analyses were done in three phases. In the first phase international, regional and national policy documents were analysed (Mannan, Amin, MacLachlan, and the EquitAble Consortium, 2011; Schneider, Eide, Amin, MacLachlan, & Mannan, 2013). In the second and

<sup>8</sup> Responses are more than 559 since some participants indicated more than one need.

third phases access to health was assessed through qualitative a quantitative methods in four or five sites in four African counties each. While findings from the quantitative component of the EquitAble study would have enhanced this dissertation the analysis of the quantitative data was unfortunately not completed at the time of its writing and could thus not be included. I will include it in future publications. The information included in this section and the discussion sections refers to Fraserburg only and was collated by me from a spreadsheet. I included it to enhance the readers understanding of the study setting.

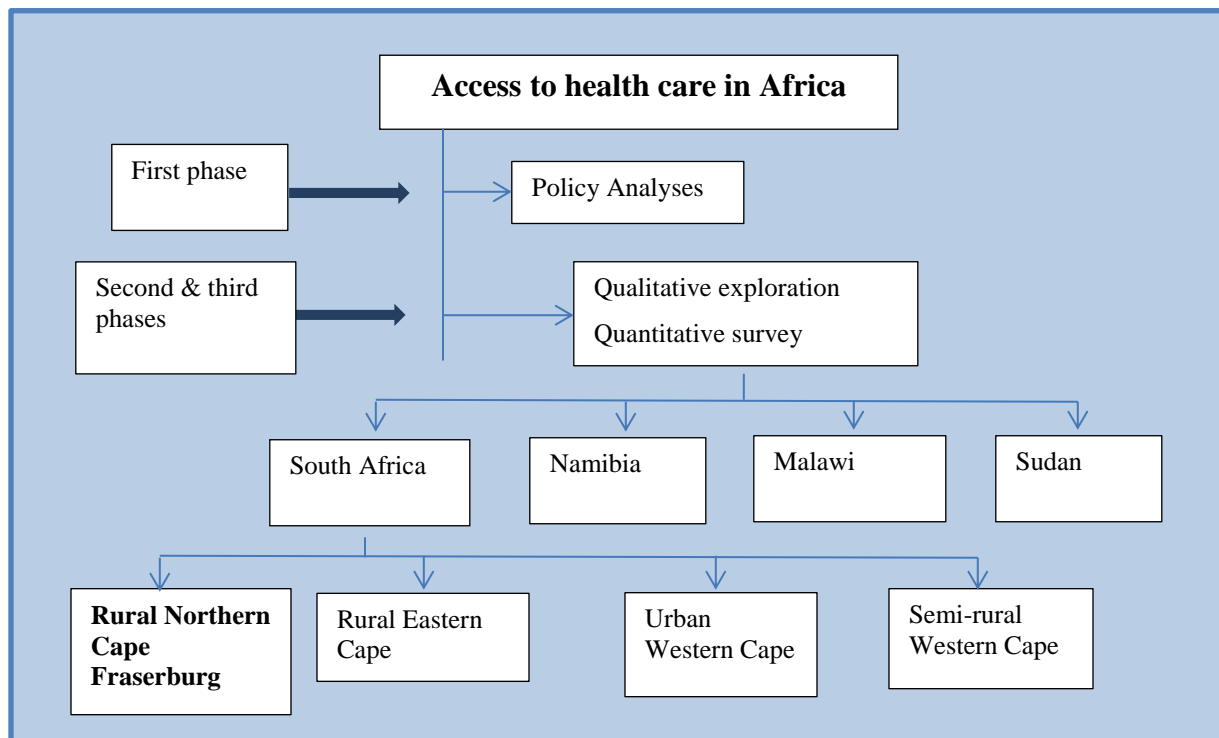


Figure 6.5. Schematic presentation of phases of the EquitAble study (Source: Visagie & Schneider, 2014)

### ***Data collection in Fraserburg***

Qualitative data were collected between March and June 2010, through 19 semi-structured interviews with 22 participants. Participants were identified through purposive sampling and included public health care users (8), a public health care non user (1), key informants (5) and



service providers (8). In addition a facility review of the Community Health Care Centre (CHCC) was done through completion of a checklist and observation.

Quantitative survey data were collected in October 2011. Data on demographics, health, and activity limitations were collected, from 1 686 individuals in 506 randomly sampled households. From these data persons with activity limitations were identified. In households where persons with and without activity limitations resided an interview was done with the person with the highest activity limitation score, and with a control without activity limitations, but who resembled the person with activity limitations closest with regard to age and gender (in some households no control could be identified). In households where there did not reside any persons with activity limitations, one randomly sampled participant was interviewed. Figure 6.6 depicts the sampling process and provides information on the number of participants in each group. The interviews gathered data on activities, participation, environmental barriers and facilitators, health conditions, health care service awareness, health care use and access, provision of rehabilitation, counselling and assistive devices, physical and mental health status.

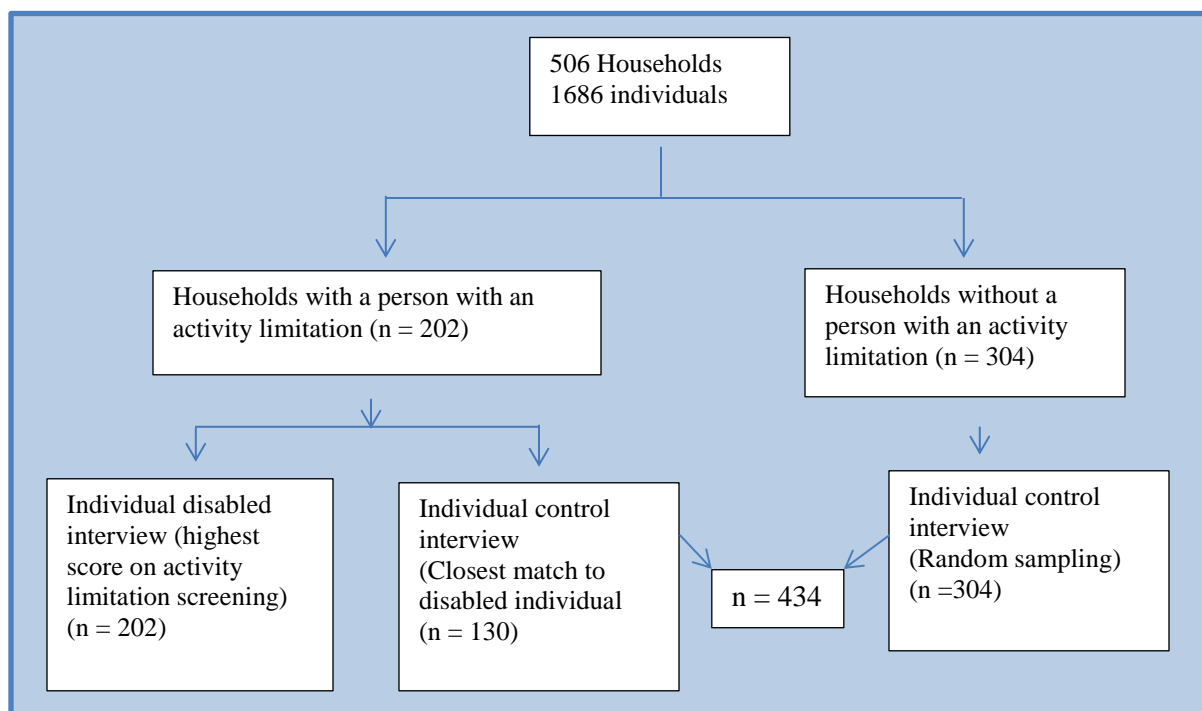


Figure 6.6. Equitable survey sampling process and participant numbers in Fraserburg

### 6.3.2 Equitable results relevant to this study

#### *Environmental barriers*

The EquitAble survey found that both persons with and persons without disabilities from the community of Fraserburg experienced environmental barriers, but that these barriers were generally bigger for persons with disabilities, as presented in Figure 6.7. Transport and geographic features created the biggest barriers, while 40% of persons with disabilities experienced barriers with regard to health care access.

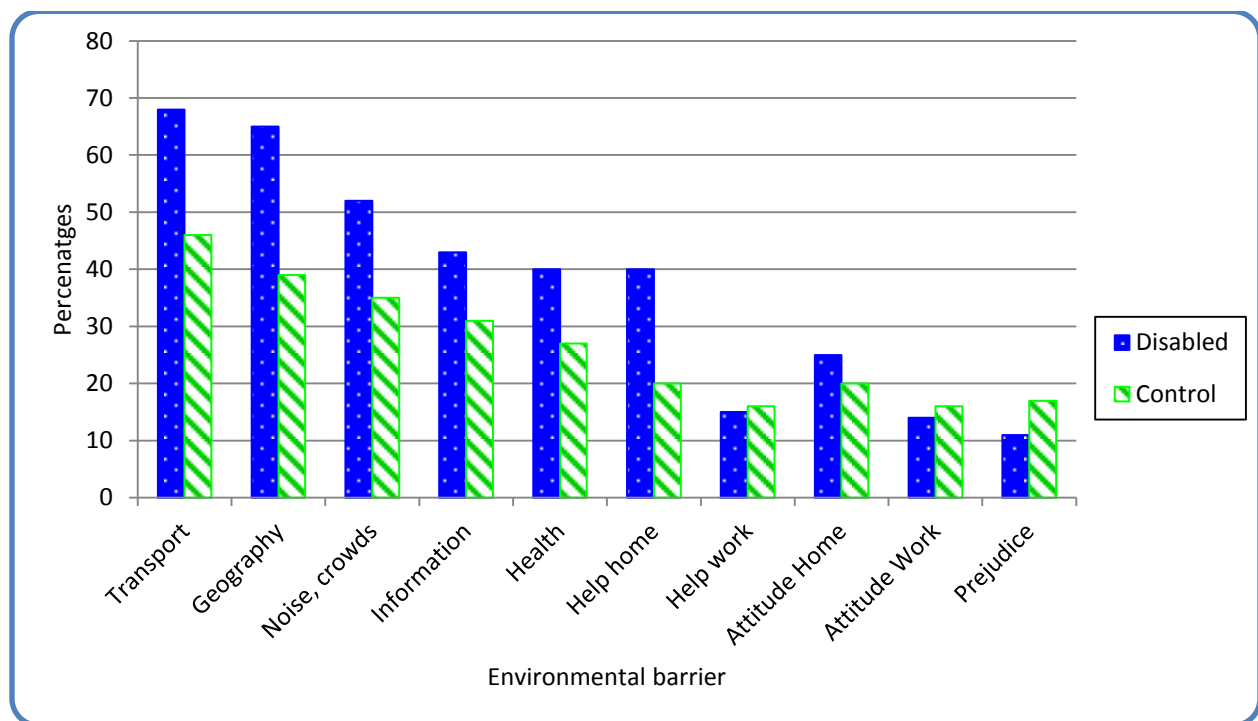


Figure 6.7. Comparison of percentage of persons with (n = 202) and without disabilities (n = 434) who experienced environmental barriers (Source: EquitAble survey)

#### *Health conditions and activity limitations*

According to the EquitAble survey data as presented in Figure 6.8, hypertension and musculo-skeletal problems were the most common in the community. The survey tool did not explore

individual diagnosis or cause of problems. Qualitative data connected musculo-skeletal conditions to the nature of the work on farms.

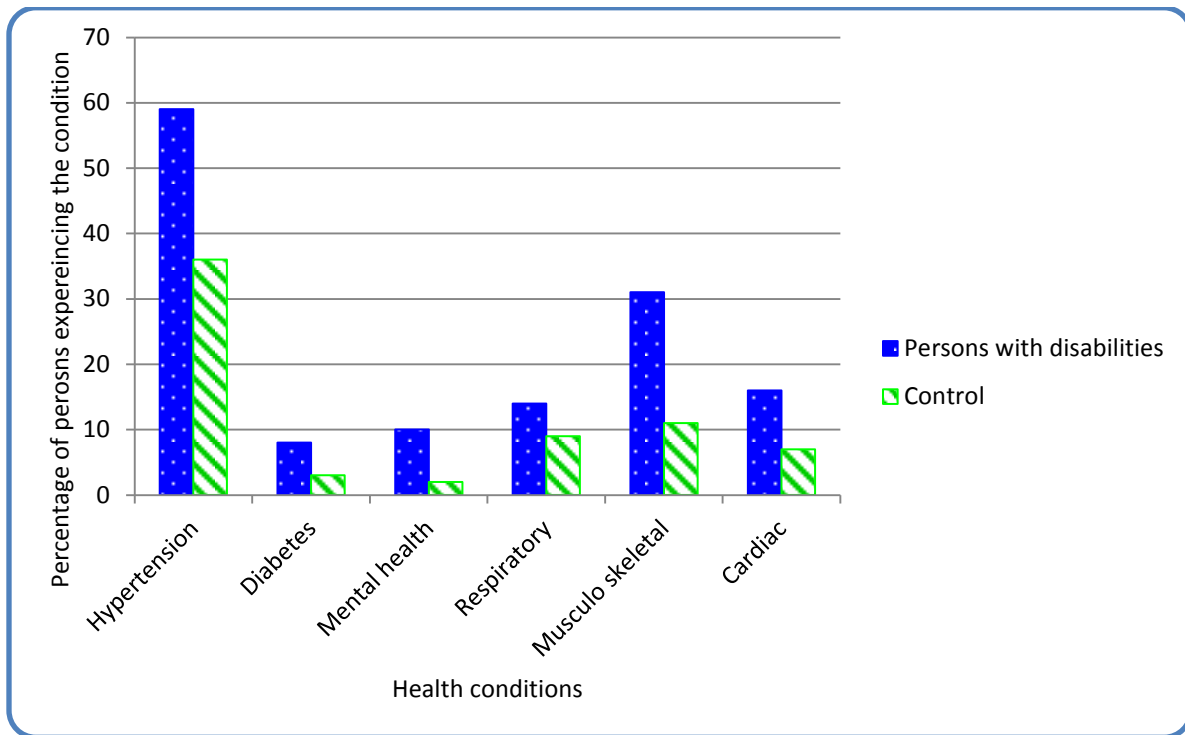


Figure 6.8. Health conditions experienced by persons with (n = 202) and without disabilities (n = 434) (source: EquitAble survey data)<sup>9</sup>

In addition, qualitative data indicated that pulmonary tuberculosis and alcoholism might be common in the community. None of the participants reported suffering from alcoholism or

<sup>9</sup> These results concurs with some findings from a South African study on the reasons for accessing PHC, which include three rural Northern Cape districts (Mash et al., 2012) i.e.:

- Hypertension was the most common complaint in both studies.
- Alcoholism was not identified as a disease in either study.

In other respects differences occurred:

- Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV/AIDS) was the third most common reason for PHC encounters in the study by Mash et al. (2012), but not mentioned by participants in the EquitAble survey.
- Mental health disorders were identified as a health problem by participants in the EquitAble survey, but were not one of the top 25 diagnoses in the study by Mash et al. (2012).
- Lower levels of musculo-skeletal complaints were found by Mash et al. (2012).

being HIV positive. The professional nurse in charge of the clinic indicated that they provided anti-retro viral treatment to six users.

The EquitAble survey findings on activity limitations are presented in Figure 6.9 and shows that limitations with walking, seeing and mental conditions were reported most often. Some participants indicated problems in more than one category.

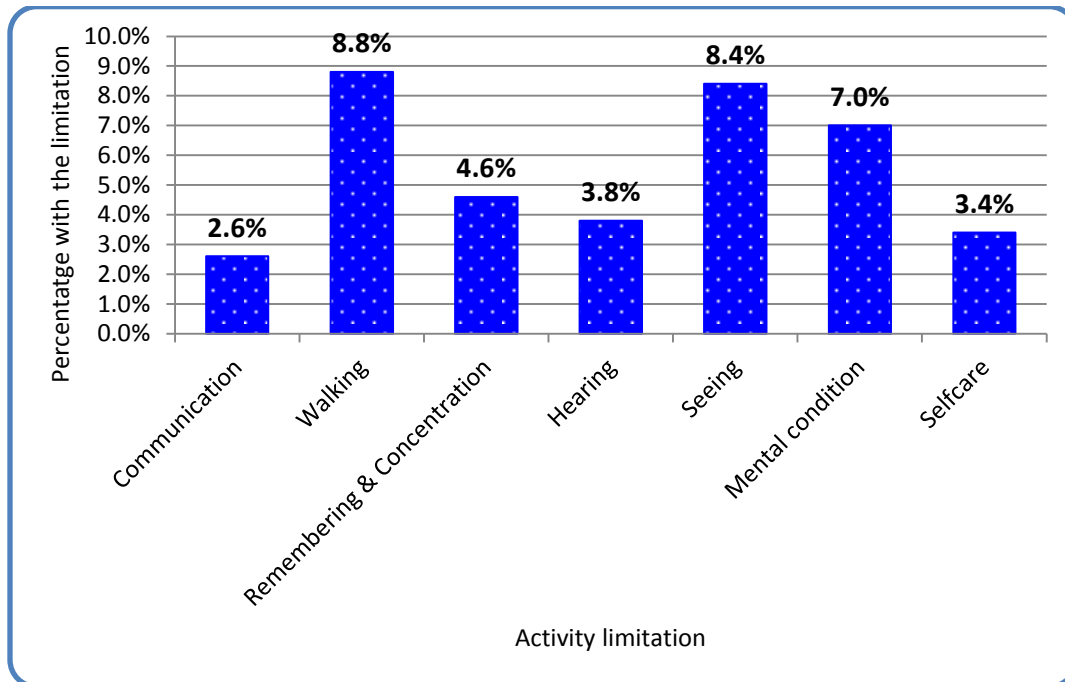


Figure 6.9. Activity limitations experienced by the Fraserburg community (n = 1686; source: EquitAble survey)

### ***Health care services***

Health care services to the community were provided through a nurse driven service at a CHCC, with overnight facilities for up to five persons, and a one bed labour ward. The service is open five days a week from 08:00 to 13:00 and 14:00 to 16:00. A professional nurse is on call for after-hours emergencies. Approximately 40 – 60 users were seen daily at the CHCC, and one to eight emergencies and labour cases were seen per week. The staff compliment and outreach support at the time of the study is presented in Tables 6.1 and 6.2.

Table 6.1

*Staff on site at the CHCC*

<b>Occupation</b>	<b>Number of positions filled</b>	<b>Number of positions vacant</b>	<b>Sufficiency</b>
Professional nurses	4	1	Sufficient
Auxiliary nurses	6	None	Sufficient
HIV/AIDS counsellors	2	None	Sufficient
Housekeeping staff	2	None	Insufficient
Kitchen staff	None - two ladies cook in bulk and food is frozen and heated by housekeeping staff before use		
Maintenance staff	1 gardener; 3 x a week		Insufficient
Emergency transport officers	3	None	Insufficient
Security officers	6	None	Sufficient
Administration officer	0	Post approved	Need 1

Doctors and therapists provided a weekly outreach service from Calvinia 200 km away. Secondary health care was provided in Calvinia while more advanced health care was mostly provided in Kimberley 800 km away. The district health care offices were situated in Springbok 700km away (See Figure 6.1).

Table 6.2

*Clinical staff doing out reach visits to the CHCC*

<b>Occupation</b>	<b>Number</b>	<b>Frequency</b>
Doctor	2	1 x per week (+/- 8 hours)
Physiotherapist	2	2 x in 2 weeks (+/- 4 hours) 1 in CHCC, 1 do home visits
Occupational therapist	1	1 x in 2 weeks
Speech therapist	1	Once a month
Dietician	1	Once a month
Social worker	1	Once a month

Positive findings on health care service delivery included:

- No users were refused treatment.
- The length of consultations with professional nurses was satisfactory.
- Pharmacy prescriptions filled out on the day of the consultation, depending on availability of stock.
- An adequate stock of walking assistive devices.

Service challenges included:

- Insufficient doctors' hours leading to short consultations (on average 10 minutes).
- Drugs being out of stock.
- No computer and no internet access.
- Transport:
  - No public transport.
  - A stretcher ambulance was used for emergency transport, and routine transport to the secondary hospital.
- Limited rehabilitation service delivery.
- Procurement of wheelchairs and buggies were challenged as described by Visagie, Scheffler, and Schneider (2013).
- Orthotic and Prosthetic services were lacking.
- Spectacles were provided by a private company that visited Fraserburg quarterly.

The CHCC (Figure 6.10) is a purpose built facility. It has five consultation rooms, a dispensary, waiting room, combined reception and records area, kitchen, laundry, delivery room, a theatre which was only used for suturing of wounds, and overnight rooms for four users.



*Figure 6.10.* The Community Health Care Centre at Fraserburg

There are no designated parking areas at the CHCC. The building has a ramp in front, but it was uneven with a pothole at the bottom and no landing at the turn. Double doors gave access to the building. One door was bolted at the bottom and top whenever I visited the CHCC. The open door was too small for a wheelchair to enter. The reception area had no dropped counter. Passages and inside doors were wide enough to allow easy access, and entrances to doors did not have raised thresholds. The entire building was on ground level. The two public toilets were not wheelchair accessible. Poster displays focusing on disease prevention were seen throughout the building and written notices informing users about the organisation of services were seen in the reception area. This information was only accessible for people who could see and read.

## **6.4 Study Population, Sampling and Participants**

### **6.4.1 Persons with disabilities**

In case studies the focus is on depth of data rather than numbers of informants (Yin, 2013). In addition one can only do the comprehensive, nuanced data analyses that IPA requires with a small sample (Smith, 2004). Participants are revisited while collecting and analysing data rather than increasing the number of participants (Groenewald, 2004; Smith et al., 2009). Accordingly

eight persons with disabilities living in or around Fraserburg were purposively sampled as the primary participants (“cases”) in the study. In order to create a rich tapestry of their lives and experiences additional data were collected from key role players in their lives (Yin, 2013). The construction of cases differed since it depended on the significant role players in the life of the person with the disability who was sampled.

### ***Inclusion criteria***

- All participants had to belong to the so-called Coloured population group. Initially the study proposal called for participants from the White and Coloured population groups since they represent 97% of the population of Fraserburg. However, the Coloured group who are in the majority (79%) experience higher levels of poverty, and unemployment, and were more dependent on government health care services. Therefore I decided to focus solely on them.
- People of all age groups were included.

### ***Exclusion criteria***

- Persons who suffered from psychiatric problems as identified by the question: “Do you have problems with nerves, sickness or depression?” were excluded since I have no clinical experience in this field and would not have been able to interpret findings.

### ***Study population and sampling***

A two stage sampling process as described by Yin (2013) was implemented. During the first stage, findings from the EquitAble survey were used to identify the study population (Yin, 2013). During the EquitAble study the Washington Group Questions (WGQ) (Washington Group on Disability Statistics, 2010) were used to collect data on activity limitations from 1 686 persons in the Fraserburg district. For the purpose of the current study individuals who scored 3 (a lot of difficulty) or 4 (could not do) in one or more of the WGQ were considered as participants. A score of 2 might be an indication of very mild disability therefore these



individuals were excluded. A total of 283 persons were eligible as study participants according to this screening process.

During the second stage of selection I used information on gender, age, type of disability, place of residence, employment and poverty status from the EquitAble survey data, prior knowledge of the population, information from EquitAble field workers, discussion with community members and provisional data analysis to identify eight study participants through purposive sampling (Yin, 2013). Purposive sampling enabled me to select a heterogeneous group of participants with maximum variation with regard to variables that might lead to different experiences on the issues under study (Domholdt, 2005). Variables that may have an impact on how disability is experienced and on health care access include:

- Type and severity of disability (Grut et al., 2012; Mechanic & Tanner, 2007).
- Being a child (Furumoto-Dawson et al., 2007; Khan et al., 2006).
- Being elderly (Lee et al., 2010; Levesque et al., 2013; McGibbon et al., 2008).
- Poverty (Butler et al., 2013; Grut et al., 2012; Lee et al., 2010; Levesque et al., 2013; Mechanic & Tanner, 2007; Peters et al., 2008; Tonoyan & Muradyan, 2012; Vladeck, 2007).
- Living far from services (Gaede & Versteeg, 2011; Goudge et al., 2009b; Hossen & Westhues, 2011; Khan et al., 2006; McGibbon et al., 2008; Peltzer et al., 2007; Russel et al., 2013; Tonoyan & Muradyan, 2012).
- Employment status (Butler et al., 2013; Lee et al., 2010; Mechanic & Tanner, 2007).
- Gender (Balarajan et al., 2011; Levesque et al., 2013; McGibbon et al., 2008; Peters et al., 2008).

Thus individual anchor participants were sampled to ensure that they differed with regard to these variables.

### *Study participants*

The first four participants all had impairments that led to mobility limitations. However, they were of different genders and ages. In addition, the severity of the impairment and the underlying health challenges differed. The next four participants had no mobility limitations. They had challenges with cognitive ability, hearing and seeing. Table 6.3 provides specific information on the study participants.

Table 6.3

#### *Characteristics of study participants and persons interviewed in each case*

	Characteristics	Persons interviewed
*Anita	<ul style="list-style-type: none"> <li>• Elderly, woman</li> <li>• Severe acquired physical disability</li> <li>• Integrated in community before disability</li> <li>• Managed through all levels of care</li> <li>• Lived in town</li> <li>• Poor but not severely so</li> </ul>	<ul style="list-style-type: none"> <li>• Anita</li> <li>• Her husband</li> <li>• Manager of the old age home where she resides</li> </ul>
Brenda	<ul style="list-style-type: none"> <li>• Girl</li> <li>• Severe, congenital, multiple disability</li> <li>• Not integrated in community</li> <li>• Managed through all levels of care</li> <li>• Lived in town</li> <li>• Very poor</li> </ul>	<ul style="list-style-type: none"> <li>• Grandmother</li> <li>• Mother</li> </ul>
Carel	<ul style="list-style-type: none"> <li>• Adult, man</li> <li>• Moderate acquired physical disability</li> <li>• Integrated in community before disability</li> <li>• Managed through all levels of care</li> <li>• Lived in town</li> <li>• Very poor</li> </ul>	<ul style="list-style-type: none"> <li>• Carel</li> <li>• His mother</li> <li>• His sister</li> </ul>

Dina	<ul style="list-style-type: none"> <li>• Adult, woman</li> <li>• Moderate, acquired physical disability</li> <li>• Integrated in community before disability</li> <li>• Managed at tertiary level of care</li> <li>• Lived in town</li> <li>• Less poor</li> </ul>	<ul style="list-style-type: none"> <li>• Dina</li> <li>• Her mother</li> </ul>
Erik	<ul style="list-style-type: none"> <li>• Adult, man</li> <li>• Sever congenital intellectual disability</li> <li>• Integrated in community</li> <li>• Managed through all levels of care</li> <li>• Lived on farm</li> <li>• Less poor</li> </ul>	<ul style="list-style-type: none"> <li>• Erik</li> <li>• His foster mother</li> <li>• His employer</li> </ul>
Frans	<ul style="list-style-type: none"> <li>• Adult, man</li> <li>• Severe acquired hearing disability</li> <li>• Integrated in community before disability</li> <li>• Managed through all levels of care</li> <li>• Lived on farm</li> <li>• Less poor</li> </ul>	<ul style="list-style-type: none"> <li>• Frans</li> <li>• His employer</li> </ul>
Gert	<ul style="list-style-type: none"> <li>• Boy</li> <li>• Intellectual, visual and/or hearing disability</li> <li>• Integrated in community</li> <li>• Managed at primary level</li> <li>• Lived in town</li> <li>• Less poor</li> </ul>	<ul style="list-style-type: none"> <li>• Gert</li> <li>• His mother</li> <li>• His aunt</li> <li>• His teacher</li> </ul>
Hans	<ul style="list-style-type: none"> <li>• Boy</li> <li>• Intellectual disability</li> <li>• Integrated in community</li> <li>• Managed at primary level</li> <li>• Lived in town</li> <li>• Very poor</li> </ul>	<ul style="list-style-type: none"> <li>• Hans</li> <li>• His mother</li> <li>• His teacher</li> </ul>

\*Pseudonyms were used throughout to protect confidentiality.

## 6.4.2 Health care service providers

I proposed to interview health care service providers who provided services to the persons with disabilities in each of the case studies. This proved difficult for a combination of reasons. At least one of these reasons applied to each participant. The reasons were:

- Users did not consult the same provider every time.
- Users did not access health care anymore.
- Users could not remember the names of the providers they consulted.
- Service providers have left the community.

I was able to have one discussion with a professional nurse about a participant where the nurse was named as a service provider. In addition, I did a focus group discussion with the three therapists (occupational therapy, physiotherapy and speech therapy) who were responsible for rehabilitation services to the community of Fraserburg in 2012. Two of them were doing their community service<sup>10</sup> year, while the third one had three years' experience.

## 6.5 Instrumentation

While the research was based on a free flowing conversation, as recommended by literature on case study research (Yin, 2013) and IPA (Smith et al., 2009), I used interview schedules for guidance and to ensure that I covered all the relevant aspects during interviews (Yin, 2013). The initial interview schedule was developed by me (Appendix 2). It broadly covered the following aspects:

- Exploring the impairment/disability and its impact on the person's life
- The participant's understanding of health and disability

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<sup>10</sup> In South Africa health care service providers must perform compulsory community service after qualification before they can register as fully practicing members of their professions (Matsoso & Strachan, 2011).

- The participant`s health care needs and health care systems used by the participant
- Exploring the participant`s experience of formal health care
- Exploring the participant`s material needs and situation
- Exploring the participant`s lifestyle and support system
- Exploring community integration and employment

Further interview schedules were developed as the data collection process unfolded and during provisional data analysis. Through reflection I identified areas to be explored in subsequent visits, with significant others and with service providers. The interview schedules for follow-up visits and significant others varied from participant to participant.

## **6.6 Pilot Study**

Since I expected cases to differ and the flow of the interviews to be varied and of different lengths, undertaking a pilot study did not seem of particular use. The format of my interviews was planned as conversations rather than a question and answer session. Thus while the interview schedule could be tested during a pilot study I could not see it serving much purpose since the schedule would not be used in the same way with any two participants. In addition, I felt I knew the people, community and context through living here as well as directing two phases of EquitAble data collection in the setting, and would not benefit in that regard from doing a pilot study. Furthermore, two of the participants were interviewed during EquitAble as well and these interviews served as a starting point in these cases.

I nevertheless selected a participant for a pilot study and performed an interview with her, and significant others in her life. On completion of this process I felt that her experiences were important for the main study. Thus I integrated the pilot into the full study.

I did learn the following from the process up to that point. The interview was done in conversation style and I only glanced at the interview schedule from time to time to make sure that I covered all aspects. I collected sufficient data to answer the aim and objectives of the study through the interview although I would have liked data with more depth. The participant

found it challenging to relate her feelings and emotions with regard to her experiences. The bulk of the data were descriptive of processes of what happened rather than of how she experienced what happened. I realised that this might happen throughout the study and entered interviews with an awareness of this challenge.

## **6.7 Data Collection**

I collected data through a series of face to face interviews of which the bulk were performed in March and April 2012. Face to face interviews were chosen as the data collection method since it allowed me to observe body language, facial expression and interaction between people. All interviews were in Afrikaans, the first language of all study participants, and my first language.

The data collection process was initiated through a visit to each primary participant. During these visits the study was described to them, provisional consent obtained and an interview date and venue decided on. This was done through a personal visit since EquitAble survey data included addresses, but not phone numbers. The process differed slightly for the two participants living on farms. In these instances I used the name of the farm to find the phone number of the resident farmer in the phone directory. The farmer was then contacted telephonically to enquire whether the participant still resided on the farm and permission was obtained to access the farm. In both instances the farmer offered to obtain provisional consent from the participant and made an appointment.

Having secured appointments with all primary respondents I embarked on the initial interviews. I met the participants at venues of their choice to ensure that they would be relaxed and comfortable during the interview (Domholdt, 2005). The interviews commenced with a full explanation of the study and obtaining written informed consent to participation and the use of a digital recorder. I allowed free flowing conversation and explored thoughts and opinions as they were offered by the participants, as recommended by Smith (2004) and Yin (2013). Before concluding the interview I ensured that all aspects mentioned in the interview schedule were covered. In instances where questions were not relevant, such as exploring conditions and inclusion at work in the case of a bed-ridden person, these aspects were not pursued. The interviews were ended with an opportunity for the participants to add anything they want, after

which they were thanked and told that I might visit them again to ask follow-up questions. The interviews varied in length from 1½ hours to 45 minutes. Interviews of varying length in this type of research are described by Groenewald (2004) and Smith (2004). During data analysis I identified some instances where follow-up questions were needed to explore comments further. I revisited participants to follow-up these issues.

In seven of the eight interviews the primary caregiver/most significant other in the life of the primary respondent was present and participated in the interview. While this situation might not have been optimal since it did not allow either the primary participant or significant other to express honest opinions that might hurt the other person, I deemed it the most sensitive and appropriate way to progress. In all seven instances the person had a very close relationship with the primary participant, and in all seven cases this person was present both when the appointment was made and at the time of the interview and acted like his/her presence was a given. Thus to have asked them for privacy could have caused feelings of resentment which I wanted to avoid. At no time during the interviews did any primary participant or significant other indicate in words or body language that they were uncomfortable to be interviewed together or that they were unwilling to answer any of the questions in the presence of the other. Should this situation have occurred I would have set up a further interview with that person to explore my observations. The presence of primary caretaker/significant other served an additional purpose in some instances such as being the mother of a child with a disability, and thus being the primary respondent, or acting as interpreter in the instance of a hearing impaired participant.

Through reflection on the initial interviews I developed the cases around each participant and identified other persons to be interviewed. These persons were also contacted in person as primary participants could not provide me with phone numbers. The study and their connection to it through the primary participant were explained to them. Provisional consent was obtained and a date, time and venue for the interview were set. Interviews with significant others were shorter and lasted between 15 and 45 minutes.

Three respondents, connected to the same primary participant, refused consent for the interviews to be voice recorded. I proceeded with the interviews and wrote down as much of the

conversation verbatim as possible. While not optimal I felt that this particular case provided important insights into the study aim and objectives and that it should be included in the study.

In addition to the interviews I made field notes and kept information that was provided to me in hard copies in order to enrich data (Yin, 2013). According to the literature, field notes should be written as soon as possible after the interview and preferably within 24 hours. In most instances I did only one interview per day and completed my field notes the same evening. These were written in a journal kept for this purpose. Notes should be descriptive and reflective in nature and contain information on what you saw, heard and thought (Groenewald, 2004). Groenewald (2004) suggest that field notes are broken down into four parts, i.e.:

- Observations during the interview.
- Theoretical notes containing reflections on the interviews.
- Methodological notes on the data collection process.
- Analytical summaries and progress reviews at the end of field days.

Of the groupings described above I felt that I did most justice to observations and theoretical notes. Theoretical notes formed the bulk of my field notes since I reflected a great deal on what was said and how participants acted. In addition I wrote down my observations of the environment and interaction between participants where more than one was present.

Methodological notes were limited to jotting down names of significant others to be interviewed and questions that needed asking from them. I did not make summaries at the end of field days and progress reviews were not so much reflective of what had happened in the research thus far as reflective of the way forward.

In instances where information was handed to me in hard copy or where interviews were written down verbatim the information were kept in a folder. The folder had a section for each participant. Signed consent forms were also kept in this folder.

For the focus group interview I contacted one of the therapists telephonically. I explained the study to her and my reasons for wanting to interview the therapists. She offered to organise a time with the other two therapists and informed me via email of a time suitable for them. I



suggested a neutral venue that they were happy with and the focus group discussion was performed there. It lasted 1 hour and 15 minutes and was digitally recorded.

## 6.8 Data Analysis

Data analysis started during the data collection process through facilitating the conversation to generate rich data, through making notes of observations and through reflection. I acted as sole data collector since gathering the data personally enabled me to develop a rich understanding of participants' worlds in order to contextualise and analyse data optimally. I personally transcribed all interviews in order to further enhance my familiarity with the data. Then I analysed the data using IPA as describe by Smith et al. (2009). Every case was analysed as described below and presented in Figure 6.11:

- The transcribed interviews were printed in the middle third of a page separated into thirds. I read and re-read this material, and in some instances listened to the recording again. While reading I wrote down my emotions and responses in a journal, which I added to my field notes and post-interview reflections on the cases. The purpose of this was to try and empty my mind of my own perceptions and remain aware of my own feelings while seeking for the experiences of participants – a process that I found difficult and not completely successful.

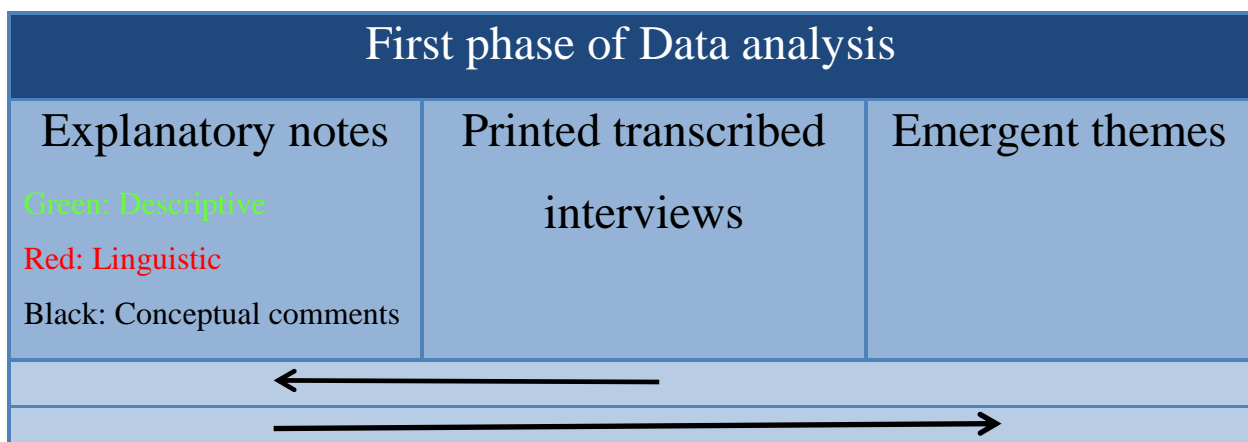


Figure 6.11. Example of a page as used during the data analysis process

- In the next step I created a detailed set of explanatory notes and comments on the data in the left hand column. I used pens in three different colours to denote different aspects. A green pen was used to jot down key words or phrases in a descriptive process. A red pen was used to make comments on choice of language, metaphors, tone of voice and non-verbal aspects such as hesitation, laughter or crying. Conceptual comments often in the form of questions that I asked of the data were written in black.
- Following this the right hand column was used to pen in emergent themes. My aim was to distil the data into themes which capture its essence while it decreased the volume of information. The themes were developed more from my notes in the right hand column than from the actual transcript but related closely to the data. Thus more of my interpretation was included while the participant voice was still retained (Smith et al., 2009).

Finally I identified connections between themes and ordered similar themes together (Smith et al., 2009). The themes were typed, printed onto paper and cut out. These were ordered and reordered on a pin-up board to develop groups that fitted together as illustrated in Figure 6.12.



*Figure 6.12.* An example of the clustering of themes into superordinate themes

Groups of themes that fitted together were clustered under superordinate themes (a theme or concept that encompasses the themes clustered under it). Superordinate themes were developed through (Smith et al., 2009):

- **Abstraction:**  
Clusters of similar themes were put together under an overarching theme that describes them. For instance, the themes diagnosis and treatment, medication, referral system, client centred care, attitudes of service providers, rehabilitation and long-term management were clustered under the superordinate theme of health care (Chapter 7).
- **Subsumption:**  
One of the themes in the cluster connected the rest and became the superordinate theme. For instance in the case of Carel (Chapter 9) health care was a theme amongst similar themes like home-based care and rehabilitation. Thus health care was used as a superordinate theme.
- **Function:**  
In some instances I interpreted what was said beyond the obvious meaning of the words to what they may imply. For instance, in the case study of Carel (Chapter 9) I interpreted the information provided on disability and the way Carel and his family talk about him to indicate that they equate physical disability to being worthless, even though they never referred to him as worthless in so many words.
- **Numeration:**  
The frequency with which a theme was mentioned was in some instances used as a relative indicator of importance. However, this was used with caution as important themes can be mentioned only once. In this study I used numeration once and then in conjunction with function to develop a superordinate theme. In Chapter 8 the number and content of comments seemed to indicate in combination that Brenda's grandmother might conceptualise disability according to the moral approach.
- **Polarisation:**  
In one instance (Chapter 13) a theme was developed based on the difference in information on the same subject.

- Contextualisation:

Contextualisation refers to the identification of key events in the lives of participants.

While I identified key events, for instance in Anita's case study (7.4), they were not used as superordinate themes.

I tried to analyse data for each case with an open mind without allowing my perceptions to be clouded by previous cases. However, I was not completely successful since I found it impossible to block out insights into the data that to my mind might explain a finding, and to prevent my mind from immediately connecting comments in the case that I was working on to insights from previously analysed cases.

After data analysis of individual cases were completed I did a cross case analysis to develop patterns across cases. First I printed the superordinate themes from each case study on pieces of paper. These I manually ordered and re-ordered into groups of similar themes to identify superordinate themes across the eight cases. I started to write this up provisionally, but moved back and forth between my writing, the themes, and discussion and reflection components of each individual case study, and sometimes the transcripts to create a comprehensive picture of the most important patterns.

I analysed the data by hand rather than using a software programme because my aim was to generate hypotheses, and place participants' experiences within the larger social context and health care system, rather than just describe the findings through thematic analyses. In addition the volume of data dealt with was small enough to allow manual analysis (Silverman, 2013; Travers, 2009).

## **6.9 Rigour**

Findings from the study might become the basis for future action. Thus they must be authentic (Denzin & Lincoln, 2005). Four criteria were used to determine the authenticity of findings:

- Credibility (truth value). Credibility can be determined through peer review, an audit to ensure results are grounded in the data, reflexivity, triangulation (McGloin, 2008; Tracy, 2010) and exploring rival explanations (Patton, 1999; Silverman, 2013; Yin, 2013).
- Transferability (applicability). A detailed description of the context and methods used must be provided to assist potential users of the findings to decide whether it might be applicable to their settings (McGloin, 2008; Silverman, 2013; Tracy, 2010).
- Consistency (dependability). The nature of qualitative research can lead to variation in findings over time. However a certain level of consistency is expected if the study is repeated with the same participants (McGloin, 2008). Consistency can be evaluated through an audit of the research process and procedures (Akkerman, Admiraal, Brekelmans, & Oost, 2008) as provided in a case study data base (Tracy, 2010; Yin, 2013).
- Neutrality (conformability). The findings must to a large extent be the results of participants and conditions of the research and not of other influences, biases or perspectives. Triangulation, reflexivity, and auditing can be used to certify that interpretations are consistent with the available data (Akkerman et al., 2008; McGloin, 2008).

In addition, Smith (2011) provided criteria against which the quality of IPA can be assessed.

These are:

- The research must be:
  - Phenomenological, interpretative and idiographic.
  - Transparent enough to allow readers to understand how it was done.
- Analysis must be logical, reasonable and stimulating.
- Themes across cases must be supported by sufficient cases to show density of proof (n 4-8: evidence from three or more participants).

I endeavoured to achieve authenticity in the current study through prolonged engagement, triangulation, thick description, reflection, providing rival explanations and providing a data base for audit.

### ***Prolonged engagement***

Sufficient time in the field may increase one's understanding of the culture, context and phenomena under study (Cohen & Crabtree, 2006; Tracy, 2010). My time in the "field" consisted of two components; that of being a member of the community and that of a researcher in the community. I function daily in the study context. In addition, my involvement in the research became known and community members approached me to share experiences on health and health care. I have accessed government subsidised primary health care services for myself and my family. I have supported employees on our farm with health related issues. On the other hand, I am the wife of a farmer, thus a member of a different social group, with limited insider knowledge of the lives of the people who formed the study population.

As a researcher I spent various periods of time between 2010 and 2012 immersed in data collecting. The longest of these was a three week period in October 2011 (EquitAble survey), a week in April 2010 (qualitative interviews) and another week in June 2010 (observing the CHCC and interviewing staff). Further data collection (the case studies, for instance), discussions about the research with community members and feedback sessions with various groups were less structured. I usually spent one night in town interviewing and talking to people and groups over the two days. This happened in 11 instances at various times during the final months of 2011, and April and May 2012. This is an incomplete record as some interviews, for instance with teachers and therapists, were done on different days that were convenient to them. In addition I spent long hours transcribing and analysing the data.

During data collection and analysis I tried to identify and focus on the factors most relevant to the study to facilitate rich data and enhanced understanding as described by Cohen and Crabtree (2006), Hodgetts and Stolte (2012) and Yin (2013).

### ***Triangulation***

The purpose of triangulation is to ensure a rich and comprehensive account of study phenomena. Triangulation can be achieved by using multiple methods, sources, evaluators and/or perspectives (Yin, 2013). Data from different sources may yield slightly differing results,

because of real nuances such as different perceptions. These differences are to be expected and should be explored (Patton, 1999). They do not weaken credibility, but rather offer opportunities for additional insights in the phenomenon under study. Yin (2013) argues that findings and conclusions which are corroborated by several sources are more convincing and points towards high levels of construct validity in case studies. Cohen and Crabtree, (2006), Denzin and Lincoln (2005), and Silverman (2013) on the other hand do not agree and argue that since objective reality cannot be captured triangulation can only serve to add rigour, depth and richness.

Triangulation of sources as described by Patton (1999) and Yin (2013) was done in the current study. The same person was interviewed at different points in time, and people with different interests in the phenomena under study such as persons with disabilities, key role players in their lives, employers, health care service providers and educationists were interviewed. In some instances additional information was received in document form from participants. An example of triangulation in the current study and how multiple sources can add rigour was the finding that little rehabilitation was done. Information from persons with disabilities, significant others and therapists corroborated this finding.

### ***Thick description***

In the results section I have tried to produce a text that will allow my readers to share in the lived experiences of the study participants as described by Denzin (2001). I aimed to show the significance of events such as Anita's misdiagnosis or Carel's lack of wheelchair training through:

- Detailed presentations of context, experiences, emotions and interpersonal relationships.
- Ample narrative examples of actual experiences.
- Presenting participants experiences first, without detracting from them by inserting my interpretations, which were presented in the next section.

### ***Transferability***

I endeavoured to provide a detailed description of the processes that were followed from study inception to the writing of this document in order to provide the reader with sufficient information to judge the credibility of the study (Silverman, 2013; Tracy, 2010) or to determine to what extent conclusions can be transferred to other settings (Cohen & Crabtree, 2006; Hodgetts & Stolte, 2012; Silverman, 2013). I explained the reasoning behind methodological choices. My interpretations and conclusions can be traced back to the discussion and results sections, narrative examples, and citing of sources. Information on sources and the narratives can be found in the data base. The data base also contains setting, dates, and duration of interviews. Finally the data collected can be linked to the study aim and objectives.

### ***Reflection***

Professionally I am a rehabilitation clinician and more specifically a physiotherapist. Personally I am a privileged, White, women, married to a farmer, thus socially not a peer of study participants. I bring this background with me and could not rid myself of how my identity and values colours my thoughts and interpretations. It impacted on the collection and interpretation of data and neutrality of results (Domholdt, 2005; Patton, 1999). I tried to empty my mind of preconceived ideas, opinions and perceptions. However, I found it impossible to be entirely successful. Who and what I am as well as my attitudes and perceptions on disability and rehabilitation intruded and coloured my interpretation of the study findings. I experienced, as indicated by Patton (1999), that the researcher cannot remove him/herself fully from the research process. My choices and actions during the research were influenced by who I am and what I knew. For example, Anita, around whom the first case study revolved, was purposively sampled because I had some prior knowledge about her experiences. Thus I had to remain constantly aware of how my prior knowledge might influence the questions I asked and my interpretation of findings. Another example would be the interview schedule. This was based partly on my prior knowledge. Thus questions asked and answers solicited cannot be seen as not influenced by me.

I tried to remain constantly aware of these issues while I sought participants' interpretations of situations and I reflected on ways in which my involvement and subjectivity could have



impacted on results. This was done mainly in the form of a journal. In addition, discussions with the rest of the EquitAble study group that included three other post-graduate students, two researchers who completed their PhDs on different but related subjects during the study periods and the study leader and promoter for this study provided opportunity for reflection.

Finally I have tried throughout this document to provide information on my own stance, values and beliefs and how that might have impacted my choices of methods and interpretations of findings (McGloin, 2008; Tracy, 2010).

### ***Case study data base***

I maintained a data base. Thus anybody has the opportunity to inspect the data, or perform an independent analysis or audit in order to verify my conclusions (Akkerman et al., 2008; Tracy, 2010; Yin, 2013). The digitally recorded interviews and transcripts of the interviews are stored in computer files, with a backup on a memory stick, and a hard copy. A printed version of the transcripts on which IPA were done as described under 6.8, and documents are kept in a folder with separate sections for each participant. My field notes and reflections during data collection and analyses are documented in a journal, and in “reflective letters”<sup>11</sup> to various participants which are stored in a computer file.

### ***Rival explanations***

In this study inferences were based on the narrated experiences of participants. Therefore I have endeavoured to explore all possible explanations for inferences in order to increase the credibility of findings. In addition I did not ignore cases that could be seen as contrary, such as the case of Dina (Silverman, 2013; Yin, 2013).

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<sup>11</sup> This letters refer to frank reflections I wrote in the form of letters to participants on topics that I found emotionally taxing and needed to reflect and debrief on before continuing with data analysis, ie., I wrote a letter to Brenda (one of the participants) after I was told of her death.

## 6.10 Ethical Considerations

The study was registered with the Health Research Ethics Committee at the University of Stellenbosch and written permission to conduct part of the study at the Fraserburg CHCC was obtained from the Northern Cape department of health.

Study participation was voluntary and this was made clear to participants. They could ask me to stop the interview at any time. They were assured that refusal to participate or withdrawing would have no negative consequences for them. No data were collected from any participant before informed consent had been obtained in writing (Appendix 1). In the instance of children informed consent was obtained from their legal guardians. I explained the study to every participant and they were given the opportunity to ask questions. I gave them ample opportunity to refuse to participate and to refuse to be digitally recorded. In cases where participants refused to be recorded I did not use the recorder.

I treated all information as well as the identity of participants in the strictest confidence. A pseudonym, which was used during analysis and dissemination of data, was allocated to each participant. However, Fraserburg is a small town and in instances where readers know the participants they might be able to deduct their identities from the descriptions (Tracy, 2010). Thus, while I doubt that anyone reading this thesis will be able to identify individual participants I have presented data in a manner that should not be hurtful or damaging to participants should they be identified. Electronic data were stored on my personal computer and hard copies are stored in my home office. All data will be destroyed once dissemination has been finalised.

Only data necessary to address the aim and objectives of the study were collected. Data were analysed fairly and accurately, only for the purposes of the study. I adhered to professional and ethical standards as well as Good Clinical Practice in Research and the Declaration of Helsinki. I treated participants with courtesy and respected their dignity, privacy and autonomy at all times. I have tried to write this report and articles drawn from this study in a way that shows respect to participants and will not assault their dignity.

I could refer participants back to the CHCC or the social worker in instances where they required assistance or where data collection left them with a need for emotional support and counselling.

## **6.11 Summary**

A case study design was used to explore the experiences on disability and health care access of persons with disabilities who resided in the community of Fraserburg. Eight persons with disabilities were purposively sampled as the anchor participants in each case. Significant others in their lives and service providers completed the cases. Data were gathered through in-depth interviews and analysed according to the principles of IPA. Rigour was sought through prolonged engagement, persistent observation, triangulation, thick description, reflexion, creating a chain of evidence, and providing rival explanations.

The results of the eight case studies are presented in the next eight chapters. In keeping with case study and IPA methodology, data from each case were analysed individually and are presented individually. The results in each case are presented before I discuss them, explore probable interpretations and connect them to excising theory. I used the following outline in each of these chapters:

1. Introduction.
2. Sampling and sources of information.
3. Background information.
4. Medical history.
5. Presentation of emerging themes with narrative examples.
6. Discussion.
7. Conclusion.

## **Chapter 7**

### **Anita's Story**

#### **7.1 Introduction**

The first case study revolved around Anita, a 68 year old woman with severe physical impairments. Anita's husband was the man who approached me in the library and asked me to come and see his wife (Chapter 1). This heralded a series of clinical consultations at their house in 2008, the content of which is confidential, and not part of this study. While I formed certain perceptions at that time which might cloud my interpretations, I tried to keep an open mind through reflection, as discussed in the Methods chapter.

#### **7.2 Sampling and Sources of Information**

Anita was purposively sampled based on my prior knowledge. Data used in this case study came from two formal tape recorded interviews, informal visits, and a discussion with the manager of the old age home where Anita resided. In April 2010 I conducted a semi-structured interview with Anita and her husband as part of data collection for the EquitAble study. This interview lasted over an hour and covered all aspects of health care access as they experienced it. I conducted a second interview with Anita in September 2012, during which I specifically focussed on the issues pertinent to the current study such as her experiences of disability. This interview lasted 70 minutes.

It must be noted that the findings in the main represent the views of Anita and her husband. They were not verified from case notes or service providers. I did not have permission from the Northern Cape Department of Health to access client folders. Furthermore, none of the therapists or doctors who were involved with her treatment were still working in the community or at the secondary hospital at the time of the study and she had not consulted the professional nurses at the CHCC in the last four years. Service providers might have perceived various situations differently; however the focus of this study is on the perceptions of the user.

Triangulation of information from the interviews as well as from the three informants in this case

study shows corroboration of findings, which increases my confidence in the credibility of the findings from their point of view.

### **7.3 Background Information**

Anita cannot get out of bed. She is cared for in the old age home in town. Before her impairments Anita managed the elder care project in the community. With a Grade 5 qualification she furthered her skills to the point where she could manage this project, with a range of components, from a feeding scheme, through enrichment activities, to managing financial aspects. She was a leader in the community and held strong opinions on, for instance, the role of women:

Three things about a woman are important to me. She must be honest . . . she must be neat and she must be a leader in the house. The man is the head of the house, but she is the one who is home most often . . . In the house she is the minister, the doctor, the counsellor. (Anita)

From what I observed it seemed as if Anita and her husband built their relationship on love and respect. They apparently lived according to a set of sturdy principals based on dignity, privacy, honour, and a strong moral sense of right and wrong, which they were not afraid to voice.

### **7.4 Medical History**

A fall and subsequent hip fracture in 2008 represents to me the first of two key life events (Smith et al., 2009) in this case study. Anita described the incident and its aftermath as follows:

The 24th of March. Yes, Easter Sunday in March – I fell. 2008. That same Sunday they took me to Calvinia [secondary hospital] in the ambulance. In Calvinia [secondary hospital] they took an X-ray of the leg. They told me nothing was broken, so I don't have to worry. I can go home . . . the ambulance driver refused to take me back to Fraserburg, because I was in pain. So I had to stay overnight - they gave me a Brufen® pill [anti-inflammatory] and told me there is nothing wrong, but I had so much pain. I lay there crying. I was treated very carelessly . . . the next morning they told me to get up. I said I

can't get up. They said I must get up and climb off; that I am a hypochondriac and other horrible things. Used bad language . . . I told them, I cannot get up. So they brought a wheelchair, and told me to get in. I could not get in, because I was in too much pain. Every movement was painful. So they helped me, but were very rough . . .

At home he [points to husband] and a few other men helped me into the house, but I could not get any further than the lounge. That is where I lay that night. Neither of us closed an eye that night. I was in so much pain. Pills didn't help. The next morning, Tuesday, he said that he was going to the clinic [pointing to husband]. They sent me a few more pills, which I took. With those I felt I was going into a trance, because of the pain. Then he said he is sorry, but he is going to call a private doctor. Whether we have the money or not he is going to call Dr [name doctor] . . . When the doctor came, he picked up my legs and put them down again and said that there was a fracture. He immediately sent for the x-rays from Calvinia [secondary hospital] and when he looked at them, he saw the fracture. While, in Calvinia [secondary hospital] the doctor had said there is no fracture. . . . He [private doctor] said that I must go for an operation. But it was too expensive for us to do privately. We had to have it done through the government. But every time they [professional nurses at the CHCC] told him [husband] that I must stay in bed for 6 weeks. Then they give him pain killers for me. So I took the pain killers and it became what, 6 months. There was no improvement. (Anita)

After nine months Anita was re-assessed by an orthopaedic surgeon at the secondary hospital who confirmed the diagnosis of a fracture by the private general practitioner, but said due to the loss of time and her being overweight nothing could be done. Anita and her husband were disillusioned: “. . . health care in the Northern Cape disappointed me bitterly, I was shocked”. They bypassed the formal health care referral system and accessed tertiary health care at Tygerberg Hospital, a tertiary hospital, in the Western Cape Province 500 kilometres away. They managed this through consulting a private general practitioner in the Western Cape Province who referred her to Tygerberg Hospital. At Tygerberg hospital, more than a year after the initial incident, doctors told her the fracture was secondary to cancer. Her husband explains:

There they told me that it was cancer, and because of that she will not recover. The results show that they can't do anything for her, but we must give them a chance to do more tests. The next Wednesday, when I got there, they said that they would give her x-ray treatment for the cancer and do a hip replacement, but I must come back in a week. When I got there, they said that they can't do what they had said they would do. They cannot do anything for her. At that point they wrote her off and told me I must find a clinic or place where she can lie and be cared for. (Anita's Husband)

They told me do not sit up, do not take the collar off from your neck it will affect your vertebra, you will get paralysed. . . .I actually came here to die. (Anita)

Her husband brought her home, but could not manage the caring duties and she moved into the old age home. Four years later she was alive and not paralysed. She questioned the diagnosis of cancer:

For me there is always that question hanging. [pause] Why am I lying here? Do I really have cancer like the doctors said? . . . We are with that uncertainty . . . because it is pain free and all the things they [doctors] told me not to do because I will become paralysed I did and I am not paralysed. (Anita)

This doubt led to what I deemed the second key event in this case study. This one was more gradual than the fall and fracture, but no less defining of Anita's future. She made the choice to sit up in bed. This gave her the freedom to explore different activities and found a creative outlet:

It was my decision. I did not want to lie on my back for the rest of my life. Even if I cannot walk anymore I want to sit up straight at least. And when I sit I do not only want to sit. I want to do something. I started to write poetry, but realised I did not thrive in that. After that I started to make greeting cards. That worked out. It works very well. So much so that people buy them and places orders with me. That motivates me to live. (Anita)

The above being the broad outline of Anita’s story according to her and her husband, I will now introduce the emerging themes that I identified.

## 7.5 Emerging Themes

Through analysis of the findings as described in the methodology I identified five superordinate themes through abstraction (Smith et al., 2009). Figure 7.1 presents these superordinate themes and the emerging themes under each.

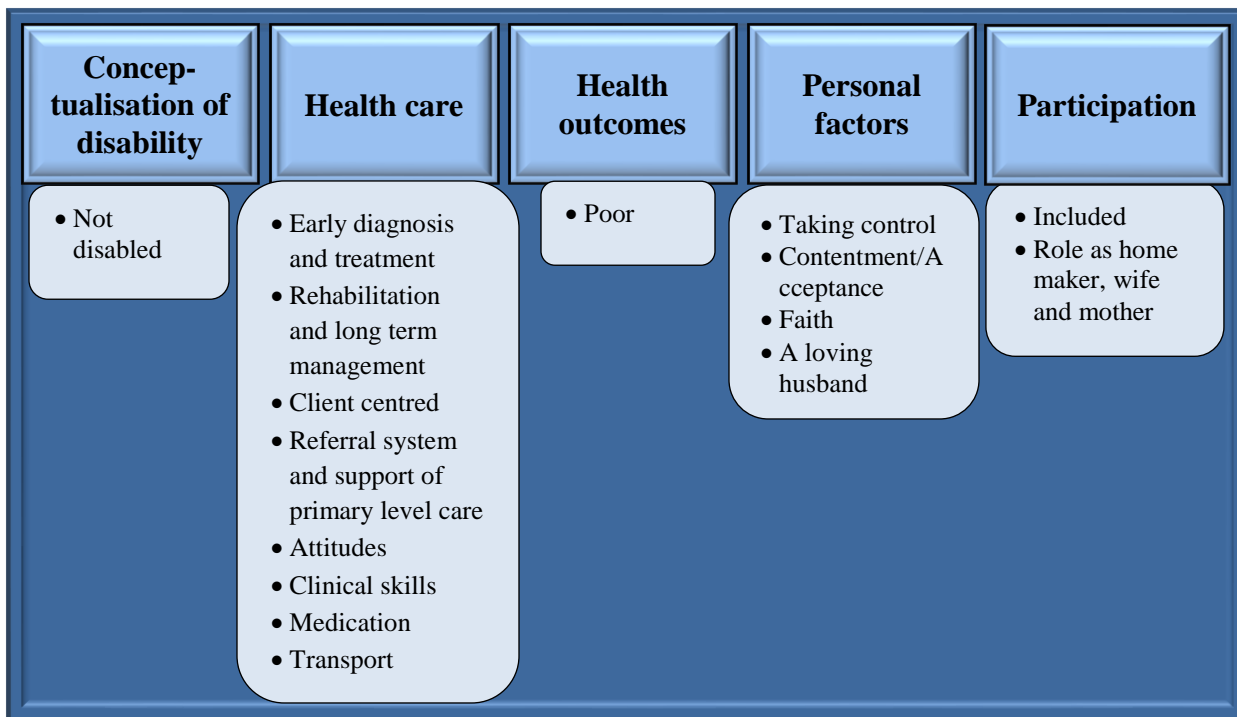


Figure 7.1. Superordinate and emerging themes identified in Anita’s case study

### 7.5.1 Conceptualisation of disability

Anita felt that she was not disabled. She said if one can still do things for oneself and help others one is not disabled. She argued that disability is more related to one’s mind set than one’s bodily abilities:

When your thoughts are disabled. You think yourself disabled. (Anita)



## 7.5.2 Health care

The findings indicated some positives and some challenges with regard to health care access. The availability of primary services and emergency transport after office hours, as well as immediate referral to secondary level, the described level of diagnostic care at the tertiary hospital and preventative health care through anti-hypertensive treatment were positive. However challenges to preventative care and in relation to transport were also identified. Further challenges revolved around a probable lack of early diagnosis, treatment, follow up, rehabilitation, client centred care, the referral system, as well as service provider attitudes, and clinical skills.

### *Early diagnosis and treatment*

It seemed as if Anita's condition was not diagnosed timeously. According to her narrative she was misdiagnosed on initial assessment. Later the fracture was diagnosed but not the cancer. According to her it took over a year for a final diagnosis of cancer to be made. By then it was too late for curative intervention. In addition, it seems no long term management and little palliative care strategies were suggested.

### *Rehabilitation and long term management strategies*

Anita was referred for physiotherapy after the second visit to secondary care. However, the physiotherapist did not do home visits and Anita could not get to the CHCC since she did not have a wheelchair and could not walk. She later sourced her own wheelchair:

We had to provide for ourselves. The wheelchair we got from a friend of mine . . . which we borrowed at first and then bought from her. (Anita)

Anita has said that after she came back from Tygerberg the physiotherapist refused to treat her for fear of causing a fracture. This was confirmed by the manager of the old age home.

Furthermore, neither Anita nor the manager of the old age home had knowledge of long term management strategies such as a follow up appointment or information on what to do should she

require further medical assistance. The manager of the old age home indicated that when she approached the staff at the CHCC to re-assess Anita they referred back to the 2009 notes from Tygerberg hospital and said nothing can be done for Anita. However, none of the predictions from the Tygerberg doctors came true and Anita is left with unanswered questions.

### ***Client centred care***

From the findings it seems as if Anita and her husband felt that service providers at primary and secondary level did not listen to them. They felt that her protestations of severe pain and that something serious was wrong were ignored. According to them service providers refused her the opportunity for a second opinion. Anita described her feelings regarding her health care experiences as follows:

It shook me terribly. (“*Dit het my verskriklik geruk*”). I knew I had pain and was not a hypochondriac. It made me feel like a nothing. They brushed me aside (“*Hulle het my eenkant toe gekrap*”). It hurt me. It felled me. (Anita)

In contrast the results showed that her condition and the possibility of secondary complications were explained to her at Tygerberg hospital (tertiary level of care). A diagnosis and prognosis that can be called devastating was provided in a way that she and her husband could understand and remember.

### ***Referral system and support of primary level care***

Anita accessed the government health care system through the CHCC and primary health care directly after the fall. She was assessed by a professional nurse and referred to a second level of care, presumably because, in the professional nurse’s opinion, the condition warranted input that could not be provided at the CHCC. However, her narrative (see 7.4) indicates that the health care provided at the secondary hospital was problematic. In addition it seems as if providers at primary level were hamstrung by a hierarchal system. Despite swift initial action, PHC service providers seemingly did not question the lack of a diagnosis at secondary level even while they must have felt Anita’s initial condition warranted emergency referral. Furthermore they did not

assist Anita to obtain a second opinion after evidence from a private doctor verified their initial opinion that something serious was wrong, and despite symptoms not having abated.

### *Attitudes*

Anita and her husband described negative attitudes amongst service providers. She reported that she was treated with rudeness and disrespect. Her husband perceived the doctor at the secondary hospital as follows:

When the doctor came past me in the passage he was so angry that I wished he would not go in to her, but I could not stop him. If his attitude was good in the first place then the work that he did would have been . . . but that her hip bone was fractured at that moment and he does not know anything about it. He sees nothing, nothing. (Anita's husband)

After Anita came back from Tygerberg Hospital primary level health care service providers apparently saw the diagnosis of cancer and a risk for further fractures as a reason not to treat her:

The doctor said she is sorry she is not touching me. She stood as far as that thing from the bed [point to the bed table, approximately half a metre from the bed]. Because she does not want to touch me. She is afraid that I will get paralysed. She does not want to be responsible for that and the physio said that he would not touch me, because if something happens, it is on his conscience. (Anita)

This refusal of the doctor to treat her was confirmed by the manager of the old age home. However the old age home staff washed and dressed Anita daily with no adverse effect.

### *Clinical skills*

According to the interviews, an incorrect or, rather, no diagnosis was made at secondary level that led to no treatment or management, except pain medication. There are however some inconsistencies in the findings. Staff from the CHCC advised Anita to take pain killers and followed a regimen of bed rest, which is the conservative way to treat a hip fracture. It is uncertain why they decided on this management strategy if they had no guidance regarding a

fracture from secondary level. It might be that they responded to the diagnosis made by the private General Practitioner or it might be that they did receive information on the condition from secondary level that Anita was unaware of. Or it might have been a wait and see approach from their side. Irrespective of the reason, the treatment plan and diagnoses was not clearly communicated to either Anita or her husband.

The findings seem to indicate high quality diagnostic services at tertiary level. A diagnosis was made. In addition it seems as if service providers explored various treatment options before coming to a decision that no treatment is indicated.

### ***Medication***

Anita indicated that she sometimes goes without hypertension treatment due to a lack of medication:

It's the second week now that I haven't got my Aldomet . . . (Anita)

### ***Transport***

A positive finding was that an ambulance was available to take Anita to the secondary hospital at Calvinia. She described this drive as follows:

You drive on this terrible gravel road and you rattle and fall about in the ambulance, because the people is in a hurry to get you there quickly since they do not know what is wrong. (Anita)

After Anita was discharged from Tygerberg hospital her husband had to provide their own transport home. Since she was not allowed to sit up she had to be transported lying down:

They told me at Tygerberg they cannot assist with transport for her. They work only in the Western Cape. . . . I rented a pick up and put her on a wooden board. I took pieces of wood and knocked them together with nails. . . . I had to drive her back on the back of a

pick-up on a wooden board. That thing could not go into my house. I off loaded her and dragged her on a mattress, like an animal. (Anita`s husband)

### **7.5.3 Health outcomes**

It seems as if an initial failure to reach a prompt diagnosis and a lack of future management strategies in the face of no cure made for poor health outcomes in this instance. Loss of time, possible errors in clinical diagnosis and no rehabilitation seemingly combined to leave Anita with numerous activity limitations.

### **7.5.4 Personal factors**

#### ***Taking control***

Anita made the decision to roll, sit up in bed, and use her hands against medical advice. She stressed that she is aware of the risks according to the doctors and that she takes responsibility for her choice:

If I became paralysed because I have sat up I will not blame anyone. . . . They did warn me and I did not listen. I took that responsibility for myself. (Anita)

#### ***Contentment/Acceptance***

Anita was content with her situation:

I did wonder why this happened to me. . . . I asked myself whether this was not God`s way to tell me to relax a bit. Relax and care for yourself. I was very busy in the community. When I lay here at first and became quiet I realise how much I neglected myself for the community. . . . Now I can read and make cards and I still have an opportunity to speak to people. (Anita)

#### ***Faith***

Her faith in God shines through:

You know it would have been different if I did not know the Lord. But I know Him and in my weakness He carries me. My husband and I talk about the goodness God shows us most nights. For us He is a rock that shelters us against all. Against our pain as well. Physically as well as spiritually and that gives us the ability to continue. That gives us the strength to be able to say it is well. (Anita)

### *A loving husband*

The interaction between her and her husband spoke of a deep love, mutual care and concern. On a question on how much he supported her she said: “A lot” with quiet emphasis.

### **7.5.5 Participation**

This superordinate theme has positive as well as negative aspects related to it. Before the injury and fracture, Anita’s life revolved around two major areas, i.e., her role as nurturer in her house and her role in the community. Anita still felt included and respected in the community, but misses her role as homemaker, wife and mother.

### *Included*

Anita was included in her family and community and provided guidance and support to many:

I am satisfied because my people did not throw me away. I have my family. We are very close. I am happy that I can still give advice to people, that people still seek advice from me. I can pray for people and talk to people. I am happy when I can do something for another person. (Anita)

He [a minister] said on days when he feel down he come and talk to me. That gives him the courage to continue. (Anita)

The local minister asked her to talk to the women in his congregation on Women’s Day through a video recording:

I talk to them about us women neglecting ourselves. We stay in front of the stove in the overall. Beautiful hair hidden under a head scarf. Instead of caring for ourselves we walk around in curlers and pyjamas . . . and even worse a woman with a “*kannetjie*” [cheap wine in a jar] under the arm and a baby on the back. Those are the things that hurt our humanness. (Anita)

In addition she found a hobby that gives her satisfaction and brings in money.

### ***Role as homemaker, wife and mother***

Anita regretted not being able fulfil her role in her house anymore. She talked about this loss with deep emotion and described a household that has lost the touch and eye of a woman:

I miss my role in my house very much. Oh no now I want to cry about it [tears in her eyes]. I miss it to be able to do the caring . . . many times I see my husband is wearing a shirt that should have been washed. He come here and told me he is hungry and I think if I were at home there would have been something for him to eat if only a rusk and some coffee. And the grandchildren. The grandchildren come here they need this or that. Sanitary towels. They cannot ask their grandfather for that. If I were at home it would have been on my monthly shopping list. Oh no, I am crying [pass her a tissue]. I asked them about the dish towels. They say it looks terrible. They will have to buy. If I were at home there would have been new ones in the drawer. All these things I miss. I miss not being able to care for them. That being a mother, that being a woman . . . (Anita)

## **7.6 Discussion and Reflection**

In my opinion this case study can be contextualised through two key life events. The first one was the fall in 2008 that triggered a series of actions that encompassed accessing various types and levels of health care services. The second one was much more subtle and not connected to a time and place. However, I see Anita`s ability to find peace, a sense of purpose and a life worth living in spite of her severe impairments and alleged medical mismanagement as no less a key event than the fall.

With regard to health care I am of the opinion that Anita's story emphasises the importance of early diagnosis and intervention. Bateman (2012), Goudge et al. (2009b) and Shakespeare (2014) have argued that a failure to provide early, effective medical management can lead to more complications, poorer health outcomes, and the need for more expensive and resource intensive input at a later stage. Anita's narrative supports these arguments. Anita experienced poor health outcomes and at least one doctor connected an inability to provide treatment to a loss of time. Anita was not disabled on accessing health care services after the fall. What seems like medical mismanagement caused impairments, activity limitations and ultimately disability.

A timely referral to a specialist and tertiary health care services would most probably have led to earlier diagnosis of the cancer. One can only speculate on what this might have meant with regard to treatment and cure, but will never know for certain. We do know that it would have spared Anita and her husband uncertainty, emotional suffering and financial expenses. While Anita described an affordable service with free of charge health care at primary and secondary level they incurred out of pocket expenses when accessing a private doctor, Tygerberg Hospital and buying a wheelchair. They took these actions because the referral system precluded Anita from seeking a second opinion, because she did not receive the necessary rehabilitation after the fracture was diagnosed at secondary level, and because they were unhappy with health care service provision in the Northern Cape Province.

Referral pathways in Government health care services in South Africa are structured in a hierarchical way where only professional nurses can refer to doctors and only doctors can refer to specialists. Thus when an individual service provider at any point in the hierarchy makes an incorrect diagnosis it can lead to inappropriate or no referral. In such circumstances, users may not receive the correct treatment and do not have the recourse of asking for a second opinion. The challenge lies in addressing this issue. However much one would like to afford all users endless choice and second opinions it is not feasible when resources are finite and, in fact, under pressure as discussed in the literature review under 4.4.1. A more feasible solution to prevent this type of occurrence might lie in ongoing monitoring of the quality of services and the skills and attitudes of service providers by managers.



In this instance there was the diagnosis from the private doctor which raised doubts with regard to the initial diagnosis and seems to indicate that the decision of the doctor at secondary level to neither treat nor refer Anita might have been a mistake. Making a mistake is unfortunate, but to be understood, since health care service providers are human. However, not to acknowledge the possibility of a mistake in the light of evidence pointing towards one and not to allow a second opinion in circumstances where a mistake might have occurred is difficult to understand. In my opinion service providers at primary level seemed unable or unwilling to initiate a process to obtain a second opinion. I am speculating that a hierarchy in health care service provision that often leaves professional nurses with little power to question the decisions of doctors could have contributed to the challenges experienced by Anita.

It seems as if Anita was referred for physiotherapy after the fracture was confirmed by the specialist at the secondary hospital. This referral seems appropriate and should have been the beginning of rehabilitation. However, her inability to walk and thus leave her home, combined with a facility based physiotherapy service that apparently did not do home visits, prevented rehabilitation. One of the purposes of rehabilitation is to compensate for loss of function through the provision of assistive devices (WHO, 2011). In this instance a wheelchair, to compensate for loss of walking ability, should have been provided. In addition to, facilitating mobility in her house and community, a wheelchair would have enabled Anita to access therapy at the CHCC. Anita sourced and bought a wheelchair without professional support. Wheelchairs are specialised devices and “one size does not fit all”. To ensure optimal function and prevent secondary complications the specifications of the wheelchair must fit the person’s morphology, physical support needs and environmental requirements. Thus selecting a suitable wheelchair requires professional support (WHO, 2008b).

Anita and her husband were unhappy with her health outcomes and decided to access Tygerberg hospital, in another province and 500km away. They described a diagnostic service of high quality at Tygerberg hospital. In addition, education about the danger of secondary complications was provided in a way that Anita remembered. However, modern sophisticated health care systems, such as the one Anita accessed at Tygerberg Hospital, should in conjunction with high quality diagnostic care, focus on quality of life and long term management. She was

diagnosed with terminal cancer and was apparently told to go home and lie on her back until she dies. She was warned that moving about in bed and sitting up might cause further fractures. However, daily ablutions and bodily functions had to be dealt with. In addition, lying in one position for an indeterminate period of time will soon become extremely uncomfortable and is sure to cause pressure ulcers. Even so, it seems as if the doctor and physiotherapist at primary level interpret the warning in a way that precluded them from providing input. The physiotherapist is trained in the precautions one should take when guiding movement necessary for toileting, change of position and in maintenance of the limbs in the presence of spinal instability. Thus in the initial phases where Anita was expected to live only a short time his role would have been to train caregivers in the safest way of rolling, washing and dressing Anita as well as in caring for her limbs.

Time went by and Anita experienced no pain, moved in bed, sat up and did not become paralysed. Four years later she was still alive. I would have expected the doctor and professional nurses to refer Anita for a follow up assessment. In addition, a referral for further therapy was required. Anita had already made the decision to sit up. In the light of this, support from a therapist with regard to using a wheelchair seems like a logical next step. A wheelchair would have allowed her to get out of bed and move around in the old age home and town, and deliver her message to the congregation in person. However, it seems as if the diagnosis from Tygerberg hospital precluded further management and rehabilitation. Unfortunately it seems as if a “cure or care” medical approach, as presented in Chapter 2, prevailed in the case of Anita and precluded comprehensive management.

The curative focus might even have led to a disregard for human dignity and negatively affected service acceptability. In this regard, I have no reason to doubt the very specific things told to me by Anita. She felt that she was treated with disrespect and little compassion, signs of an unacceptable service as described under 4.4.2. I think most of the service providers who treated her would be as upset as I am when they read about her being driven home on a piece of wood in the back of a pick-up, or about health care service providers who refuse to touch her. Not being able to medically or physically contribute anything should not preclude human contact.

Touching someone on the arm or shoulder or even gently moving her limbs, will not result in spinal fracture, but will go a long way towards telling that person that she is cared about.

A possible explanation for the situation might be a lack of experience; the PHC physiotherapist and the doctor were doing their community service year. They might have had no or limited experience in treating a person with pathological fractures due to cancer. Alternatively the lack of transport home from Tygerberg hospital and the lack of referral for a second opinion might be because service providers work in a system that have through regulations and bureaucracy created a situation where they struggle to see beyond the disease to the person. On the other hand service providers might have used rules to shield them from the need to find creative solutions as described by Van der Walt and Swartz (1999).

At secondary level it seems as if the doctor did not wish to be called out on Easter Sunday and this perceived attitude might have been the cause of the missed diagnosis. But this cannot explain the general experience on Anita's part of rudeness from staff. It is possible that the doctor's impressions were carried over during handover and in medical notes. However, it is both difficult and sympathy evoking to think that staff can be so demoralised that notes can colour their perception of a patient to the point where no one took the time to re-assess the situation. The fact that this incident occurred on Easter Sunday might be in part an explanation for the situation. Junior staff might have been on duty, staff might have been in a festive spirit and not overly keen to be bothered by emergencies, or they might have been overworked. Literature as described in Chapter 4 indicate that staff shortages and resultant overwork can create situations where service providers act inappropriately towards users.

Despite the perceived challenges with regard to medical management a distinct change in Anita's attitude was detected during the second interview. Her focus shifted from an inward scrutiny of body and health to an outward responsiveness to life and happiness. She decided life was about quality and doing the things that one loves even in the face of medical risks. She showed autonomy and took control of her life instead of leaving the final decision with medical professionals.

Lindsay (1996) found that persons with disabilities related wellness to self-respect and self-love, connecting with others, creating opportunities for growth, celebrating life, transcending the physical body and achieving a state of grace. This finding seems to me descriptive of Anita. It seems as if her inner strength, her relationship with God, the support from her husband, finding a hobby and being able to provide advice and support to others, combining to help her find happiness and satisfaction. From what I have observed and from what Anita told me she was appreciated and respected in the community. Others sought and listened to her opinion. This opportunity to be of service left her content and in her own mind not disabled. I have described arguments in the literature review that function does not equal health and that functional ability does not determine disability and quality of life (Krahn et al., 2009). Anita's case study and composure served to emphasise that point. She was apparently sick, bed bound in a small old age home room, she needed help with activities of daily living. But the concept of disability did not feature in the perceptions of Anita or that of the people whom she dealt with. She was content with life, respected for who she was and included as a valuable member of the community.

## **7.7 Conclusion**

In my opinion Anita's narrative suggests that health care service provision to her did not adhere to the principles of PHC as presented in Chapter 3. Her health needs were not met, she was not guided optimally through the health care system, she was not included in decision making, essential drugs were not always provided, and one is left with some doubt regarding the skills, both biomedical and social, of health care service providers. Furthermore she did not receive rehabilitation as described in Chapter 5. Functional independence was not encouraged, compensation of loss of function through issuing a wheelchair and training wheelchair dexterity skills were not done and caregivers were not trained. However, Anita took control of and responsibility for her life, and move past medical uncertainties. She showed that overall quality of life cannot simply be equated with the absence or presence of disease. She overcame great odds to live a life of quality and happiness. Anita's story describes the experience of a female adult who acquired a severe, physical impairment. The next chapter describes the experiences of Brenda, a child with severe, congenital physical and intellectual impairments.

## Chapter 8

### Brenda's Story

#### 8.1 Introduction

Brenda was born with physical and intellectual impairments. I met her when she was a four year old and knew her until her death at age six.

#### 8.2 Sampling and Sources of Information

A community leader told me about Brenda. I sampled her purposively as a study participant on the basis of information received from him. The findings presented here pertain to four interviews, three with Brenda's grandmother and one with her mother, a short discussion about Brenda's health care management with a professional nurse employed at the CHCC, and information on Brenda's therapeutic management gathered during the focus group discussion with the therapists. While Brenda was present during every interview with her grandmother, my contact with her was limited to playing with her and a superficial physical evaluation. She tolerated interaction with me for a short period of time before she would make complaining noises and strain in the direction of her grandmother.

I conducted the first interview with her grandmother in October 2010. For that interview, I visited them in a one roomed corrugated iron shack in the informal settlement in town. Since then their living conditions have changed for the better and in 2011 they received a newly built, government supplied house, where I performed a further two interviews with her grandmother (See Figure 8.1). In between interviews I visited them in both abodes. Demographic data were sourced from the EquitAble survey data set.



*Figure 8.1.* The informal settlement in Fraserburg and government supplied houses

Information from the various interviews and sources was triangulated. In some instances different sources corroborate findings while in other opposing opinions were voiced. Corroborating and opposing findings are pointed out in the presentation of the results.

### **8.3 Background Information**

Brenda`s grandmother adopted her as a baby. The grandmother was her primary, and in many ways, sole caregiver. Her mother visited, but stayed in another house with a younger sibling and boyfriend (not Brenda`s father) and was not accepted by Brenda to the same extent that she accepted her grandmother. None of them had any contact with her biological father and he did not provide financial support:

He paid only in the beginning. It is probably three years now that he has not paid anything and we hear nothing of him. He has no contact with her [Brenda]. (Mother)

Brenda suffered from genetic impairments that affected multiple organs and body systems. Diagnosed with Cornelia de Lange syndrome, she showed the typical physical features, including small stature, long eyelashes, fine eyebrows, flat nose, low ears, excessive body hair growth and upper limb deformities. In addition, many of the other impairments connected to this syndrome, such as severe speech and motor delays and poor social interaction, were present (Kline et al., 2007). At six years old she was incontinent and not walking or talking. She was not participating in any form of schooling or other formal activities with the aim of stimulating her.

However, Brenda was not completely dependent. She moved about the house with a combination of rolling and sideways shuffling on her buttocks. She could sit independently on the floor and manipulate objects between her arms. For instance she could hold a baby bottle and drink from it without support. She could stand and give a few steps with a little support around her hips. She made eye contact and looked at people speaking to her. Though not able to talk, she communicated through gestures, facial expressions and noises.

I found Brenda neatly groomed for every visit. Both abodes were clean and well kept, but had very little furniture and the floors were bare concrete. In the government supplied house they had indoor plumbing, but no electricity.

#### **8.4 Medical History**

Brenda was born in January 2006 by way of an emergency Caesarean section when her mother was seven months pregnant. Her mother, 16 years old at the time, suffered from pre-eclampsia.

Brenda's genetic condition predisposed her to aspiration and chest infections (Kline et al., 2007). It seems as if her health was precariously balanced; requiring frequent visits to health care service providers and a tendency to get very sick very quickly:

It is not that she is ill, but she gets ill easily, she often gets a bad fever. (Mother)

It seems to me she has trouble with her chest (“*Sy is mos nou lyk dit my met `n bors gepla*”). She gets ill quickly. I cannot wait long when she is ill. I have to go to the clinic immediately. (Grandmother)

According to Kline et al. (2007), children with Cornelia de Lange Syndrome can progress and reach developmental goals over time, although progress is slower than for other children.

Brenda's mother, grandmother and, according to them, the doctor that treated her, believed in her ability to progress:

The doctor told me it will take a long time before she walks and talks. (Grandmother)

The way they [doctors at the tertiary hospital] explained it to me, she will get better, but not in the same time as a normal child. It will take a long time. Slower. (Mother)

However, Brenda passed away at age six. Her grandmother described the final days of her life as follows:

On Sunday she was very, very sick. I walked to the clinic again [this is in the wake of five visits in three weeks where she was either turned away or received medication other than antibiotics]. They put her on a drip, but did not give antibiotics. I asked for antibiotics and why she was on a drip, but the sister spoke Xhosa and English and I did not understand her. We slept at the clinic. At day break Monday she was blue and gurgling. They put us on an ambulance to Calvinia [secondary hospital]. There the doctor said she had chest infection and an enlarged heart. He said her body was filled with fluids and that her heart is not able to take the strain. (Grandmother)

She died on the Tuesday.

## **8.5 Emerging Themes**

I found that performing the interviews over a period of time added richness and depth to the data. Movements over time, such as the improvement in housing circumstances and the deterioration of Brenda's health were observed. I ordered the emerging themes under five superordinate themes through abstraction, function and numeration (Smith et al., 2009). These are presented in Figure 8.2:



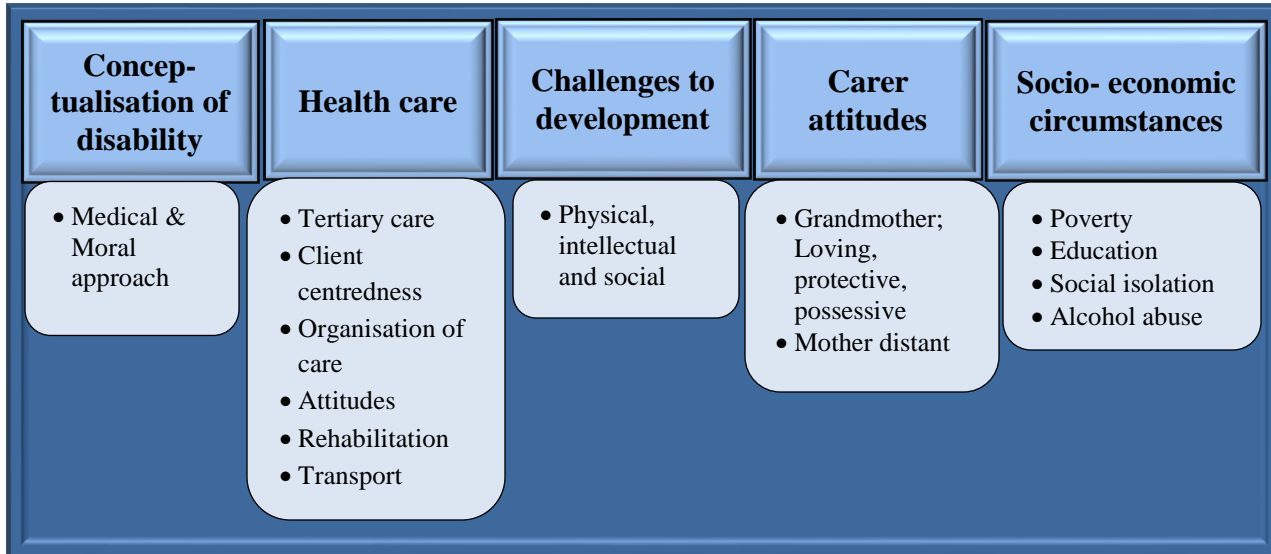


Figure 8.2. Superordinate and emerging themes identified in Brenda’s case study

### 8.5.1 Conceptualisation of disability

Brenda’s mother viewed her as disabled and related her frequent illnesses to physical disability: “she has a tendency to get sick, see she is physically disabled” (mother). Her grandmother showed duality in her acceptance of the term disability. She linked Brenda to children with disabilities: “. . . we have a meeting about the children who are not healthy, . . . the disabled children.”, and: “Like [name of woman’s] child. He is also disabled”. However, when asked if she thought Brenda was disabled she became upset:

I do not know whether she is disabled or not, but I hear people and the doctor say the disabled child. The people hurt me so bad. It is nobody’s fault that she was born like this. It is just the way it is. I do not like it that they call her that [disabled]. (*“Ek is nie lekker dat hulle vir haar so sê nie”*) Look she did not ask for it nor can she help that she was born like this? No! no! no! I get very angry. (Grandmother)

Her voice was initially softer than usual and then became raised.

References to a divine cause, Brenda not being accepted by all, feeling sorry for her and receiving charity were made frequently by her grandmother. The frequency might be an indication that Brenda's grandmother saw disability as a moral issue (Smith et al., 2009):

We cannot help it. It is God's work. (Grandmother)

I do not like it when people come and ask about her. The children told me people talk about her with no hands. I do not want to mix with them. (Grandmother)

When I am in town I see them talk about her, saying ach shame. They feel sorry for her. (Grandmother)

They said they do not come to my place since I have a disabled child. (Grandmother)

The White woman from [name farm] asked me to come and show her. When I did they were very sorry for her. (Grandmother)

He [a farmer] felt so sorry for me that he gave me R100.00 to use for her. (Grandmother)

I told him [Brenda's uncle] you do not give food to her. You do not give her something like other people. Look at the White people whom I do not even know. They take something out and give it to her. (Grandmother)

### **8.5.2 Health care**

Brenda primarily accessed formal health care, but some evidence of simultaneous use of all three health care systems was seen:

They held a service [church] here. I asked the pastor to pray for her. (Grandmother).

It is called fever bush [a shrub that grows in the region]. I wash it and put it in a jug of water and boil it and then I give it to her to drink. That breaks the fever. (Grandmother)

. . . take a piece of Disprin®. (Grandmother)

However the grandmother made it clear that in many instances only antibiotics helped to cure the chest infections. Consequently she frequently accessed services at the CHCC over the years.

These visits and the way in which services were delivered created a further timeline in the data. The grandmother described a supportive service initially that gave preferential treatment to Brenda: “It was always like this, when she got ill they assisted me immediately”. It seems this support got progressively less:

But now it is a sad business. There is only one sister on duty and you have to wait for that sister. You go in the morning and sit there the entire day. Then they tell you to go away and come back in the afternoon. The way the clinic is now, on Monday they hand out pills, and Tuesday (unclear), Wednesday is doctors day. Then you cannot go to the clinic at all, because then they will not help you. And like today [Friday] then it is people from the farms, then you sit till late before they help you (“*tot hier watter tyd ook al voor hulle jou help*”). (Grandmother)

### ***Tertiary health care***

High quality health care at tertiary level was described by both Brenda’s mother and grandmother. Information from the interviews pointed towards comprehensive assessment and an interest in the causes of the condition:

The doctor told me she had fluid in her body. And there is something wrong with her heart and in her little brain. The doctor wants to find out what the problem is. Why the one child was born like this [like Brenda] and the other one not [Brenda’s sibling who did not have Cornelia de Lange Syndrome]. (Grandmother)

### ***Client centredness***

From the data I got the impression that health care services did not display an optimal level of client centredness. While allowing for alternative explanations of the findings, for instance that

health care service providers did provide explanations, but that grandma did not remember or hear them, because of the stress she experienced, the quotes do make a strong case that the service lacked client centredness when one looks at them in combination:

I do not understand why sister [name professional nurse] took away the milk.”

(Grandmother)

. . . they do not tell me I do not know whether it is for the stomach. (Grandmother)

. . . they did not tell me what was wrong with her. (Grandmother)

Medication played an important role in Brenda’s health. The grandmother pointed out the need for antibiotics and that it was the only remedy to cure her chest infections. However, she did not always receive antibiotics. Other medication was prescribed which in her grandmother’s opinion was detrimental to Brenda’s health:

They gave me a jar with nose drops. But I do not give that to her. I gave it to her once. I put it in each nostril. When we looked again she was sick. We took her to the clinic and they sent her to Calvinia [secondary hospital]. She got infection in her chest from those drops. (Grandmother)

Really, I do not give that [type of medication] to her. She [professional nurse] gave me pills, they were long, looked like pills for grown-ups, but I do not know. I have to give it to her. I did not give the entire pill. I broke it open and mix it on a spoon. She drank it. Then she started to rattle in her throat and she vomited. I took her back to the clinic, but they do not tell me what is wrong. (Grandmother)

Again I do not know whether the grandmother’s perceptions of the effect of the medication are true or not. However, she believed it to be true and that belief negatively impacted compliance.

In addition it seems as if her opinion was not sought or listened to by health care service providers:

I can understand that she lost weight, because she had a runny tummy and she vomited. Then she ate little. She did not eat like she used to, but they [professional nurses] do not take notice of that (“*maar hulle vat mos nie daaraan nie*”). (Grandmother)

I felt bad, because I told sister she drank the milk, but no, the milk is taken away.” (Grandmother).

With regard to tertiary level care a move towards inclusion was described. From the narrative it seems if the doctor might have tried to explain things to the grandmother through a video, but failed to realise that she did not understand the explanation:

Her entire body is covered with hair. The doctor showed me on a video that this is not good. I wonder about that, but when I go there again I will ask the doctor . . . he did not tell me why it is not good. (Grandmother)

### ***Organisation of care***

The earlier quote on the organisation of services under 8.5.2 shows that in the grandmother’s opinion it hampered access to services. In addition, organisational factors seemed to create challenges surrounding access to tertiary level care. Strange environments, travelling times of close to a day and three days waiting in Kimberley combined to intimidate the grandmother:

We left here on Sunday morning just past eight. We got to Kimberley 6 o’clock Sunday night. The doctor saw us on the Wednesday. I was tired, flustered and sad. I do not know the place [Kimberley] and [Brenda’s mother] could not go with me. (Grandmother)

Finally it seemed as if referrals were delayed or not done in instances as promised and follow up dates were not set:

They will let me know when they want to see her again. (Grandmother)

We were supposed to go back [to tertiary hospital] in January [this interview was in April], but I have not heard anything from the doctor. (Grandmother)

### *Attitudes*

Initially Brenda's grandmother trusted the professional nurses at the CHCC to the point of asking them to phone Kimberley hospital and find out about Brenda when she heard rumours that she was born with deformities:

I went to the hospital. I asked [name of professional nurse] if she knew the child was born with one finger, each hand have only one finger. She said no. . . . She turned around and went to phone the doctor immediately while I was present. The doctor explained to her that she was born without arms and with only one finger. (Grandmother)

This trust was slowly eroded by what seemed to her like uncaring attitudes and rudeness:

They told me, what is it with you, do I have to speak English [very much a foreign language in Fraserburg] or do I have to speak German to you? You will not get assistance today. (Grandmother)

She described a situation where consultations became rushed and professional nurses were pressed for time. “. . . they just want to finish helping you quickly. . . quickly give some medication and well yes. I have to accept what they give. She ascribed the challenges to a shortage of staff.

This perceived deterioration in primary health care service provision was also seen in preventative services. Initially as a three year old Brenda was placed on prophylactic TB treatment when the grandmother suffered from TB. However as a six year old CHCC staff did not give her the required immunisations. This was subsequently done at the secondary hospital during a visit there.

### *Rehabilitation*

Health care providers and family identified the need for rehabilitation:

The doctor said that the people who gave the exercises must come often. See I . . . do not know how to do it . . . He [doctor] talked about it [exercises] but nothing further.

(Grandmother)

They [professional nurses at the CHCC] said they will let me know when the people who give exercises come again. (Grandmother)

When I was visiting I said to my daughter, shucks (“*hene*”), the therapists are coming to this child and I do not have the hospital’s number to phone and ask about it. When I came here I heard they were here. Gosh then I was sorry. (Grandmother)

It seemed as if Brenda received very little rehabilitation:

The people, who give her exercises, were here very long ago. In Windhoek [the informal settlement where they lived]. Not again after that. (Grandmother)

One therapist said that Brenda did not attend a follow-up appointment:

Last year there was a girl like that, if it is her [she did not recognise the name, but made the identification through my description of Brenda]. I never went to their house. They came to the clinic once. We saw them once and gave a follow up date, but we never saw them again . . . I planned to do early intervention, like the beginning of language. At that time her language was nowhere. (Therapist 1)

None of the other therapists in the focus group treated her, but the one who saw her indicated that she was seen by a previous therapist from another profession who has since left. The therapist further indicated that lack of continuity created challenges and that they were hampered by transport with regard to doing home visits:

The continuity is lacking. You want to follow up very much, but you cannot always go on a home visit, since there are three and everyone must be somewhere [they have one vehicle for their use]. (Therapist 1)

No assistive devices were provided to Brenda and although a wheelchair was mentioned by primary and tertiary level health care providers it seems as if they did not refer her for one:

Sister [name of professional nurse] told me when the people come again I have to talk to them about a push chair for her. (Grandmother)

. . . the doctor in Kimberley said I must ask them for a push chair when they come again. But when will they come again that I can ask? (Grandmother)

No consumables such as nappies were provided. They do not give nappies. We buy nappies at PEP [Pep Stores – a shop]. (Mother)

A CHCC professional nurse responded to my questions on rehabilitation by saying that Brenda had received no rehabilitation since her condition was genetic. Furthermore she talked about arm prostheses for Brenda.

According to the grandmother she received no training or education on the prevention of complications like aspiration or on functional stimulation.

### ***Transport***

They walked to the clinic in all kinds of weather, day or night: “I always walk [to the clinic]”, and “It was probably 12 o’clock at night when I took her to the clinic”. There is an ambulance in town, but one needs to phone a call centre in Calvinia from where the ambulance is despatched. They had no phone in the house and I did not notice any pay phones in the vicinity of the house.

An ambulance provided transport free of charge to secondary and tertiary services.

### **8.5.3 Challenges to physical, intellectual and social development**

In my opinion Brenda was developmentally severely challenged. The genetic condition played a role, but pre-, peri-, and post-natal as well as early childhood challenges also impacted negatively on progress and normal development. These challenges were caused by an array of



interactive variables such as the family, community and context that she was born into as well as her health condition.

Development in utero was challenged by her mother's health status during the pregnancy:

I had high blood pressure and my sugar was very high and problems with my kidneys . . . I had to take medication, lots of pills, during that time. They had to give me medication to save my life and hers. (Mother)

In addition, her father allegedly physically abused her mother and forced her to try folk remedies to induce an abortion. This information came from Brenda's grandmother and was not corroborated by her mother:

He kicked and stepped on her while she was pregnant. (Grandmother)

. . . he let her drink red wine so that she can have a miscarriage ("*dat die kind kan afkom*"). (Grandmother)

The premature birth: "I was seven months pregnant when they took her out" (Mother), and emergency caesarean section created further challenges for Brenda. A positive with regard to her development in this peri-natal period is the fact that her mother did skin to skin (kangaroo) care.<sup>12</sup> Back home from Kimberley hospital, Brenda suffered physical and emotional neglect and poor nutrition according to her grandmother.

My sister-in-law phoned me and told me to come. The child was suffering. I am going to lose the child the way [name of mother] and the boy ("*klong*") is carrying on. [Daughter's name] leave her without care and follow him. When we got here Brenda was not here. She was on [name of farm] with her other grandmother. She [other

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<sup>12</sup> "Kangaroo care is skin-to-skin contact between an infant and parent, where the infant is usually held chest-to-chest in an upright prone position. It is a very simple, beneficial developmental intervention for both baby and parent". (DiMenna, 2006, p. 405)

grandmother] just took the child off the mother's breast and takes her to a farm.  
(Grandmother)

This claim was not verified from other sources, but her grandmother told me this story in two separate interviews more than a year apart which makes me inclined to believe that even if not entirely correct the broad strokes are possibly correct. In addition social services would not have placed Brenda in her grandparents' care if there was not sufficient reason for it. When her mother was asked about the reason for this placement she said that it was because she wanted to go back to school.

It seems as if nutritional challenges continued through Brenda's life as poverty prevented her grandmother from providing fully for her dietary needs:

I feed her, but it gets very expensive. I take flour and roast it, and then I give it to her in the bottle. (Grandmother)

Malnutrition leaves a person with less resistance to viral and bacterial infections and can lead to stunting, developmental delays and learning difficulties in children (Bamford, 2013; Ingstad & Eide, 2011, Parnes et al., 2009).

As she got older, Brenda's development depended on more than food, physical and emotional care. Stimulation, relations with other children and various types of toys were necessary (Bruder, 2010). These were not available due to poverty which lead to a lack of products, both for personal use such as toys, a chair and table to sit at, and medical such as a wheelchair, but also probably due to a lack of knowledge and education on the side of her carers. By her own admission Brenda's grandmother did not have the knowledge to stimulate physical and cognitive development. A lack of knowledge on the side of her grandmother could have led to a lack of stimulation, treating Brenda like a baby (I met them in the street once; Brenda was lying flat in a pram covered with a blanket) overprotection and failure to allow other children close enough to build relations:

You get rude children. Then I tell them, do not ask about her. (Grandmother)

#### 8.5.4. Carer attitudes

##### *Grandmother: Loving, protective, possessive*

I arrived at this theme through function. Grandmother was Brenda's primary and sole caregiver. She impressed me as committed to her role, protective, deeply loving and caring, but also possessive:

When Brenda was a baby the grandmother fought to get custody of her:

We [she and the paternal grandmother] nearly fight about the child . . . I went to the social worker [when the paternal grandparents did not bring Brenda to town when they promised they would] and told her my child is on the farm. Look at [name of mother] breasts, filled with milk. It overflows. What does the poor child drink? (*“Waarvan lewe die arme kind [Brenda]”*?)  
(Grandmother)

Furthermore she will fight to keep Brenda:

This is my child. [Name of mother] can have her when I am dead (*“die dag as ek uit die vleis uit is”*). Will they care for her the way I do? (*“Want hoe gaan hulle nou regeer met die kind soos ek met haar aangaan”*?). At night when she is sick I sit up with her.  
(Grandmother).

She wanted financial assistance: “they wriggled out of it (*“uitgedraai”*) he and his parents they give nothing for this child”, but no involvement in the physical and emotional care of Brenda. “I said no you will not help me with this child, because I know this child”. It seems she did not trust anyone else to care for Brenda as well as she did:

Look how big I got her. I am satisfied with her. I will not give my child to other people. They do not care about her. (Grandmother)

However, she said it was difficult to care for Brenda; comparing it to being in jail in a figure of speech:

The road is hard (“*hardepad*”<sup>13</sup>) and look since when am I walking it, am I raising her.  
(Grandmother)

She showed concern for Brenda’s health and worried about unexplained symptoms.

Unexplained symptoms seem to disempower her and caused more stress than the occurrence of severe chest infections and diarrhoea which she knew and had fought before:

Sister said it is tonsils, the doctor said it is an abscess, I will ask the doctor in Kimberley when we go there again. What kind of gland is it? It does not get bigger, it just stays there, the little gland. What can it be? I cannot help her. I cannot take it out. Hopefully the doctor will tell me. [Referring to a little hard nodule underneath the skin below Brenda’s left scapula]. (Grandmother)

She worried about Brenda’s future after her death and clearly expected to die before Brenda:

I do not know what will happen to her [Brenda] the day when I die. Oh I stress about that. (Grandmother)

This shows that while she expected Brenda to live into adulthood, she also expected Brenda to require ongoing care even while she said she thought Brenda will improve over time.

### ***Mother distant***

Brenda’s mother, as opposed to her grandmother, spoke about her in a neutral almost dispassionate way. While she said that she wanted her back none of the deep care and concern that grandmother displayed shined through. One wonders how she will cope with emergency illnesses; night trips to the clinic and the general impact that caring for Brenda might have on her life. The bond between mother and child seemed to be tenuous. I base this assumption both on my observations as well as on information from the grandmother, but will explore the issue further in the discussion and reflection section:

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<sup>13</sup> The term “*hardepad*” is an Afrikaans idiom referring to a jail sentence with physical labour included.

Brenda will not manage with her [mother] since she does not know her. I tell her mother she [Brenda] can sleep with you tonight. While I lay in bed [in the next room] I hear the child complaining. She moans and groans. I tell her mother give her back to me. Then she is quiet as a mouse and sleeping. . . . The other Sunday I told her mother to feed her. Nothing. She [Brenda] does not want to eat. She turns away and only looks at me.  
(Grandmother)

### **8.5.5 Socio-economic circumstances**

#### *Poverty, lack of education, social isolation, alcohol abuse*

Poor members of a poor community, their context seemed to have been shaped by a lack of money and assets. They lived on a foster care grant that her grandmother received for looking after her. This was just over R1 000.00 per month at the time of the study. Poverty played a major role in the challenges with regard to nutrition and a lack of products and technology as discussed under 8.5.3.

The grandmother was illiterate and socially they were isolated to an extent as earlier quotes showed. Alcohol abuse amongst family members who could have assisted with the provision of food added strain to the situation:

The son-in-law who lives with me pay [receives his salary] today. He said he will bring a food hamper, But I will have to wait and see. (Grandmother)

She was worried that he will buy alcohol instead of food. As I left he came home intoxicated and without the food hamper.

### **8.6 Discussion and Reflection**

I have discussed the negative impact of poor socio-economic circumstances on health care access, health outcomes and disability in Chapter 4. It seems to me as if Brenda's case study provides a case in point. Poverty, a lack of education, substance abuse and poor social networks seemingly interacted in various ways to hamper health care access, health outcomes and

participation. While all government health care services, transport to and accommodation at referral centres were free of charge poverty left them without choice with regard to what health care service or service provider to access. Poverty led to a lack of nutritious foods as well as a lack of products for play, stimulation and mobility, all of which are important for early physical and intellectual development (Adnams, 2010). Their physical circumstances improved with the move to a sturdy, well-built house which kept the elements out. However, Fraserburg has sub-zero winters and hot summers. No electricity in the house and no money to pay for other forms of fuel meant no heating in winter and no fan or air conditioning in summer. Brenda's grandmother cooked on an open fire outside the house with smoke a constant companion; not good for already compromised lungs.

A lack of education and knowledge might have influenced the grandmother's perceptions of disability, expectations of Brenda, and interactions with health care service providers. The grandmother seemingly approached disability from a moral angle; Brenda was well cared for, but to an extent hidden away, charity was given and accepted, Brenda's impairments was seen as God's will; all characteristics of the moral approach as presented in Table 2.1. Thus the grandmother might have seen the impairments as negative and something to be ashamed of and therefore chose not to mingle with the general public, and discouraged children from asking about Brenda. Her own ambiguity and attitudes about disability might have created feelings of discomfort about Brenda's impairments. In addition she might not have had the skills to educate and guide community members and other children about disability and how to play and interact with Brenda. Whatever the reasons, the grandmother's choice isolated Brenda and limited much needed contact with peers, community members and the rest of her family. If children were allowed closer they might have befriended Brenda and provided peer stimulation. In addition it could have exposed them to a child with a disability and taught them about children with disabilities (Yeo & Moore, 2003).

The grandmother complained about the strain of the caring duties, but it seems as if she was not ready to share it with anyone. She allowed Brenda's mother to do some caring, but did not assist her in nurturing a relationship with Brenda when her attempts to bond with Brenda failed. A stronger bond between mother and child could have led to sharing of the care giving duties and

thus the physical and emotional demands connected to it. The grandmother took Brenda from her paternal grandmother with the assistance of authorities. She seemed critical of the paternal grandmother even though it seems as if Brenda's paternal grandmother was the first one to identify challenges with regard to Brenda's care as a baby. Thus her actions and attitude might have led to estrangement between Brenda, her father and his parents, and might also have caused the lack of support and contact from their side.

With regard to health care the grandmother was quick to decide it was needed and to access it, but passive with regard to what service providers did or did not do. She apparently demanded little, kept quiet when her opinion was not listened to, and did not question service providers. She was waiting for an appointment and for therapy, but did not ask why it was postponed for what seems like months. The only action she seemed to take was to be non-compliant with treatment in some instances. Her perceived passivity might be because she was dependent on the service providers. She had no choice but to access the CHCC and state referral routes for health care. Or it might be due to her view of disability or a lack of education. A moral approach to disability might lead to passivity, being thankful for whatever you get, and believing that you do not have a right to ask for more. A lack of education might have left her feeling ill-equipped to confront health care service providers (Balarajan et al., 2011).

It seems as if health care services were provided according to the medical approach. Quality, tertiary, and peri-natal health care intervention probably ensured that Brenda survived the peri-natal period. However, interventions focused on reducing infant mortality must be supported by actions that improve the prospects of those who survive (Kline et al., 2007; Olusanya, 2011; Schonkoff, Richter, van der Gaag, & Bhutta, 2012). This can be done through early childhood development strategies in the form of adequate, healthy nutrition, health care, early learning opportunities, parental education, emotional support and family social services (Bamford, 2013; Olusanya, 2011; Schonkoff et al., 2012). Opportunities for learning and development occur in the home and community as well as in formal development programmes (Bruder, 2010). According to the findings, Brenda did not receive optimal stimulation at home and was not included in the community or in formal developmental programmes.

Brenda should have been in school or pre-school (Kline et al., 2007). The only mention of school was made by doctors in Kimberley, but they referred to a school in Calvinia. Isolating Brenda from her grandmother by placing her in a school 200km away is against South African policy of mainstream education. There are pre-schools and schools in the community and apparently other children with disabilities have been integrated. I do not know why Brenda was excluded. It might be any one or a combination of the following reasons: Her physical appearance, she had no wheelchair and was not mobile, she was incontinent, she could not talk, her grandmother wanted to protect her and did not want her to go, the community did not recognise it as necessary. Unfortunately Brenda's exclusion seems to be the norm rather than the exception in South Africa. In 2011 approximately 34% of children of up to four years of age with disabilities were attending early childhood development facilities in South Africa, and 27.3% of children with disabilities in the Northern Cape Province were attending such facilities. The figure increased for five year olds with disabilities of whom 82% (83.4% in the Northern Cape) were attending educational institutions (South African Department of Basic Education, 2013).

Furthermore most of the early childhood development and learning occurs within the context of the family (Bruder, 2010; Olusanya, 2011). It is my perception that Brenda's grandmother was eager to assist Brenda, but she needed training and education since, by her own admission, she lacked the necessary knowledge. Providing family training and education is part of the role of service providers in health care (WHO, 2011), rehabilitation (WHO, 2011) and early childhood development (Bamford, 2013; Bruder, 2010) and crucial in the instance of Cornelia de Lange syndrome (Kline et al., 2007). Brenda's grandmother seemingly did not receive adequate training.

In addition Brenda required input from a comprehensive health care and developmental team comprising various specialists such as a paediatrician, dietician, social worker, educational specialist, physiotherapist, occupational and speech therapist (Bruder, 2010; Kline et al., 2007; Olusanya, 2011). Brenda received care from some of the various team members mentioned above, but unfortunately they never formed an integrated team. Thus she never received the benefit that can be derived from the integrated management that a team can provide (Bruder,



2010; WHO, 2011). I acknowledge that it would have been virtually impossible to create a traditional health care/developmental team in this setting. But the crucial aspects of trans-disciplinary teamwork (which is mentioned by Bruder (2010) as the most effective teamwork approach in early childhood development intervention) could have been implemented and would have suited the setting well. Through the trans-disciplinary approach one professional could have consulted with various service providers and experts and then provided interventions across professional borders (Bruder, 2010). Modern technology makes it possible for persons in different locations to have interactive meetings of the type necessary to orchestrate functional goals in a trans-disciplinary way for users like Brenda.

It seems as if Brenda's impairments in conjunction with health, systems and contextual challenges left health care service providers with few answers. The focus of services providers seemed to be on curing the recurring infections. Chest infections and stomach upsets were successfully treated on a regular basis. However, this seemingly high level of curative care was apparently not supported by actions focussed on preventing acute episodes or by rehabilitation. The lack of rehabilitation might be due to the rarity of the condition, but the activity limitations that Brenda presented with are not rare. Rudimentary communication, potty training, free play and mobility can be addressed by therapists with basic training. In addition, specific information is readily available through the internet and other resources.

Furthermore, Brenda needed a wheelchair. Wheelchairs were issued from Kimberley hospital. Thus the doctor in Kimberley who indicated she needed a wheelchair could have referred Brenda to the wheelchair procurement officer at Kimberly hospital for possible immediate assessment. If a suitable wheelchair was in stock Brenda could have been seated and her grandmother trained during the visit. If not the prescription could have been completed and the wheelchair delivered and fitted at a later stage.

A physiotherapist apparently did treat Brenda on a few occasions. This therapist left and it seems as if Brenda was not handed over to the therapist that replaced her. Admittedly hand over is challenging in situations where services are provided by community service therapists. Often the one has already left when the other starts and the only handover is written notes. A lack of

continuity of service has been identified in the literature review as one of the challenges to providing rural health care (Arcury, Gesler et al., 2005; Bull, Krout, Rathbone-McCuan, & Shreffler, 2001; Russel et al., 2013; Turner-Goins et al., 2005; Van Deventer et al., 2008). However, in Calvinia there are senior therapists who can provide continuity through creating a link between community service therapists from one year to the next.

The speech therapist has been doing outreach services to the community for three years and saw Brenda once. From the focus group discussion with therapists it seems as if her grandmother did not always attend appointments. It also seems as if therapists visited them infrequently. The speech therapist indicated that home visits were difficult since they were three therapists with one vehicle. I find this hard to accept since the entire town is no more than 4km<sup>2</sup>. Thus with some planning the car can be parked at a central point and the therapists can walk to the various houses.

Apart from the actual physical services there is also the nature in which services were provided. It seems from the narrative as if availability of care decreased over time with a negative impact on the experienced acceptability of care. Preferential treatment and supportive actions (such as phoning the tertiary hospital) seemingly gave way to long waiting times, and what seems like disrespectful attitudes. Grandmother connected these challenges to a shortage of service providers. The narrative seems to me to support the description in the literature review (3.5.3) of the detrimental effects of the challenges service providers face with regards to the service they deliver. In addition it is possible to speculate that as time went by and the situation settled from an acute to a longer term management picture, in a context of high demand and low resources, PHC providers may have started to limit their personal engagement with Brenda and her family. If this did indeed take place, it may be explained in terms of the emotional burden that long-term care in the context of scarce resources places on care providers (Van der Walt & Swartz, 1999). Or service providers might have stopped preferential treatment since Brenda's condition did not constitute an emergency.

Other aspects related to service acceptability which were addressed in the narrative were communication and education. It seems as if service providers did make an effort to explain the

condition and prognosis to Brenda's grandmother and mother, and that they did have some understanding of it. The narrative also shows that her grandmother did not understand all of the explanations. In addition it seems as if grandmother was not included in the decision making process and her explanations and requests were not listened too. Take for instance the challenges around medication. She knew Brenda since she was a baby and had lots of experience with caring for her and ministering to her health. Through the years she must have gathered insight into what medication Brenda reacted best too and which were less optimal. This experience was not sought and when given seemingly ignored. This perceived lack of inclusion through explanations, education and listening to her could have led to a lack of trust and poor adherence to medication dosages. In addition communication challenges were experienced because in some instances the professional nurse who treated Brenda and the grandmother did not share a common language. It seems as if a translator was not utilised in such situations. These experienced challenges with regard to service acceptability left the grandmother with unanswered questions and anger at Brenda's death. She believed Brenda did not get the attention from health care workers that she needed and that this might have led to an untimely death.

A lack of time could have been at the root of many of the challenges listed above. If service providers were pressed for time they might have given a lot of information in a short time, they might have appeared rushed, or little opportunity might have been created for questions. Often people need time to absorb information and then have further questions to ask at the next consultation. However visits to the secondary and tertiary hospital were rare and an opportunity to ask further questions of service providers at these levels might not have arisen. Therefore it is essential that service providers from referral centres communicate ongoing management, education, and support strategies clearly to providers at primary level in order for them to be able to explain to, and answer questions of, users. According to Iezzoni (2006c) rushed consultations, failure to explain conditions to users, failure to listen to users and to involve users in the decision making process, sent a message that health care service providers do not credit the intelligence of the user and do not respect the user. The relationship with the user will suffer, critical information might be missed and outcomes and compliance might be jeopardized, as seen in the case of Brenda.

## 8.7 Conclusion

I concluded from Brenda's narrative that she did not receive PHC as described in Chapter 3. Common illnesses were dealt with. However, her grandmother was not included as part of the health care team, health promotion and prevention was neglected, as was addressing her nutritional, developmental, and rehabilitation needs. With regard to rehabilitation:

- Service providers did not work as a team.
- Too little time was spent on improving functional ability.
- She did not receive the required assistive devices.
- Her caregiver was not educated and trained in stimulation and preventative activities.

In conjunction with the above challenges Brenda's impairments, being born into poverty, and having a caregiver with too little knowledge and understanding of her health and rehabilitation needs, and ambivalent feelings about disability, caused her health to be precariously balanced, impeded her development, and prevented community integration.

In the next chapter the reader is introduced to Carel. Similar to Anita his impairment was acquired and physical in nature, but less severe.

## Chapter 9

### Carel's Story

#### 9.1 Introduction

Carel was a 47 year old single man with a physical disability. He was illiterate and received a disability grant.

#### 9.2 Sampling and Sources of Information

I identified Carel as a study participant through information provided by one of the EquitAble data collectors. I gathered information for this case study during two interviews, one with Carel and his mother and the other with his sister. Carel and his mother were shy, but welcomed me into their house. Initially I felt that they were deferring to me. I struggled to get more than a few words in answer to questions or prompts. As the interview progressed they started to open up and spoke more freely. I also wanted to interview his brother and sister-in-law and they indicated that they were willing to participate when I met them and made an appointment. However, they did not keep that or two subsequent appointments.

I paid Carel and his mother two more visits. On the first of these his mother was not well. It was very hot and she complained of pain in her back and legs that made her lethargic. She thought some of her medication might be the cause, but she did not see her way open to go to the CHCC and enquire about this. She said she would go in two months' time when her next appointment was scheduled. On the second visit Carel's brother and sister-in-law were pushing an old, broken car into the yard and did not acknowledge my presence. At first his mother also did not acknowledge me, although she looked at me. When I walked closer she said to me: "We are very busy today". I indicated that I would not take any of their time, but just wanted to give her some vegetables from my garden. She accepted the vegetables and thanked me briskly.

### **9.3 Background Information**

Carel's legs were paralysed. He had a wheelchair but never got out of bed. He could eat by himself, but could not wash or dress. Though he was continent, he could not get up to use the toilet. His mother, who was 81 years old, performed all caregiving duties except washing him and changing the bed linen. These activities were performed once a week or less often, when his sister came to assist his mother. He spent his days talking to his mother or paging through old magazines.

Carel lived with his mother in her house. His brother and sister-in-law also lived with them. The house had two bedrooms, a bathroom with a flush toilet, kitchen and sitting room. The house was clean and neat, but the impact of poverty could be seen in sparse, dilapidated furniture and worn floor coverings. Carel and his mother shared a bedroom that was furnished with two single beds, a dresser and a cupboard. The house had two outside doors. From each of these there were four steep steps to ground level.

I found them pleasant people and I could see the bond of love between mother and son in their nonverbal communication.

### **9.4 Medical History**

Carel had been a healthy young man, who was employed as a farm labourer, when he contracted what sounds like an infectious disease of either the spinal cord or brain an indefinite time ago. None of the persons interviewed could indicate when he contracted this disease or exactly what it was: "The doctor said he had spinal cord fever." (Mother). What could be surmised was that he was already an employed adult with a wife and that it was at least 18 years ago, because he received tertiary care in Cape Town. Since 1994 health care users from Fraserburg have been referred to Kimberley for advanced care, and are no longer referred to Cape Town. Thus it seems he contracted the disease as a young adult, probably in his twenties.

It seemed from the various interviews that he received extensive medical care at the time of the disease to the extent of being referred to a tertiary hospital and having his life saved from what,

according to his sister, is usually a fatal condition. The disease left him permanently impaired since his legs were paralysed. It seems as if further interventions were considered at a later stage but not implemented:

He did go there [hospital in Kimberley]. They wanted to straighten his legs, afterwards they said no. Then they wanted to amputate his legs in Kimberley. But we did not want that. That will be very painful. [*“Toe wil hulle eers die bene daar in Kimberley afsit. Toe sê ons nee maar ons sien darem nie daarvoor kans nie. Dan het hy darem te vreeslik seer”.*] (Mother)

## 9.5 Emerging Themes

I organised the emergent themes, identified through IPA, in Carel’s case study under five superordinate themes (Figure 9.1). The first two themes were arrived at through function, the third one through subsumption and the last two through abstraction (Smith et al., 2009).

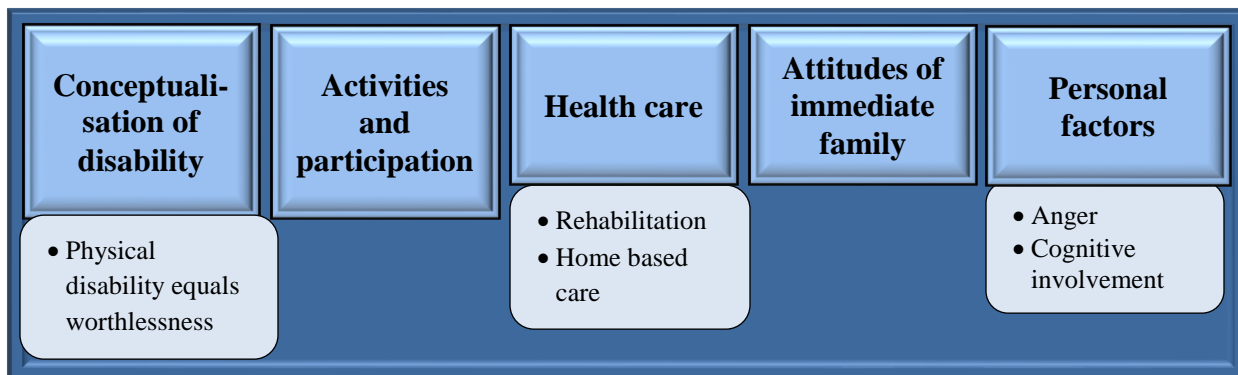


Figure 9.1. Superordinate and emerging themes identified in Carel’s case study

### 9.5.1 Conceptualisation of disability

#### *Physical disability equals worthlessness*

In this instance I interpreted what the participants said beyond the actual words into what I believe they were implying about Carel and his mother’s perceptions of him. They never used

the word “worthless”. However, the interplay of phrases and the choice of words (Smith et al., 2009) seems to portray that Carel’s life was without worth. It echoes in his words: “I do nothing but lie here” and in his inability to think of anything that he contributes to the household or family:

Researcher (R): Tell me what you think your role in the family is?

Carel (C): [Silence]

R: What do you do or give?

C: [Silent, with a frown on his face]

R: It sounds to me like you are your mother’s memory [they have referred before to the fact that he remembers where she puts things like her purse]?

C: [Laugh, but no words]

R: Is there not really anything that you think you add?

C: No. [Carel moves his body around in the bed]

His mother, while openly loving and caring, might have contributed to his perception of himself as her remark shows:

His brother lives with us in the house. I do not want him to leave me since there is not another man in the house. Without [name of brother] and his wife it is only me and Carel. (Mother)

Both Carel and his mother were adamant that he was not to be called disabled. In addition they were unable or unwilling to define disability. Questions on what disability is or meant were met with silence. According to Carel the medical professionals told him he was disabled, but he did not see himself as disabled and did not want to be called disabled.

R: Do you think you are disabled?

C: They said so, the doctor said so.

R: But what do you say?

[No answer]

R: Let me use another word. Do you think you are cripple?



C: [Silent laughter] No, walking with a limp [“*mank*”].

R: According to you what is it like when someone is disabled?

[Silence]

His mother did not like the term and saw it as derogatory and wounding. Even though her words might indicate that she does indeed think Carel is disabled she would not call him disabled and it hurt her when others did:

His sister-in-law says: “Here you lie. Disabled”. Oh I find it such an ugly word. It hurts my heart. In other words she says, look at you, lying here, not being able to do anything. You disabled thing. They make it something ugly. It is not as if he had a choice in the matter. He cannot help it. He was a healthy person. (Mother)

Her final sentence and another quote from her connected his impairments to being sick: “He worked for years [as a farm labourer]. You can work if you are healthy”. Carel also referred to his impairment as being sick: “I am sick, I cannot walk”.

The importance of physical ability and the pride felt in good physical performance showed in both their explanations of the cause of his impairment. They ascribed it to sorcery (“*paljas*”) performed by a jealous co-worker because Carel could perform the work better and had a more privileged position on the farm. When I asked about causes he initially said madness (“*mal*”), indicating that the madness started in his head and worked its way down to his legs. When I probed further into their thoughts on the cause of his condition the questions was met with long silences. This might be because they did not trust me with thoughts on sorcery. They might have thought that because I am White I would not understand and might think them primitive, or they might have thought that I might react negatively to such thoughts, since I might have represented Western medicine in their eyes. However, in the end it became clear that they believed this to be the cause of his condition:

R: Why did this happen to you. [Long silence] Can you think of a reason? [Again silence]. Earlier you mentioned “*paljas*”, is that not witchcraft?

C: Yes it is witchcraft.

R: Do you think you were bewitched?

C: Yes.

R: How did it happen?

C: The thing hurt me.

R: What thing?

C: The witchcraft.

R: Why did it happen?

C: This [name of man]. He bragged a lot, but I was a better worker than him. He could not walk as fast as I could when we fetch sheep. He rested often and I passed him with the sheep.

R: So you think he was jealous?

C: Yes

I do not believe in it [witchcraft]. They say one should not believe these things. He [Carel] stayed on the farm and he was the foreman. He drove the pick-up (“*bakkie*”). This man became jealous and coveting since he could not do those work. That is why he hurt him. (Mother)

Carel sees witchcraft as the only way to improve his condition: “I must get another sorcerer that can take the stuff out [to get better].” He said he does not know of anyone that can perform the task.

### **9.5.2 Activities and participation**

At the time of the study, Carel did not have the functional ability to wash, dress, and transfer to or propel the wheelchair. Previously his mother assisted with transfers and pushed him in his wheelchair. When that wheelchair broke he lay in bed waiting for a replacement. When he received the replacement he could not get up into it, and hence lay in bed all day. They ascribed his inability to use the wheelchair to a combination of factors, such as his inability to balance in sitting, getting nauseous, not being able to transfer himself or assist with transfers, as well as his mother’s advanced age and back problem:

(R): Do you ever get into the wheelchair?

Mother (M): No, I think it's hopeless. Because he is lying now . . . since he came from Kimberley he is lying like this. I have nobody to help me and he is very heavy as well.

R: And you cannot get into the wheelchair by yourself?

C: No.

R: Did they show you in Kimberley how to get in the wheelchair?

C: No.

M: Everything lies in his back, because when he sits up in the wheelchair he gets nauseous.

R: And the wheelchair just stands here? [His mother showed me the wheelchair which was standing in a corner of the room covered with clothing and blankets].

M: Yes sister that is the way it is [*“dit is nou maar dit”*].

Thus an impairment, severe, but restricted to the lower limbs, became a complete barrier to participation and community integration (according to the EquitAble survey data, Carel could not prepare meals, do housework, care for his personal items, care for others, maintain friendships and intimate relationships, go shopping, participate in community and leisure activities, or work). Carel did not exit the house and socially his contact was restricted to family members since neighbours stopped visiting due to the rude and violent behaviour of his sister-in-law when she was drunk. A minister in the community provided some inclusion through performing an occasional service in their house.

### 9.5.3 Health care

Despite referring to his impairment as being sick, both Carel and his mother declared him to be healthy and not in need of health care:

R: Carel do you need to go to the clinic often? [No response]

R: Or do you not get sick?

C: No [I do not].

R: So do you have health complaints?

C: No.

R: Do you sometimes go to the clinic?

C: They [professional nurse] tell me to come to the clinic when the therapists come.

R: So then you go?

C: Yes.

R: How often is that? [No response]

R: When was the last time you went to the clinic?

M: Last year. He went to the sister [professional nurse]. That time they said they cannot do anything for him (“*Toe se hulle ook nou hulle kan niks aan hom doen nie*”) . . . Well now we do not go anymore.

R: So they cannot help you at the clinic.

C: No.

R: Are you happy with what they do or do you want them to do more?

C: No sister, what they do is fine (“*daai wat hulle doen is orriaat*”).

Carel and his mother had no recollection of his having received promotive or preventative health care services. The last time Carel accessed the CHCC an ambulance fetched him at the house. He was carried to the ambulance on a blanket and driven to the CHCC. There he was pushed in on the stretcher and examined by the professional nurse while lying on it.

When some ailment did surface his mother took responsibility and managed it according to how she saw fit. This included “*bossies*”<sup>14</sup> and herbs as well as over the counter medication such as Disprin® (aspirin) and cough syrup. Carel was not always a passive recipient of all she wanted to give him:

Bossie<sup>3</sup> medicine and herbs. He drinks the herbs, but he does not want to drink it if it tastes bitter. He coughs constantly but gets angry when I want him to drink the herbs. The herbs help. If he would only drink it he will get relief. (Mother)

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<sup>14</sup> An Afrikaans word that literally translated means shrub and refers to the vegetation found in the study setting. These shrubs are believed to have medicinal properties.

### ***Rehabilitation***

Carel and his mother can recall outreach visits from therapists, but they could not describe what the therapists did. None of the therapists currently doing outreach in the community knew him; thus the nature and aim of these visits could not be explored. What was known was that a therapist provided him with a new wheelchair in 2010 after his previous wheelchair broke:

The other one was too small; it did not want to open. He ended up sitting in the front not against the back. Then it is difficult to push him. (Mother)

He could not use the new wheelchair as described under 9.5.2.

I sketched Carel's scenario to the therapists during the focus group discussion and asked if they could go on an outreach visit to his house. They agreed and said that they would contact me to go with them on this visit. However, they never contacted me.

### ***Prevention of secondary complications***

Carel's impairment, i.e., paralysis of the legs, rendered him susceptible to secondary complications such as contractures of the muscles of the lower limb and subsequent joint stiffness (Bromley, 2006). This has happened to such a degree that it led to a decrease of functional activities:

He asked for the pan and I gave it to him and the bed stays clean. Now he cannot get onto the pan anymore. Because of the legs. They are stiff, the one foot lies like this [show crooked angle with her hand]. Now he cannot lift the legs to get onto the pan. (Mother)

Neither he nor his mother was able to shed any light on whether he was taught measures to prevent contractures. Thus it is not possible to determine whether the cause of this problem is related to health care systems or to personal factors.

### *Consumables*

Other services of a rehabilitative nature which should be ongoing through his life were offered to him in the past but were terminated: He got “ointment to rub into his legs and pain pills”, but not anymore. He had received a monthly supply of incontinence diapers. This supply had now been stopped:

We used to get it [diapers], but strangely it just stopped bluntly with no explanation. Now we do not get the nappies anymore. They just said it was finished. I did not ask why. (Mother)

Consequently his mother used old undershirts as nappies which she washed for re-use. This was not always effective and sometimes the bed linen became soiled. Development of preventable secondary complications and a failure to provide ongoing supplies of nappies increased his dependency:

The most difficult is that he cannot get onto the pan. He used it for years, but now he cannot get onto it anymore. I use vest rags. Like a baby. (Mother)

Carel and his mother did not request explanations. While they missed the nappies, they accepted the stoppage thereof as something they have no power over.

### *Home based care*

Home based care had been rendered but was stopped:

Two of them came to wash him in the mornings. Once a week on a Tuesday. I make sure that we have enough hot water and we put clean linen on the bed. Now they do not come anymore. (Mother)

#### 9.5.4 Attitudes of immediate family

His mother was openly loving and caring, and both of them indicated that they supported each other emotionally. From what I observed she cared for him and the house as best as she could. But ailing health and old age made it difficult for her, and she complained about back aches, dizzy spells, headaches and painful knees: “I am not the person I used to be, I am finished”. She admitted that caring is becoming a struggle: “It is not easy to look after a person like him. If only he could sit up”. While she loved him and cared for him she might have contributed to his feelings of worthlessness and to his disability through her attitude, as previous quotes and the use of “a person like him” in the above quote shows. His mother also expressed concern about his care after her death, but did indicate that the local minister had said he could go to the old age home.

With regard to his siblings, his sister expressed love and caring concern. She went to their house to assist with caring and expressed willingness to take Carel in after his mother dies. According to Carel and his mother, his brother talked to him and joked with him, but did not contribute anything towards his care.

Carel and his mother described his sister-in-law as aggressive and abusive towards both of them. She showed little respect for Carel’s personal space: “She came and sit-fall on my legs” and apparently called him a worthless thing as an earlier quote showed. It seemed that the brother did little to curb or control his wife even when she assaulted his mother:

She hits me that is why I have problems with my ear, She hits me, She hits me [says this softly]. He [brother] is angry and unhappy, but she drinks more than he does and then he cannot talk to her. If he asks food she shouts at him. She is not an easy person (“*Sy is `n baie verkeerde mens, hene*”). (Mother)

R to C: Does she hit you as well?

C: One Saturday she sat on top of me. Then I told her I am going to stab you with a knife and I put my hand underneath the cushion. That made her move away quickly.

### 9.5.5 Personal factors

#### *Anger*

One of the ways proposed by Smith et al. (2009) to look for patterns in data is through numeration, i.e., the frequency with which a theme is referred to. While not the only indicator of importance it can point towards importance. At six different times during the interview the issue of Carel getting angry came up in various contexts:

He becomes livid (“boos”). He will get a heart attack as angry as he gets. (Mother)

#### *Cognitive function*

Nothing was said in so many words that could lead me to question Carel’s cognitive function. However, he seemed to be laughing inappropriately throughout the interview. There were also the references to him getting angry easily. Then there were his physical inabilities which were beyond what one would have expected from his impairments and might be in part due to a lack of motivation, which can be related to decreased cognitive function. The EquitAble survey data indicate that he felt he struggled a little bit with concentration and to learn new skills.

### 9.6 Discussion and reflection

On reflecting on the information after the interviews my thoughts revolved around four points. Their unwillingness to discuss disability. The severe levels of participation restriction experienced by this man, who had on the face of it, not such severe impairments. The actions of his sister-in-law, the negative impact of these and what seems like an inability or unwillingness of all involved to curb her. And finally, what seems like a narrow focus of health care services on how to manage disability. It seems as if only his impairments were visible while none of his potential was realised.

For someone who cannot sit up, stand or walk to refer to himself as walking with a limp surprised me. Carel and his mother’s inability or unwillingness to engage in a discussion on disability might be due to the connection his mother made to disability as being something



negative. She called it ugly. But they could not tell me why they saw it as negative. Another aspect of the findings on disability in the interview that I think important was the way his mother pointed out that he was a victim who could not help what had happened. This innocence seemed to be significant to them and connected to not being willing to call Carel disabled, and disability being a negative or indeed “ugly” concept. It might be related to the way his sister-in-law used the term. It seems as if she used it as derogatory and to insult him. These perceptions of disability and their belief that the disability was caused by sorcery led me to conclude that they saw disability from the perspective of the Moral approach (Goodley, 2011).

Both parties were unwilling or unable to explore the concept of disability further, even on a theoretical level. The lack of theoretical response might be because they could not extrapolate on the thought. But I perceived that it was more related to an unwillingness to engage with it since, if fully explored, they might have to admit that Carel was indeed disabled. A reality that might be too painful to acknowledge, since they seem to equate disability with worthlessness.

Apparently his sister-in-law called him worthless. She might have been the only one willing to acknowledge her thoughts in words. The quote may to a degree be indicative of what both he and his mother think, even if only on a subconscious level. In a culture and community where physical ability and strength is important as a means of employment and fending for yourself, one might begin to understand this connecting of physical disability with worthlessness (Grech, 2009). The financial contribution Carel’s disability grant (DG) made to the household income were not acknowledged by them. This lack of acknowledgment is in contrast with other studies in South Africa where researchers have found that a DG or old age pension improved the financial status of households (Loeb et al., 2008) and gave grant holders decision making power, authority and respect within families (Case & Menendez, 2007; Graham et al., 2014).

Carel experienced higher levels of activity limitations and participation restrictions than I would have expected from someone with his impairments. The ICF framework on disability makes it clear that the relationship between impairments, disability, function and participation is not linear (WHO, 2001). Carel’s case study is a case in point. His impairment should not prevent him from being able to perform activities like rolling in bed, sitting up, washing and dressing himself,

transferring to a chair or wheelchair, self-propelling the wheelchair and using the toilet, or from community integration and participation (Bromley, 2006). He could not perform these activities. I can only speculate on why not and developed theories in this regard, which could have separately or more probably in combination caused his activity limitations and participation restrictions.

Carel resided in a rural area of a province where according to service providers no organised rehabilitation services existed. The professional nurse indicated in an interview that rehabilitation was not their responsibility. The therapists indicated that they provide follow up therapy to those who are referred to them, but that many are not referred. In my experience Carel would have received more comprehensive rehabilitation and follow up if he was a resident of the more urban and better resourced neighbouring Western Cape Province. In addition to inpatient rehabilitation at a specialised unit the Western Cape Province provide follow up services to persons with disabilities through an orthopaedic after care system. Professional nurses operate in all health districts of the Western Cape Province and provide follow up for all who require assistive devices and or consumables (not only to those with orthopaedic needs). Carel would have benefited from both inpatient rehabilitation and follow up services. Rehabilitation for persons with paralysis of the lower limbs includes retraining of function that enables them to perform activities of daily living and wheelchair dexterity activities independently and are usually taught as part of inpatient rehabilitation (Bromley, 2006). Carel did not have this opportunity and was as far as I could gather not trained in these skills.

However, in my experience people with paraplegia can in time develop these functional skills even without rehabilitation input. Carel did not do that either. This might be due to a possible lack of personal drive and motivation, which might have been caused by unidentified cognitive impairments or a progressive condition. The narrative does not indicate the presence of a progressive condition, but the study participants showed limited understanding about the health condition that caused the impairments. Therefore a progressive condition such as multiple sclerosis or cognitive damage due to a type of meningitis cannot be ruled out.

Furthermore Carel, his mother and family saw him as being of no worth (not even a man, as his mother's words indicated), with had no role in the household. Negative thoughts, lack of expectations and verbal abuse from his sister-in-law could have led him to create an image of himself as helpless (Harrison et al., 2010; Hughes & Nosek, 2001); an image to which he conformed in spite of the possibilities within him.

Optimal management for Carel might include a period of in-patient rehabilitation. One might think this impossible from a resources point of view. However, doctors at tertiary level indicated a willingness to use resources to amputate his legs, an expensive surgical procedure which would involve some time in hospital. If this option is a possibility, inpatient rehabilitation could also be possible. Carel might not agree to in-patient rehabilitation since he seemed convinced that health care services could do nothing for him. Peer exposure to people suffering from the same impairments, who function independently, might show him the possibilities and help to change his mind (Boschen, Tonack, & Gargaro, 2003; Ljungberg, Kroll, Libin, & Gordon, 2011).

It is possible that not only Carel, but also medical service providers need education with regard to his functional possibilities and the role that rehabilitation can play in his life. According to Carel health care workers told him they cannot help him to get better. This seems like an example of "diagnostic overshadowing" that Tom Shakespeare talks about "whereby the diagnosis becomes the most important thing, and the individuality of the child or adult is ignored or lost" (Shakespeare, 2014, p. 58). It seems as if service providers are of the opinion that the only illnesses Carel can have must come from his impairment and that if the impairment cannot be cured nothing can be done for him.

Carel's impairments may be incurable, however, health care services have other roles to play in Carel's life. He did receive a new wheelchair, but service providers did not ensure that he could use it. User training in the use of the device is an essential part of providing assistive devices (WHO, 2008b). Providing an expensive assistive device without ensuring that the person can use it is a waste of scarce resources. In addition health care services could have assisted through the provision of consumables, assistance through home-based care and education on the

prevention of secondary complications. The lack of continence care especially could have caused him embarrassment and further negatively impacted his already very low self-esteem.

Finally there is the issue of time. It seems as if the health care services that Carel received deteriorated over time. He did receive nappies; he did receive home-based care. These services were terminated and he did not know why. It seems as if it might have been difficult to sustain service over time. Home-based carers often work on a voluntary basis or are paid very little. While satisfying, the work they perform can be physically and emotionally draining. It is thus possible that a lack of financial incentive combined with the strain caused by the job caused a decrease in the number of home-based care providers over time with a resultant decrease in service provision. Financial difficulties might have caused the provision of incontinence diapers to stop.

## **9.7 Conclusion**

Carel's legs were paralysed and he could not walk and work as a farm labourer anymore. It seems as if this inability made him and those around him accept that he is not worth anything, that he can be treated with contempt, and can be seen as somehow less than human. In addition it seems as if health care service providers did not realise the role that rehabilitation can play in his life. Carel needed to be involved in a rehabilitation programme that:

- Exposed him to peer counselling and training.
- Provided a suitable wheelchair and dexterity training.
- Retrained bed mobility, transfers, and toilet use.
- Identified a person, for instance his brother, who could be guided to build a ramp at an outside door.

These interventions usually come about when rehabilitation teams implement orchestrated, evidence-based rehabilitation service programmes of which no evidence was found in this case study. Following the experiences of three people with severe physical impairments, we will explore Dina's story. She had an acquired physical disability but of a much less severe nature as those of Anita, Brenda and Carel.

## **Chapter 10**

### **Dina's Story**

#### **10.1 Introduction**

Dina was 33 years old. She had a number of physical impairments, as I shall discuss.

#### **10.2 Sampling and Sources of Information**

I selected Dina for the pilot interview, and had not intended to use her story as part of the thesis. However, the findings with regard to health care access differed substantially from those of the other case studies; therefore I decided to include it. Data for this case study came from one interview with Dina and her mother. Both participants seemed friendly, relaxed and welcoming. Demographic data came from the EquitAble survey.

#### **10.3 Background Information**

Dina and her two daughters resided with her parents. She came, as she called it, “home” to her parents after she suffered a compound fracture of the tibia and fibula of her left leg in a motor vehicle accident in 2010. Before the accident she had lived in Saldanha (a town 600 kilometres away) where she was employed as a security guard.

At the time of the study Dina was unemployed. She wore a built up shoe on her left foot and used one crutch when she walked long distances. She performed household tasks such as doing the laundry, cooking and cleaning. She accessed the community through walking, did shopping for her and her children, attended church activities and visited with friends.

The family lived in a four roomed house that belonged to her parents. Apart from Dina, her two daughters and her parents, two other adults were sharing the house. The house was neat and clean and furnished with appliances such as a fridge and electric stove. A television and lounge suite adorned the sitting room.

## 10.4 Medical History

The fracture has mended, but Dina's left leg is 5cm shorter than the right one and the bones set in a valgus angle<sup>15</sup>. At the time of the interview, Dina complained of instability in the knee and some stiffness in the ankle. Since the accident in 2010 Dina had had 12 operations on the leg and was awaiting the thirteenth one. According to her the purpose of the proposed operation was to lengthen and straighten the leg.

## 10.5 Emerging Themes

Findings from this interview were analysed as described in the methodology. Superordinate themes identified through subsumption, function and abstraction are presented in Figure 10.1.

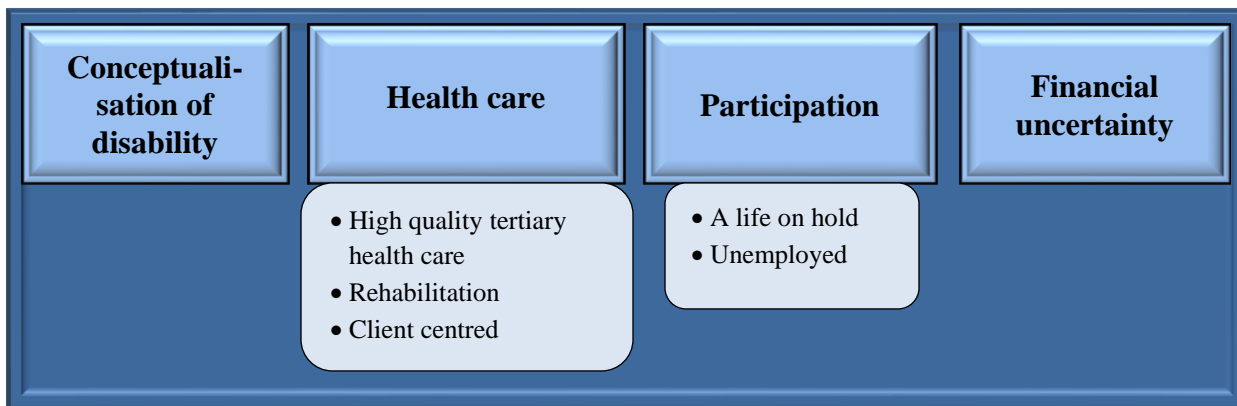


Figure 10.1. Superordinate and emerging themes identified in Dina's case study

### 10.5.1 Conceptualisation of disability

Dina said that some people might see her as disabled, but that she felt since she could still do all tasks for herself she was not disabled. She referred to people who cannot do anything physically for themselves as disabled:

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<sup>15</sup> The part below the fracture angles outward (Solomon, Warwick & Nayagam, 2010).

OK people might say I am disabled. But I think when someone is really disabled it is when they are completely out of action, not walk . . . I saw cases there [Groote Schuur, a tertiary hospital in Cape Town], children who are so disabled they cannot eat by themselves. They are pushed in a wheelchair. They are deformed. (Dina)

### **10.5.2 Health care**

#### ***High quality, tertiary, health care***

According to Dina she did not access the local CHCC at all. She received all health care at tertiary level. Her accident occurred in the Western Cape Province and she was initially treated in that province. Currently she still received follow up treatment at a tertiary hospital (Groote Schuur in Cape Town) in that province even while residing in the Northern Cape Province. She attends six-monthly appointments. Transport was organised by the local CHCC and provided by the Northern Cape. She reported no problems in this regard and accessed Groote Schuur it seems, effortlessly.

About the treatment she said:

The operations were successful. Every time. My foot was like this [shows inversion, plantar flexion position]. The muscles did not work. I could not lift the foot. I received a lot of Physio. It was terribly painful, but as a result of that I can walk again. It was not always easy, but it was worth it. (Dina)

#### ***Rehabilitation***

She received therapy which while painful was, according to her, necessary and successful as the above quote indicates. She received the necessary assistive devices, including two pairs of store bought, built-up shoes. She was promised that she could bring new shoes to be built up and that the service would be provided on the same day since she lives far from services:

They told me to phone for an appointment and when I go again they will do it for me right there [Groote Schuur] at once [building up of a new shoe]". (Dina)

### *Client centred services*

Dina received preferential treatment because she came from far away. In addition, service providers ensured that she was fully informed:

They explain things clearly. But it is mostly English. Then I tell them I do not understand English well. Then most of them revert to Afrikaans or they find another doctor to come and explain to me. (Dina)

Service providers spent enough time with her:

Abundantly. When they have done they ask whether you are satisfied and if there is something else. Even if lots of patients are waiting they seem to take their time with every patient. They are really good. They are busy but not hurried. (Dina)

Dina showed a high level of satisfaction with the services she received:

O goodness they are excellent. Really they go out of their way. Not only for me for all the patients. They take trouble. From the doctors to the nurses. Nobody has any airs. If you need help you only have to ask. (Dina)

### **10.5.3 Participation**

#### *A life on hold*

This theme was derived at through function. The way in which Dina presented her life and especially participation in life roles led me to interpret that her life was on hold, waiting for a cure:

It is uncomfortable to walk with the leg like this. The crooked leg puts strain on the knee. My knee can take nothing. Not even a wrong step. After the next operation it will go better with the knee. (Dina)

Thus she did not want to become too involved in community activities at the moment:



There are things one can do, but I do not want to commit myself at the moment because I have to go again [to Cape Town] and maybe I get a date [for the operation] . . . And I do not know how long I will be out of action [after the operation]. (Dina)

I go to church and women's service and things like that. (Dina)

Dina felt that she was integrated into the community to the extent that she wished to be. She could walk where she wanted to go and could access all buildings in town. She also indicated that she was accepted by all people in town. She said this during the interview and EquiAble survey data confirm this since she indicated no problem under community integration questions except employment (big problem) and personal financial management (little problem).

### ***Unemployed***

While as integrated in the community as she wished, she was unemployed. Dina had a relatively small impairment and no activity limitations (according to interview findings and EquiAble survey scores). She ascribed being unemployed to the challenges she experienced with walking and a lack of jobs:

I think I will be able to walk better and thus have a better chance to find employment if they operate my leg. (Dina)

There is no work in town. (Dina)

About her ability to walk she said:

The only problem is that I cannot stay on the leg for too long or walk very long distances. If I do that my ankle gets swollen. (Dina)

She does act as housekeeper in her mother's house, a situation which she and her mother seemed to find satisfactory:

I help inside the house. I do the washing and the ironing. (Dina)

Baking bread, you take things out of my hands. She helps a lot especially with the washing. (Mother)

#### **10.5.4 Financial uncertainty**

While the house, its furnishings, Dina, her daughters and her mother were not in a condition of poverty (especially relative to others in her community), Dina did not have any income or money of her own. This left her financially dependent on her parents. Dina expressed a sense of unhappiness about that:

I am happy at home, but only financial. My parents care for me and the children, but that is not pleasant. (Dina)

This situation was created by a series of events. She got payment from her employer for a year after she was medically boarded. At the time when this money stopped, October 2011, she received a form to be completed for a DG. This form has yet to be completed since the DG officer visits the Fraserburg CHCC sporadically and had not visited since she got the letter (six months). There was a Road Accident Fund (RAF)<sup>16</sup> case pending, but she did not know how the case was progressing, when it would be finalised and what the nature of the settlement would be.

Dina had no idea of the cost of treatment and said that the bills were sent to a professional nurse in Vredenburg who dealt with third party claims.

#### **10.6 Discussion and Reflection**

This interview provided a positive picture of public health care services with regard to availability, acceptability and affordability. Dina was brimming with satisfaction because she received what she experienced as acceptable care of high quality. She received curative care, follow up as needed, and rehabilitation. Even transport over provincial boundaries seemed to

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<sup>16</sup> “The Road Accident Fund (RAF) provides compulsory cover to all users of South African roads... against injuries sustained or death arising from accidents involving motor vehicles within the borders of South Africa.” Road Accident Fund (2011)

provide no challenge. It seems that for Dina the 500km distance created none of the barriers to accessing health care that were described in the literature review. It seems as if physiotherapy sufficient in quality and quantity to ensure functional outcomes was provided. An especially heartening finding was that Orthotics in the form of built-up shoes were provided. This is in contrast with other findings on the subject of prosthetics and orthotics. Both the therapist interviewed during the first round of EquitAble data collection and the therapists participating in the focus group discussion for this study indicated that orthotic and prosthetic service delivery were problematic and often not provided (Chapter 15). The differences between what Dina experienced and the service that therapists described might be due to the service being provided in two different provinces, and/or at different levels of care (tertiary versus primary), and/or in different settings (urban versus rural).

In South Africa, Provincial Governments independently manage health care service delivery in their respective provinces (Coovadia et al., 2009; Republic of South Africa 2004a). Inequities in health care service delivery and capabilities of health care service providers across provinces have been described (Coovadia et al., 2009; Mayosi et al., 2012). The Western Cape Province has been identified as one of the provinces with more resources and better health outcomes (Coovadia et al., 2009). On the other hand the quality of services might be related to tertiary level of care or the specific tertiary hospital. Coovadia et al. (2009) indicates a skewing of human resources towards provinces with urban based medical schools (Groote Schuur hospital is situated in Cape Town and one of the primary training facilities for the health Sciences Faculty of the University of Cape Town). It could possibly be thought that because Dina has a RAF claim and can thus be seen as a paying customer, she was receiving better quality care than others. However, since the money will not be paid to service providers, but rather to the institution, I do not think that would influence the way in which services are delivered; nor is there any empirical basis for the contention that health care providers in the public sector treat patients differently depending on whether they pay.

Dina found her lack of financial independence upsetting. However, she seemed to be putting more emphasis on getting a DG than getting employment. This seemed like a contradiction to me since she did not see herself as disabled and indeed it might be difficult for her to obtain a

DG. The DG is issued for persons who, according to the Social Assistance Act of 2004, are “owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance.” (Republic of South Africa, 2004b, p 10). It is left to the discretion of the medical officer who completes the DG application to decide whether the applicant is unfit to be employed. In my opinion Dina’s limitation is moderate to mild. Coupled with the fact that she had matric (school leaving certificate) and was thus not limited to work requiring physical labour some DG officers might feel that she was not eligible for a DG. In fact, according to the guidelines provided in the Assessment Tool and Training Manual on the Harmonised Assessment Tool for Disability Grants and Free Health Care she does not qualify for a DG (South African Department of Social Development, 2005). There is considerable concern, though, that in situations of poverty and in the absence of employment opportunity and other forms of social security, people (and their families) access DGs in order to survive (Schneider, Waliuya, Musanje, & Swartz, 2011).

On the other hand, Dina was temporarily disabled, but did not receive a temporary DG. The described time lapses are worrying. The DG form was apparently only given to Dina once her income stopped. She has now been waiting six months for that to be completed. If Dina’s family did not provide for her, she and her children would have been destitute. In my opinion Dina should have received a temporary DG as soon as payments from her employer stopped.

Unemployment is a huge problem in South Africa (Loeb et al., 2008; Stats SA, 2011) and finding employment in Fraserburg and South Africa as a whole is challenging. This might be why Dina focussed on a DG rather than employment. However, it seems as if Dina did not try to find employment. She said there were no jobs, but she did not look for employment thus she did not base this opinion on personal experience. In addition she is not limited to Fraserburg with regard to finding employment. She seemed to be waiting for the cure that she expected to come from the operation before she resumed her life fully and looked for employment. What if the operation does not cure her completely? What if the leg remains shorter or the knee remains unstable? These possibilities are very real. Could she accept that and continue with her life?

## 10.7 Conclusion

Dina's case study showed the importance of good quality curative and rehabilitative care and how that can decrease impairments. Dina could have been left with an equines deformity (Solomon et al., 2010) of the ankle, without built-up shoes, with non-healing of the fracture, but was not, mainly due to the medical intervention she received. However, it seems as if Dina's medical approach to her condition made her focus on the impairment and a cure. She did not convert her functional ability into full community integration and employment. The possibility that she will have a minor physical impairment for life is real. Finding sedentary employment in the agrarian town of Fraserburg will be difficult. She hopes for a DG, but will most likely not get it, because the impairment is minor. Thus she requires emotional support/counselling to help her focus on realistic expectations and set goals for the future.

The first four participants suffered from physical impairments. In the next chapter the reader is introduced to Erik. He was the first of three participants purposively selected because they suffered from impairments that did not impact that much on physical abilities and mobility.

## Chapter 11

### Erik's Story

#### 11.1 Introduction

Erik, a single man of 21, lived with his foster parents on a farm 45 kilometers outside town. He had an intellectual disability.

#### 11.2 Sampling and Sources of Information

Erik was known to me since I completed the EquitAble survey questionnaires in his household. Information presented here was gathered during an interview with him and his foster mother and an informal talk with the wife of the farmer on whose farm they resided. Erik could not be interviewed individually since he was extremely shy. He responded very little and would often redirect questions to his foster mother. Information from the EquitAble survey provided demographic details.

#### 11.3 Background Information

Physically well-built, Erik struck me as strong. He could walk where he wanted to go; wash, dress and groom himself as well as perform basic household tasks. However, he needed supervision and guidance with all tasks that required more than basic cognitive ability. Erik was cared for by his foster mother, the sister of his biological mother, since birth. His foster mother indicated that her sister was not a good mother and that she, herself, could not conceive, thus she saw him as a gift from God:

She was actually a poor mother, she was young, 18 years old. . . . It felt to me like God gave me the opportunity to raise him. (Mother)

She did not explain why she saw her sister as a poor mother. She further painted a picture of in-laws not acknowledging him:

The parents of the man who had sex with my sister never admitted that Erik was his child. (Mother)

Whether this was related to his disability or the fact that the man was not married to her sister is unsure. Currently Erik is like a child in her house. His relationship with her husband was not as good as with her:

Sometimes they are amicable, but he often snaps at my husband. (Mother)

They lived in a three roomed house on the farm, which is the property of the farmer. There was solar power and running water in the house. Their only means of transport to town was with the farmer. This was provided free of charge:

We ask when we need to go [to town] and then they say we can go that day or that day. (Mother)

#### **11.4 Health Status**

Erik's intellectual disability seemed to be related to his having been born with hydrocephalus. At the time of the interview Erik suffered from hypertension and received chronic medication for this condition. In addition he received pain killers since he often suffered from headaches.

According to his foster mother he sometimes exhibited impulsive behaviour that could be dangerous to himself. An incident of eating paper was described as well as a few incidents where he walked to other farms, some far away, without informing anyone of his intentions:

He walked to [name of farms]. Those times it seemed to me as if he had a severe restlessness, hurt, I do not know if he longed for those people, but he does not share with us. (Mother)

He went through periods of moodiness and aggression. According to his foster mother doctors ascribed this to nerves. His foster mother has learned through time to identify bad mood days and how to calm him down.

## 11.5 Emerging Themes

Scrutiny of the findings let me to identify five superordinate themes through abstraction and subsumption, and clusters under each as presented in Figure 11.1.

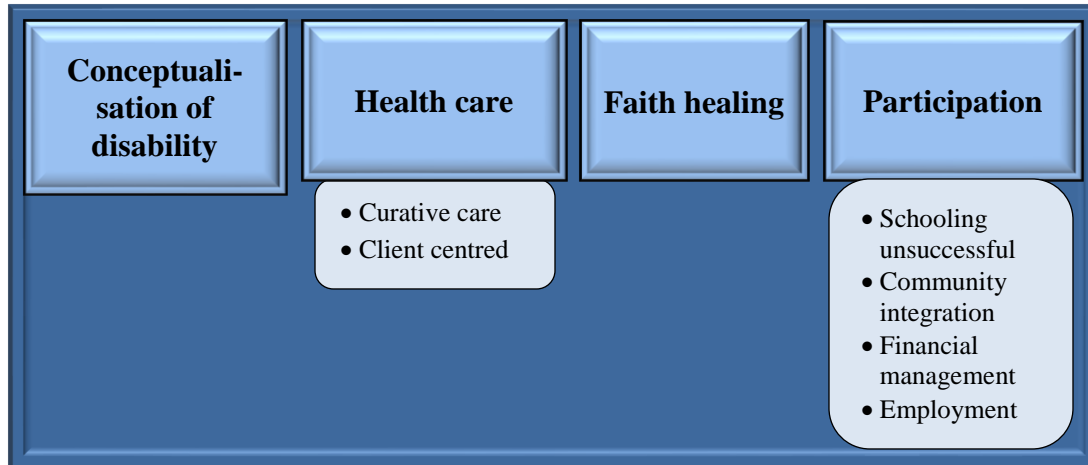


Figure 11.1. Superordinate and emerging themes identified in Erik's case study

### 11.5.1 Conceptualisation of disability

One of the few times Erik responded directly to a question was when asked whether he was disabled. He responded with a clear, "No". However, he could not be drawn into any discussion or explanation as to why he did not see himself as disabled or what his perception of disability entailed. His foster mother on the other hand indicated that she thought he must be disabled. However her words indicated a level of uncertainty:

I will say that he probably has a disability on him. (Mother)

When he cannot truly concentrate on things, and many of his words, he used them the wrong way round ("*hy vat hulle verkeerd om*"), his words does not always come out correct. (Mother)



## 11.5.2 Health care

### *Curative care*

Erik accessed primary and tertiary level health care. When he was an 11 month old boy his foster mother took him to the CHCC, because he could not sit yet. He was referred to Tygerberg Hospital in the Western Cape for tertiary care:

I drove with him, drove again and again [to tertiary care]. First they said he had water on his brain. As a baby. Then they put him through the machines and said if there was water it restored itself. After that they [doctors] said he had too much brain tissue. And they saw the problem with his eyes (he squinted). I went there again for them to correct the eyes. They did an operation. They corrected the eyes and he can see well now.  
(Mother)

It seems as if he received curative care, but no mention of cognitive stimulation and rehabilitation to enhance cognitive function, like sensory integration and speech therapy or training for his foster mother was mentioned. EquitAble data indicate that he received inoculations, but no HIV testing or counselling. I think this is an important omission in the case of an active young man who may be sexually active and may participate in unsafe sexual practises or be in danger of becoming a victim of sexual assault, because of his impairment.

### *Client centredness*

The family were satisfied with health care at primary level and indicated a positive attitude and medication that was always available:

They [professional nurses] understand him well. They know him since he was a child. The sister asks what the problem is and always has a joke for him. They always have a positive disposition towards him. (Mother)

Neither Erik nor his foster mother knew what caused elevated blood pressure in one so young or how to manage it except through medication. EquitAble survey data indicate that explanations

from health care service providers were average. In addition the survey data indicated that they were not involved in decision making and that they could not consult a health care service provider of their choice.

### **11.5.3 Faith healing**

The findings presented a strong belief in prayer and faith healing. In the past:

She [farmer`s wife] prayed and she said: “Take this prayer with you, do not forget, take it with you. Pray this prayer always.” . . . everything got better . . . not long after that he did not even crawl he just got up and walked . . . God is there, He helped. I trust in God.

(Mother)

And more recently:

It seems to me he feels he needs prayer, when we go to services he always asks for prayer. (Mother)

His foster mother thought that only a miracle from God could give further improvement or heal Erik.

### **11.5.4 Participation**

According to the EquitAble survey data, Erik had multiple activity limitations. He struggled a lot to learn new skills, to concentrate for 10 minutes, to talk with strangers, and to maintain friendships, and he struggled a little to do his daily tasks. He also experienced many participation restrictions such as doing shopping, taking care of others, interacting with strangers, having intimate relationships, managing his finances, participating in leisure and community activities and political life.

#### ***Schooling unsuccessful***

As a child Erik went to a mainstream school, but could not progress academically:

He could never progress. They did the adjustment class at that time, but he could not progress. The people started to say he has a problem and pointed fingers to him. He does this or that. He has a problem or he bothers the children. Therefore I took him out of school. (Mother)

### ***Community integration***

Apart from attending church services Erik was not included in the community. He had no friends of his own age:

Older people show affection to him. They talk to him and joke with him. But he has no young friends. It seems as if the young group is not interested in him. (Mother)

Incidents of mocking and teasing did happen and EquitAble survey data show that Erik felt he experienced prejudice:

Often they will tease him quietly. That makes him very unhappy. He does not talk back to them. He is basically shy. Becomes unhappy and stay on the side. (Mother)

His foster mother spontaneously elaborated on the role of the evangelist who came to preach on the farm. It seems as if this man took trouble to include Erik:

The one that actually understands him well is [name of evangelist]. He understands him very well. He prays for him often. He will always ask him how he is. When he see him sitting flat on the ground he will tell him: "Young man take a chair and sit on that". (Mother)

### ***Financial management***

Erik had a bank account into which his monthly DG was paid. He drew the money and handed it over to his foster mother to buy what he needed since he could not do the necessary calculations. She included him in the shopping process and gave him choices:

He gives the money to me, then I ask him what he wants me to buy for him. Then he says he wants this or that and not those things. He goes with me to the shops. Then I take the stuff and give the money to him and say, Ok, pay for it. (Mother)

### ***Employment***

At the time of the interview Erik was not formally employed on the farm, but helped his mother in the garden by raking leaves or trimming edges. Other odd jobs such as washing the vehicles also fell to him. Since then, a talk with the farmer's wife indicated that his employment status had become more formalised and that he now had a role in her house. His job entailed general household chores like doing dishes and vacuuming. The farmer's wife said that she had to experiment to find the best way to manage his work. In the end she realised that Erik functioned best if commands came to him through his foster mother. Thus she would tell his foster mother what he was to do on a specific day. His foster mother related it to him and managed the quality of his work. She gave feedback to the farmer's wife in turn. Thus she could be seen as his line manager and the situation worked according to the farmer's wife because his foster mother understood him and knew how to communicate information and tasks to him. In addition she seemed to have a good sense of what tasks he would be equal to or could be taught and which ones would demand too much of him.

### **11.6 Discussion and Reflection**

Erik had an intellectual disability severe enough to make him need more or less constant supervision, and to struggle with many activities. Thus I would have thought he had a severe disability which would lead to little participation. But one contextual facilitator, the support of his foster mother, made a big difference. She guided him through employment much as a formal job coach would do (Wehman, Targett, & Cifu, 2006). She assisted him with his financial affairs and included him in shopping.

While reflecting on this interview I marvelled at the simplicity of it all. The best source of support and the people best suited to facilitate integration are often family members. Erik's foster mother had the wisdom to do this seemingly instinctively and identified what was required

without guidance. Others might be as willing, but might need guidance on how to provide support that would ensure optimal integration.

Another environmental facilitator was his employer. It would probably have been easier for her to appoint one of the wives of the other farmworkers or find a house keeper in town than to employ Erik. However, she was willing to take the trouble and provide him with an opportunity of employment. A challenge with regard to this situation was that Erik did work that was seen in his community as women's work. According to findings he was already excluded by his peers. This situation might be exacerbated through him doing what they will see as woman's work and through not having a common topic of conversation with regard to the work his peers do. Ideally, his foster father could have taken him to the fields with the men. However, their relationship was not of a nature where the foster father would have been able to act as a job coach like his foster mother did.

The picture painted with regard to health care service provision was positive. It seems as if an acceptable service was provided. Primary health care workers engaged with Erik and took notice of the person beyond the impairment. Erik did not experience any discrimination in the way he was treated. However, in my opinion there are some omissions with regard to service delivery. Erik received hypertension medication, but apparently no guidance on lifestyle factors that influence blood pressure, such as dietary practices and exercise (Lip & Beevers, 2007). The importance of this apparent omission is underscored by literature findings that indicate improved compliance with regimes and improved outcomes in hypertension management when individuals understand the condition and are involved in decision making on their health care management (Brunton, 2011; WHO, 2003). Hypertension is a precursor of many diseases that can lead to early mortality and morbidity and as such should be a focus of comprehensive primary health care programmes. Holistic management and prevention of hypertension is of special concern in the study setting since EquiAble data showed that hypertension was common in this community (Figure 6.6). Erik's case study exposes challenges with regard to the management of hypertension in the setting. However, I cannot draw any conclusions from one case study. The extent and nature of these challenges is an area for further research.

In addition, no HIV counselling and testing were done. This would be an important service for any man in his early twenties, but even more so for one with intellectual challenges. EquitAble data show that 13% of persons with disabilities and 22% of persons without disabilities received HIV counselling while 36% of persons with disabilities and 45% of persons without disabilities received HIV testing at the Fraserburg CHCC. These figures are rather low for both groups and could be the reason for the omission in Erik's case. On the other hand, Groce (2005) indicates that persons with disabilities are often not tested for HIV due to an erroneous belief amongst health care service providers that they are not sexually active. Thus either one of the explanations might be valid in Erik's case.

An aspect of Erik's narrative that does seem to indicate challenges are with regard to education. This was not explored in-depth since it was not the focus of the study. However, there is a need to explore the role of education with regard to developing life skills and teaching specific physical skills that can lead to employment (such as sheep shearing) to children with severe intellectual disabilities in this community.

## **11.7 Conclusion**

I was positively surprised with Erik's levels of integration and applaud his foster mother and the farmer's wife. The way in which health care service providers interacted with him was also positive. However, I would have liked to see more involvement of him and his foster mother in his care and I would have liked to see improved preventative strategies according to the principles of PHC. Erik should have received HIV counselling and testing. He should have been educated on the prevention of sexually transmitted diseases. His foster mother should have been trained in early childhood stimulation when he was a child. Both of them should have received training on the holistic management of hypertension instead of just medication.

In the following chapter we explore the experiences of Frans, a man with an acquired hearing impairment.

## **Chapter 12**

### **Frans's Story**

#### **12.1 Introduction**

Frans was a 58 year old man with a severe, acquired, hearing impairment. While he could hardly hear anything, he could talk clearly and it was easy to understand everything he said. Frans could not lip read or understand sign language. We could only communicate with the assistance of the farmer, in whose employ he was. It might seem strange to use an employer in this regard, but as the results will show their relationship was much more complex than simply that of employer and employee.

#### **12.2 Sampling and Sources of Information**

One of the EquitAble survey data collectors told me about Frans. I thought that he might be a candidate for a case study, perused his survey information and indeed sampled him for the case studies. Information for the case study of Frans came from an interview with him and the farmer and from the focus group discussion with the therapists. Demographic information came from the EquitAble survey.

#### **12.3 Background Information**

Frans was estranged from his wife and lived alone. He had a brother in Loxton (a neighbouring town 110km away) who he would sometimes visit for a weekend, and sisters in Fraserburg. He did not finish primary school education, but could read and write, abilities that were important to him in his work.

#### **12.4 Medical History**

According to Frans, medical testing showed that he had no hearing in his right ear and 15% hearing in his left ear. He linked the cause of his hearing problems to a disease he had as an adult:

. . . it rained slightly [he became wet]. I did not know I had chicken pox . . . the chicken pox affected my ears instead of my lungs. The doctor struggled for three weeks with me and told me I will become deaf in time. (Frans)

Frans was also aware that a hearing aid or operation might improve his hearing:

They can do that operation. It is a delicate procedure. (Frans)

Frans did not seem keen to pursue the avenue of an operation. He said that at 58 years of age the operation might not be worth the effort anymore. The farmer suggested that he first do the deaf ear only. But he kept quiet. Then the farmer suggested that he was afraid of the operation and of going to Kimberley. While not acknowledging this he also did not refute the statements. He laughed and said: “Yessss, but let us first organise our things.” He could not explain what things he referred to.

Apart from the hearing challenges Frans had no health complaints.

## 12.5 Emerging Themes

In the case of Frans the super ordinate themes as presented in Figure 12.1 emerged through subsumption, abstraction and function as described by Smith et al. (2009).

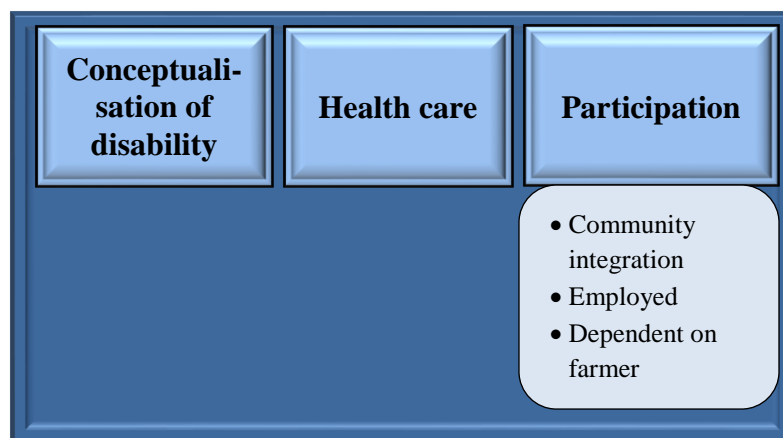


Figure 12.1. Superordinate and emerging themes identified in Frans's case study



### 12.5.1 Conceptualisation of disability

Frans linked himself to people with disabilities: “the treatment for us disabled people . . .”, but made it clear that there was nothing wrong with him except that he could not hear:

I do everything myself. There is nothing wrong with me. The only problem I have is that I cannot hear. There is nothing wrong with me. (Frans)

### 12.5.2 Health care

Frans accessed formal health care, but showed frustration with services throughout the interview. EquitAble data also indicated that Frans was unhappy with the services. It seems as if his attitudes were formed through challenging interactions.

According to him he had to get medication from the CHCC to stop the weeping from his ears (otitis media) before an operation could be done or a hearing aid fitted. This was confirmed by information from the speech therapist in the focus group discussion. The medication he got made him worse:

They could not help me here [at CHCC]. It felt to me the stuff they gave me made me a lot worse. I felt to me like I was turning around all the time. (Frans)

He then received medication from a private doctor, whom he consulted with the assistance of the farmer. That cured the otitis media:

The missus phoned all over and in Williston [neighbouring town – 80km away] from Dr [name of private doctor] she got medication for me. She got my ears that they are healed. (Frans)

At the time of the interview he was waiting for the professional nurses to make an appointment in Kimberley for the hearing aid to be fitted, which according to him they have not done:

It is their responsibility to tell the people that I am ready, they have to come back, but they do not come back. (Frans)

The farmer disagreed with him on this and said that they did call with an appointment. He then said that his ears were still weeping at that stage. He did not inform the professional nurses when the otitis media was cured.

He described two other incidents that left him unhappy and not inclined to use the services. In the one he was ill and did not have his folder number with him. He was sent home with no treatment:

See the hospital card was at home. And I had this headache. I told the sister I forgot my number. The number is out of my head. They told me if you do not have your number you must go away. We do not have time to wait for numbers. The computer is not here. It is in Calvinia. If you do not have that number you have to leave. I had to leave, because they did not have time [indignant]. They were unhappy that morning. I do not know what happened to them. (Frans)

In another incident he was told to sleep in town in order to be at the clinic early the next day:

I must sleep over in town the night. Then they can work on my ears. Because they have a lot of work to do and I must come the next morning at 8 o'clock. Then 8 o'clock became 12 o'clock, but they do not get to my ears. I just left them. (*“toe los ek hulle maar”*). (Frans)

The farmer assisted with obtaining appointments and providing transport to a specialist in George (400km away) for an assessment and a general practitioner for medication and in both instances paid the accounts. However, no money was available for the expensive further treatment that was required:

It [the operation] is hellishly expensive to do privately. (Farmer)

Frans had a hearing aid that was donated by a member of the community after an appeal by the farmer, but was not fitted yet:

He asked in church whether anybody had a hearing aid for me. He got one. I gave it to the doctor in Calvinia. The doctor said it needs batteries and must be fitted to my ear.

(Frans)

### **12.5.3 Participation**

#### *Community integration*

Frans did his own shopping. He visited his sisters and brother from time to time, but seemed not to enjoy these visits and seemed to be excluded from conversation, as a result of his hearing challenge but also due to attitudes:

It is never nice when I am with other people, even with my sisters. I just cannot get it to go well. When the sun goes down I think I must have been with the boss (“*baas*”<sup>17</sup>).

When they talk then I think oh I should have been with the boss. When the night is over and the boss comes to fetch me then the goodness start again. If I do not hear the boss tells me what and what. When I am with people who do not know my problem they may say, if you are deaf leave it be. Maybe they talk soft and when I ask again they do not feel like saying the same thing twice. (Frans)

The farmer also indicated that piece workers who visited the farm such as shearers sometimes mocked him.

#### *Employment*

Frans had been working for the last 15 years for the same employer as a farm labourer. While his hearing did cause some challenges they have overcome this:

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<sup>17</sup> Common form of address used by South African farmworkers when referring to farmers, especially before 1994.

If his back is to you it is a struggle. I have made peace with it. I wait till he turns around and look at me then I show him come. We are used to it. (Farmer)

Two tools assisted in communication. The one was written lists with jobs to be done and the other was a two way radio that Frans could hear.

### *Dependent on farmer*

The findings indicated a connection between Frans and the farmer, but also vulnerability on Frans's side:

“I am never leaving. I will stay there [on the farm]. The boss helps me if I cannot do something. The boss helps me with everything. Without the boss I am nothing. I only want to be with the boss. (Frans)

Some mornings when I get up I cannot hear a thing. Then I become full of fear and I think today is the day that the boss says ach no. Then I will be finished, because with other people I cannot hear. (Frans)

The farmer called him a part of the family:

. . . he is a part of us. He is on the family photo and everything. (Farmer)

## **12.6 Discussion and Reflection**

Frans impressed me as a strong, assertive man who knew what he was about. The only vulnerability he showed was in his relationship with the farmer. Here was a man on whom he was dependent, not only for work but to intervene in the hearing world on his behalf. While he showed little concern about negative attitudes and little contact with his family he worried that the farmer might get tired of him and his hearing problem.

Whether this vulnerability was based on anything substantial that did not show during the interview was impossible to ascertain. The farmer did not indicate anything of that nature. Frans

did not provide reasons for the fear, but then if the vulnerability was based on a veiled threat or even more overt actions Frans would not be able to disclose it to me in the presence of the farmer. As already indicated using the farmer as a translator was not an optimal choice. However, as also indicated, the farmer and his wife were the only people who could act as translators. Based on the findings that Frans has been working for 15 years for him, that he was involved in his health care to the point of making appointments and paying for consultations, and Frans' own indication that he experienced goodness when being with the farmer, I would say his vulnerability was related more to personal insecurity than facts.

Being dependent on the farmer for translation left Frans socially isolated. He lived in a community where farmworkers and farmers did not mix with ease socially. Thus the farmer would most often not be present in social situations where Frans mixed with his peers. However, Atkinson (2007) indicates that farm workers in remote settings might form closer relationships with their employers than with peers. According to her the relationship between farmer and farm worker, while often paternalistic, might exceed traditional employer-employee boundaries. Similar to findings of this case study she describes farmers providing support in issues of health care, transport, communication and finances.

It seems to me that the health care services and rehabilitation that Frans received were suboptimal. Frans described a service that he found unacceptable and made him reluctant to go back. The unacceptability he experienced might have been caused by unavailability of resources such as a computer as well as stressed and overworked staff. The farmer and his wife assisted to facilitate better health care access. They provided transport and finances for private consultations when public services seemed to fail. The therapist who thought she knew him remembered him because she remembered the farmer's wife calling about him. However, this did not seem to have the desired effect. His hearing device was still not fitted and he did not have an operation. It seems as if he was at least partially to blame for this. Whatever his reasons he seemed unwilling to have the operation. Maybe he was afraid of losing what little hearing he had. Or it might be that the surgery and what it entails was not fully explained to him. Maybe he was overall happy with the quality of his life (he did indicate his physical health to be good and his mental health to be very good in EquitAble survey data) and thus not willing to face

uncertainties, travel and strange environments and deal with a service that he was on the whole dissatisfied with.

He had once reached a point where he chose to walk away from services, and at the time of the interview seemed unwilling to access further services. I listened to many stories of ongoing dissatisfaction with government health care services during data collection for this study, as well as during qualitative data collection for the EquitAble study, and it led me to wonder why people go back if they are so dissatisfied. I concluded that it was dependence and lack of choice. But Frans seemed to choose deafness above the challenges and risks of assistance from government health care. In this I think he provides an example of a person with an impairment who chooses not to have further medical intervention even if that intervention might improve the impairment; a choice that was described in the literature review and which must be respected by service providers and significant others.

## **12.7 Conclusion**

The study findings raised concerns with regard to provision of PHC and rehabilitation. I was left with questions about the responsiveness of public health care services, the quality of treatment and the functionality of referral systems. In addition, surgery to modify the impairment was not done and an assistive device to compensate for loss of function was not fitted. It seems that Frans is at least in part responsible for these challenges.

Frans was his own man, independent; he showed this through his assertiveness regarding health care services. However, as discussed, he had one vulnerability: his dependence on the farmer. Imagined or true he feared the farmer might end their relationship and what that would mean to him. The farm and farmer offered much more than employment to him. It was a sanctuary. The farmer was his connection with the hearing world.

In the final two chapters of this section we meet Gert, a boy with visual, hearing and intellectual challenges as well as Hans, a boy with intellectual challenges.

## Chapter 13

### Gert's Story

#### 13.1 Introduction

Gert was a 10 year old boy who impressed me at first sight as physically active and healthy.

#### 13.2 Sampling and Sources of Information

I included Gert as a study participant because the EquitAble survey information indicated that he had a visual impairment and was in school. I found this inclusion in a mainstream school in a rural area positive and I wanted to explore the situation. Data were collected through four interviews and the focus group discussion with therapists. I interviewed Gert, his mother, his mother's sister, in whose care he was in the afternoons after school, and his class teacher, all separately. The first interview was with his mother. I was perturbed during and after this interview. Gert's mother seemed unwilling to talk to me. While she did sign the consent form she came across as sullen and uninterested, maybe even depressed. I suggested that we stop the interview, but she said she wanted to continue. After this interview I felt that I had so little data that I considered not continuing with this case study. However, reflection made me realise that the information added important insights and must be explored further.

I made an appointment to interview Gert at his aunt's house. Since Gert was a minor I wanted his mother to be present during my interview with him. She refused saying that she was going to sleep and gave me written consent that I could speak to Gert without her presence. Despite our appointment Gert was not home and his aunt did not know his whereabouts. I visited her house one more time and again she could not tell me where to find Gert. Thus I went to the school, interviewed his teacher and ask if I could interview Gert at school. The teacher agreed and I interviewed Gert at school, on the playground, where he was at ease, but after break so no other children could observe or distract us. In addition to the interviews one of the therapists in the focus group discussion knew him and provided information. Furthermore his teacher gave me a

speech therapy report and the referral she wrote to the school psychologist. Demographic data were sourced from the EquitAble survey findings.

### 13.3 Background Information

Gert attended one of the two public schools in town. He was repeating Grade 3 and the teacher indicated that he was not progressing. The quality of Gert's schoolwork was inconsistent and both his aunt and teacher referred to an improvement at the beginning of 2012 with a subsequent regression. Gert was passionate about rugby; enjoyed playing it and was apparently good at it. His afternoons were spent playing with friends.

Gert's mother worked during the day and his father was a long distance truck driver who came home one weekend every fortnight. He has a younger brother of three years old. Gert spent most of his time after school with his aunt. Gert said that he liked his mother and that he prefers to be with his mother rather than his aunt.

### 13.4 Emerging Themes

I identified three superordinate themes, the first two through abstraction and the third one through polarisation, as presented in Figure 13.1.



*Figure 13.1.* Superordinate and emerging themes identified in Gert's case study

#### 13.4.1 A conundrum of impairments

Nobody that I interviewed thought Gert was disabled or sick. However, the participants described varying impairments. Gert and his family described a visual impairment with physical



signs like redness and weeping of the eyes and possibly having an impact on schoolwork such as an inability to write correctly from the black board:

I struggle to see when I sit in the back of the class. I can see in my book but not on the board. (Gert)

There is a problem with his eyes, because he writes stuff incorrectly from the board. He cannot see on the board. This hampers his schoolwork. He can read but not correctly. He cannot write his words and letters. He confuses letters. His eyes become bloodshot and weepy in the sun when it is hot. His eyelids stuck together in the mornings, because his eyes weep at night. It has been like that since he was a baby. (Mother)

He was born like this. My mother knew about his eyes, but she is dead now. She bought him dark glasses that helped. (Aunt)

Gert and his aunt also referred to a hearing impairment:

I cannot hear on the one side. I pushed a wad of paper into my ear. More than a year ago. (Gert)

In addition Gert complained of severe headaches.

His teacher said there was nothing wrong with his eyes and ears and his problems were cognitive and behavioural in nature. In her report to the school psychologist she described a boy who impressed one verbally as intelligent, but who struggled with elementary mathematical and literacy skills like counting to 20, naming shapes, confusing letters and being unable to connect sounds and form a word. During the interview she said:

I did not pick up that anything was wrong with his eyes. He can see on the board. He sits in front and can see well. He confuses sounds. He can sound but cannot put the sounds together into a word. He is inconsistent. It was better in the beginning of the year. (Teacher)

For her, behavioural challenges were the main concern:

Behaviour, terrible behavioural problems. Aggressive, impertinent. He does not listen when you talk. Daydreams, does not know where he is. He will give you any answer, anything that he is thinking of at the moment. He shows no respect. No matter who you are. (Teacher)

The teacher connected his behaviour to problems at home, but did not expand on this except to say that his parents were not involved in his schooling, since his mother did not keep appointments with her or sign forms when required.

His mother also identified behavioural challenges and said he was:

. . . defiant and quarrelsome. I struggle with it. He is cheeky. Does not want to listen. (Mother)

She did not connect his struggles at school to the negative behaviour that she described. But she did indicate that she did not know how to manage his behaviour.

The adapted set of Washington Group Questions (WGQ) used in the EquitAble survey identified a severe problem with vision, but no hearing or intellectual impairment (His mother is listed as the respondent).

The various impairments were addressed in the following ways:

- The teacher referred Gert to the school psychologist and speech therapist. The speech therapist's notes indicated that he attended group sessions with her, that she found him and the rest of the group pleasant to work with, but that they made little progress due to limited time. She did three sessions over eight weeks in 2011 and indicated a need for further intervention. However, speech therapy input for Gert was terminated at the end of 2011 since the high numbers of children in need of this service caused the speech therapist to prioritise:

I see approximately five per group. It gets difficult to control the children when the group gets bigger. Thus you have a limited number . . . we sat and decided we will give preference to those who only struggle as opposed to those who had already repeated a year. It is very difficult to determine who you help and who not. But you have to try something somewhere. That is why he [Gert] is not a part of the group this year.

(Therapist 1)

She could not recollect Gert in enough detail to answer specific questions:

- His mother previously took him to the CHCC where he received ointment for his eyes and headache tablets. She said that this helped, but that she did not go back the CHCC to have the prescription renewed when it was finished.
- His mother indicated that she wanted to get his eyes tested, but did not get around to it yet (Eye testing is done by private ophthalmologists who visited the community every three months. A test cost R100.00 at the time of the study and one had to pay for glasses should they be needed).
- The professional nurses at the clinic referred him to Calvinia to have the wad of paper removed from his ear, but his mother did not take him at the time of the appointment. She said the ambulance fee were too expensive (R35.00). His hearing was not tested.

#### **13.4.2 Environmental barriers**

Both health care and educational policies and services probably caused barriers to Gert's participation. Health care policy dictates that he should access private services for glasses. While the service provider does visit the community regularly and is thus available, users have to pay for these services which make it unaffordable for some users, including Gert. Furthermore the availability of speech therapist services was limited and it seems as if Gert did not receive the input that he required.

In addition, educational services caused challenges. Classes were big and this seemingly negatively impacted on student performance:

They had very few teachers the previous year. Thus there were 60 children in one class in grade three. So quite a few of them did not pass. (Therapist 1)

With regard to relationships and support I think he could have received more nurturance from both his mother and aunt. For whatever reasons they seemed to be less involved in his life than I would expect; a situation that might have led to him not accessing health care in a fashion that I deemed necessary for his impairments. Where they were involved the involvement might have hinderer instead of helped his progress in school:

I write everything nicely in a book and he has to copy it. He copies all wrong. Then I tell him to look carefully. Then it goes better. He can correct his mistakes. (Aunt)

The teacher said she knew someone did his homework for him because of the nature of the sentences. It seems like his teacher tried different options to assist him, but she did not identify the hearing and vision problem which might be at the core of his struggles, and might have caused the behavioural challenges.

### **13.4.3 My experience of Gert**

This final theme was identified through polarisation (Smith et al., 2009). The difference between the boy I interviewed and how the adults in his live depicted him was startling. All three of the adults I talked to painted a picture of an aggressive, rude boy. They felt that Gert would probably refuse to talk to me. Then I met him. What a pleasant surprise. He looked at me with bright eyes full of life. He smiled and I saw two beautiful dimples that he kept showing to me throughout our talk. He sat with me and openly answered my questions. This person in front of me was so far removed from the boy described to me, the difference was so surprising that I was sure I was talking to the wrong child and asked him his name again halfway through the interview. But no, this was Gert and his answers about his life experiences correlated with that of the adults. He admitted that he angered easily, but showed none of the expected rudeness or anger during our interview. Behavioural problems can be variable, episodic, and/or related to a specific situation or pressure to achieve (Kaufman & Brigham, 2010). Thus while I have not

seen the behaviour challenges described by the adults in Gert's life I believe these to be present and problematic.

### **13.5 Discussion and Reflection**

On initial reflection I thought the teacher was correct and Gert's impairment was intellectual in nature. I thought his mother and aunt reduced it to something physical like eyes and ears, because that is more concrete. I still think cognitive ability or a condition like dyslexia are important issues to keep in mind. However, Gert's impairments were not only of a cognitive nature. His eyes did show physical signs and he had a foreign object in one ear. Vision and hearing impairments can account for the headaches and some of the challenges he experienced in school. Visual and or hearing impairments can in some instances be addressed with basic intervention which in turn might improve classroom performance (Parnes et al., 2009). The possibility exists that a lack of early diagnosis and intervention might be seriously hampering Gert's scholastic performance, which in turn might be causing the behavioural challenges described (Rutter, 1975). Without a comprehensive assessment it is impossible to pinpoint problems and determine the appropriate intervention.

According to his mother she could not afford accessing diagnostic and intervention services. Triangulation of information from other sources confirmed the cost of eye testing and spectacles, but did not confirm the cost of transport to the secondary hospital. According to CHCC staff, accounts are raised for the transport if users cannot pay the fee and very often the fee is waived. I am also surprised that he needed to access secondary services for the removal of a foreign object from his ear. I would have thought the professional nurse or outreach doctor able to do this at the CHCC. This information, in addition to the findings that his mother did not take him back to the CHCC to renew a prescription that helped him, lead me to surmise that maybe his mother did not ensure that his health care needs were addressed as timeously as they should have been. In addition, the teacher painted a picture of her being uninvolved in his schooling. In my interview with her she came over as distant and depicted Gert in a negative way. She seemed unable to deal with his behaviour, to provide nurturance or to discipline him. His aunt, in whose care he spent most of his time, provided food and a bed, but seemingly little structure and

guidance to his life. She did his homework for him. While this might have completed the immediate task, it would not help him to progress academically.

According to Rutter (1975) behavioural challenges in children may be associated with suboptimal parental involvement, family disharmony and problems with discipline, poor socio-economic circumstances and living conditions, a history of parental criminal offences or psychiatric disorder, and conditions at school. Children need stable, nurturing relationships with adults in order to develop to their full potential. Their cognitive, emotional and social abilities are intertwined and dependent on early nurturance and development (Rutter, 1975; Schonkoff et al., 2012). Thus the lack of parental controls as well as what I viewed as a possible deficit in nurturance might provide another explanation for the scholastic and behavioural challenges Gert experienced.

The support and assistance of Gert's mother and father is crucial to assessing and addressing his impairments. His mother seemed uninterested. I thought she might be depressed and checked the EquitAble survey data, but she did not report any depression. Thus if she was depressed she did not recognise it or did not admit to it. On the other hand her reaction could be due to despondency born out of a situation that she did not know how to handle. It might be that she did not know how to deal with Gert and the challenges that he represented. That might explain the lack of action in certain areas that seemed like neglect on the face of it. Maybe it was the fact that her husband was on the road and not home enough to assist with the children (Rutter, 1975). Whatever the reasons for his mother's behaviour I think she needed support and I do not know of formal support systems in the community that could assist her. In addition, whatever the reasons for his struggles in school his story confirms McKenzie et al.'s (2013) opinion that mainstream schooling in South Africa currently does not equal full inclusion since it does not respond to the support requirements of individual children.

### 13.6 Conclusion

It seems to me that environmental barriers such as insufficient access to health care, therapy and assistive devices, insufficient support at school, poverty and a lack of love and nurturance were at the core of Gert's challenges. None of his impairments were fully assessed. Any one of a combination of them probably led to poor academic performance and behavioural challenges. If things continue like this Gert might exit school without being able to read and write properly. It seems as if Gert can benefit from School-based PHC services, which are being re-introduced in South Africa, and focus amongst other things on reducing health barriers to learning through basic screening for vision, speech, hearing, fine and gross locomotor problems (Matsoso & Fryatt, 2013). In addition he could have benefitted from the screening and support services that ward-based primary health care outreach teams can provide. Such teams have not yet been deployed in the study setting.

One area that particularly concerned me was that his mother and aunt did not seem to identify any cognitive challenges. Therefore I introduced Hans into the study to see if I could replicate the finding where a mother did not identify cognitive disability (Yin, 2009).

## **Chapter 14**

### **Hans's Story**

#### **14.1 Introduction**

Hans was a 13 year old boy in grade four with cognitive impairments.

#### **14.2 Sampling and Sources of Information**

I identified Hans as a study participant through convenience sampling (Domholdt, 2005). I approached a teacher known to me and asked her for the name of a child in her class that struggled with schoolwork due to what she thought was cognitive challenges. She provided the name of Hans, indicating that she knew of many other children, but that she was especially worried about him. Information came from two interviews; one with Hans and his mother and one with the teacher. His mother tended to answer questions with one word or short sentences. The interview was short and literal. No descriptions of feelings could be elicited.

#### **14.3 Background Information**

I found Hans to be very shy. He responded to questions with a nod or shake of the head. During the interview he hid behind his mother, who was sitting on a bed, tucked his head into his chest and glanced at me from underneath. Physically he was very active with arms and legs constantly moving.

His teacher described a silent child who experienced challenges at school:

He does not communicate with a person. He has now been in my class for four months and he has not had one conversation with me. He only nods his head.



We are not doctors, we cannot diagnose, but I think he has got FAS<sup>18</sup>. I see the signs. His eyes are too close together. He has no attention span. He does not laugh aloud, only shows his teeth. Emotionally unstable, crying a lot initially. That improved. He does not write, it is a scrawl. He needs lots of input. He stands there shyly. For him to scream and shout and run around is an achievement. He can be accused of things, because he does not defend himself. Life lies before him. I am afraid for him. What about bullies? When he is accused of something that he is innocent of he withdraws into himself. They will make him a scapegoat. (Teacher)

She described his schoolwork as follows:

He works in a grade R work book. Name, surname, draw yourself. But it is expected the child is on grade four level. I do intervention. When the other children go home he stays till 3 o' clock. (Teacher)

One on one attention did seem to bear fruit:

At his desk all [writing] is just black and careless; when he sits with me it is pretty. I see him relax when he is on his own with me. The special attention is good for him. He cannot give his best in the class room situation. (Teacher)

In the teacher's opinion he should have been in a support class:

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<sup>18</sup> Four criteria must be met for a diagnosis of foetal alcohol syndrome (FAS):  
“. . . a characteristic pattern of minor facial anomalies including at least 2 or more key facial features (palbebral fissures, thin vermilion border, or smooth philtrum); evidence of prenatal and or postnatal growth retardation; evidence of deficient brain growth; confirmation of maternal alcohol consumption" (May et al., 2013, p. 820).

"Other organ systems are also involved in FASD. Ocular problems including impaired vision, optic nerve hypoplasia, and retinal vessel tortuosity have been described. Auditory and vestibular systems can be affected, causing delay in maturation, hearing loss, and vestibular dysfunction. Intelligence suffers as a result of prenatal alcohol exposure. Functional MRI has revealed differences in spatial working memory, verbal working memory, verbal learning, sustained attention, and response inhibition in children with FASD." (Pruett, Waterman, Hubbard, & Caughey, 2013, p. 64).

We had a support class where these children were assisted. I get angry and sad. I want to cry about the support class. [Tears in her eyes]. (Teacher)

The school psychologist did see learners but according to the teacher his focus was not on counselling. He only had enough time to write reports to motivate for learners to repeat a class.

By his own admission from the shake of a head and his teacher's observation, Hans played little with other children and tended to be on his own.

Hans's mother had a grade seven education according to EquitAble survey data, but could not read and write. She was unemployed. She struck me as much older than her years with a lined and scarred face. She struggled to answer my questions and I had to phrase them in a concrete manner. She admitted to drinking alcohol while pregnant with Hans:

R: Did you drink while pregnant with Hans?

M: I did but not much.

She could not quantify the amount that she drank. The family lived in poverty. With her partner doing odds jobs and she not working the only steady income was the R750.00 in the form of child support grants for her three children. This money sustained a drinking habit of both parents and had to buy food and other basic stuff. The mother indicated that money was often not enough: "It is actually not enough. It pinches (*"is maar so knap weg"*).

#### **14.4 Identifying Cognitive Impairments**

Hans's mother did not indicate that he experience cognitive challenges in the EquitAble survey. During the interview with me she confirmed that she thought he had no problem. She further said that he was no different from his brothers.

Hans's mother told me he was in Grade three whereas he was actually in Grade four. She did not know the name of his teacher and indicated that she had no contact with the school or teachers. This was confirmed by the teacher who said she never attended parent teacher meetings or approached her. His mother said she could not help Hans with his homework since she was

illiterate. The teacher said that no homework had been done in the three months that he was in her class. The teacher painted a picture of a boy who would not be able to do the homework without assistance and his mother by her own admission could not help with it.

#### **14.5 Discussion and Reflection**

This case replicates (Yin, 2013) the finding from that of Gert, that parents in the study community did not identify cognitive disability. In addition, Hans's mother indicated that he was no different from his brothers. It might be that his mother does not have the ability to distinguish subtle differences in cognitive functioning between the boys or it might mean that his brothers also experience intellectual challenges that have not been identified. One cannot extrapolate these two cases to the population. However, the baseline report to the United Nations on the implementation of the UNCRPD in South Africa also indicates high instances of undiagnosed intellectual impairments in poor and rural communities (DWCPD, 2013). In addition, Schneider (2012) indicated that increased age, low levels of education, poor socio-economic status and speaking Shangaan (one of South Africa's official languages) might negatively impact the ability to answer the WGQ on remembering and concentrating, which is used to determine intellectual disability. The ability of the Washington Group Questions (WGQ) to identify intellectual disability in diverse communities is important since the South African census questions are based on the WGQ. If census questions fail to accurately identify intellectual disability in a community, prevalence figures might be misleadingly low with a resultant failure to identify and quantify needs and resources in this regard. Thus further quantitative research is necessary to explore the issue.

Furthermore, environmental and personal barriers hampered Hans's development. The poverty this family lived in did not support learning. Proper nutrition is one of the building blocks of brain function (Adnams, 2010; Schonkoff et al., 2012) and it seemed from data that it was often in jeopardy in the case of Hans and his brothers. In my opinion his mother did not have the skills to assist him with regard to intellectual development and providing learning opportunities, another building block of brain function (Schonkoff et al., 2012).

## **14.6 Conclusion**

The possibility that cognitive impairments are underreported in this community needs exploration since underreporting of cognitive impairment can lead to lower prevalence figures and thus the allocation of too few resources to manage it.

The final chapter on results contain the results of the focus group discussion with therapists.

## Chapter 15

### Focus Group Discussion Results

#### 15.1 Introduction

In this chapter the results from the focus group discussion with the three therapists who provided outreach services to the community is presented and discussed.

#### 15.2 Emerging Themes

The following themes were identified:

- Lack of knowledge on the role of therapists and rehabilitation.
- Functional focus of therapists' interventions.
- Compliance.
- Assistive devices.
- Lack of time.
- Communication between service providers.
- Community based rehabilitation.
- Role of home-based carers.
- Intersectoral cooperation.
- Monitoring.

##### 15.2.1 Lack of knowledge on the role of therapists and rehabilitation

According to the therapists, both users and professional nurses lacked specific knowledge about the role of therapists. They felt that not all users who could benefit from their services were referred to them:

It is like an extra little thing. If we are here, we are here; If we are not . . . (Therapist 2)

We struggle a lot with referrals. You try to create awareness of what you do. . . . I think my biggest task this year was to educate the sisters at the clinics. I am still doing it every day of my life. (Therapist 2)

It [education of service providers on the role of therapists] covers posters, talks, and one on one discussions with sisters. (Therapist 2)

The sister [at the secondary hospital] will say if you want the patient to stay for rehabilitation you have to wash, turn, clean and feed the patient [activities that will increase the workload of nurses if the patient stays in hospital]. They do not understand what we do. (Therapist 2)

According to the therapists late referrals negatively impact users' prognosis:

“It is very difficult. The longer you wait the more difficult it is to restore function. The sisters do not understand this. (Therapist 2)

They seem to feel that the education has not yet had the desired effect. Although one therapist who has been providing services to the study community for more than a year did see a difference:

There is growth. Definitely. It is slow but definitive. (Therapist 1)

Furthermore the therapists indicated that users might not always understand the benefit of therapy and seem to be seeking a cure:

I think they think the tablet you take, the medication will make everything better. (Therapist 2)

. . . one session will make me better, a quick fix. (Therapist 3)

Comes back to education of people and we can do that till we are blue in the face, but it does not seem to help. You win one or two. (Therapist 2)

### **15.2.2 Functional focus of interventions**

According to the therapists the focus of their interventions was on function:

To get them as functional as possible. For them to be able to move around in the house with a frame or wheelchair. We focus on what they struggle with in the house and how they can do things. (Therapist 3)

### **15.2.3 Compliance/adherence**

Therapists found some users non-compliant with regard to keeping therapy appointments and doing home exercises:

It is very difficult [to do rehabilitation]. Some patients come back and others just disappear. (Therapist 2)

I think they think it is unnecessary to exercise. The oral exercises might seem simple and I think they do not understand how that will help. (Therapist 1)

People are not compliant with exercises. We do not focus on that much. They do not remember exercises or the paper get lost. (Therapist 3)

Therapists could not provide possible explanations for what they see as non-compliance.

Not all users were non-compliant:

But there are people that come faithfully. It is often women who bring the patient. I think it is because if grandpa or their husband struggles with functional problems like walking then they are the people that struggle with that. Therefore they are sure to come to be assisted. To decrease the burden. (Therapist 1)

#### **15.2.4 Assistive devices**

According to the therapists, the provision of walking devices was adequate. As were the provision of hearing aids:

We get hearing aids. It is fitted once a month. The patient has to go to Kimberley for the diagnostic tests. We do not have a problem. It happens quickly. (Therapist 1)

The provision of wheelchairs seems to be more challenged:

You measure the person and send the application form to Kimberley. All applications go to Kimberley. Then you wait and see when you get it. They decide in Kimberley whose need is the biggest and who gets first. You can indicate on the form if the person will develop contractures or any other detrimental things that can happen. (Therapist 2)

Other devices and services were even more problematic:

We do not get splinting material. Patients have to go to Kimberley for a splint. No prosthesis. O&P [orthotic and prosthetic services] did not come this year. Not even after we phoned and decided on a date with them. (Therapist 2)

#### **15.2.5 Lack of time**

The therapists were aware of the limited time they spent in the community and how that impacted their service delivery negatively:

We lose a lot of time on the road. Four to five hours of the working day is spent driving. The time here is limited. (Therapist 2)

. . . we have so many referrals [at schools] that we have to see the children in groups. That is not ideal either. (Therapist 2)



### **15.2.6 Communication between service providers**

The therapists described a lack of communication between service providers and challenges with regard to the referral system:

A woman phoned this morning to say she phoned the clinic months ago to ask for an appointment with one of us, but nobody comes to see her. We have never heard of this woman. Thus somebody takes messages, but the messages do not reach us. (Therapist 3)

No we do not get answers back [from Kimberley]. We write letters, but the referral back is very poor. The patient cannot give feedback to you. Then you try to phone. But you cannot phone with the folder number only. You need an oncology or ENT number. Every department has a different number for the patient. (Therapist 1)

One of my patients went back to Bloemfontein for follow up after a year. But they refused to see her because she did not have a referral letter from Kimberley. She came back to me because she did not know who to ask in Kimberley. Now she will have to go back to Kimberley and they will not be able to get an appointment in Bloemfontein immediately. (Therapist 1)

### **15.2.7 Community-based rehabilitation**

Therapists could not provide examples of this in the study community and could not theorise on how it might be feasible in the study community.

### **15.2.8 Role of home-based carers**

The therapists were unsure of the role home based carers could play in rehabilitation in the community and were not aware of the presence of home-based carers in the community:

I do not know if they have a role. I do not know if there are any. (Therapist 3)

. . . will love it if there is someone to do it (children's group). You will achieve more even if it is not on the same level as when you do it yourself. (Therapist 1)

### **15.2.9 Intersectoral collaboration**

I had to explain the concept of intersectoral collaboration to the therapists and they could not think of any examples where this was happening. I see their outreach to the schools as an example of that:

. . . we go to the schools. To create work for ourselves. (Therapist 2)

### **15.2.10 Monitoring**

The therapists said that services were not monitored. In addition, they explained the following with regard to handover for community service therapists:

The therapists told me about the programmes that the previous therapist ran. She told me which programmes worked and which ones did not. She asked me with which projects I wanted to continue and what new projects I wanted to start. . . . we do not write it down. (Therapist 2)

There were no projects handed over with which we could continue. (Therapist 3)

## **15.3 Discussion and Reflection**

It seemed as if therapists focussed on individual persons and activity limitations rather than communities and community integration. Their focus was on improving functional abilities. I see this as a positive finding, in the sense that activity limitations were addressed and users should show functional gains. However the role of rehabilitation with regard to environmental barriers seems to be forgotten. This might be because services were mainly rendered at the CHCC. Thus function was addressed in a clinical environment where fewer barriers are encountered than in the home and community environment. Or it might be due to the severe time

constraints therapists faced. One can do very little in three to four hours per week and might then choose to focus on one aspect only.

A positive finding was the availability of walking devices and hearing aids, although the case study of Frans did not confirm the availability of hearing aids. The challenges with regard to wheelchair and prosthetic services were worrying. These devices are often necessary to ensure personal mobility. In a setting with no public transport and little private transport personal mobility is very important to ensure community access.

According to therapists' views, it seems as if both the community and the professional nurses at the CHCC showed limited understanding of the role of therapists and how rehabilitation can ensure community integration for persons with disabilities. This view is supported by EquitAble findings which showed that 40, 45 and 48% of persons with activity limitations in the community were not aware of physiotherapy, speech therapy and occupational therapy services respectively (unpublished data). The therapists felt that rehabilitation was seen as a non-essential extra, that users focused on a cure and if they were not cured they often stopped coming for treatment. However, this is the perception of the therapists and it seems as if they have not fully explored the reasons for what they see as user non-compliance since they could not provide other possible reasons for this behaviour. Van der Walt and Swartz (1999) have argued that users may use non-compliance as a passive way of expressing power over authority structures. It may be possible that users were unhappy with the service for one reason or another and thus chose not to come back instead of entering into a discussion on the issues that concerned them with service providers. In the Western Cape Province study by Maart and Jelsma (2013) 67.5% of participants indicated that they did not access rehabilitation services because they were unhappy with the services. Another possibility might be that users felt the gains during therapy were not worth the effort and cost (financially, emotionally and physically) as described by Grut et al. (2012). Especially since the functional gains one can expect in conditions such as stroke and traumatic brain injury from one 30 minute therapy session per week are very small, if any (Puckree & Uthum, 2013). Maart and Jelsma (2013) found that 37% of participants in their study stopped rehabilitation since they felt that rehabilitation did not lead to improvement. It is also possible that practicing functional activities in a simulated environment at the CHCC hold

little value in the day to day practicalities of life. Or in some instances it might be that spontaneous recovery negated the need for further intervention and that users were happy with the achieved level of function as also described by Maart and Jelsma (2013).

A related worrying aspect is the challenges regarding referrals. It seems as if professional nurses lacked knowledge on the role of therapists and rehabilitation and that could have led to the late or non-referral of some users. Late referral can impact patient outcomes negatively as pointed out in the focus group discussion and literature review. Other challenges with regard to referral services included fragmentation in referral systems, poor lines of communication and more than one hospital number used in the same facility. One hospital number should be adequate to access patient information from a different level of service. The communication challenges between various levels of service provision and between service providers can lead to loss of time as described, and impact service delivery negatively. It can lead to increased severity of conditions, increased cost and might lead to adverse health outcomes, and increased morbidity and mortality.

Another issue that is related to communication is handover between therapists from year to year. I would have liked a written report that therapists could go back to as needed. In addition, I would expect more guidance and supervision to community service therapists, both from more senior therapists at the secondary hospital and district and provincial rehabilitation managers. Giving community service therapists a choice of what they wish to do is good in the sense that it might allow them to do things they like and thus enjoy their work. However it might mean that aspects essential to the needs of a community are left unaddressed and that continuity is lost. Therapeutic input should focus on burden of disease in the community, be based on clear evidence based intervention programmes and be assessed through measurable outcomes. Services like CBR programmes require a commitment that continues over years. In addition, a junior therapist might find the lack of guidance unnerving and might struggle to cope. Another aspect that requires handover and continuity from year to year is the training of professional nurses and the community on the role of therapists and rehabilitation. If the emphasis is placed on different aspects and if varying expectations are raised every year it can cause confusion.

A final worry is the lack of monitoring of services. To provide effective rehabilitation within a reasonable budget service effectiveness, quality and relevance as well as client satisfaction with services must be monitored (WHO, 2010c). Without monitoring therapists have no way of assessing the impact of what they are doing and to identify aspects of the service that can be improved on.

#### **15.4 Summary**

The therapists described a service focused on functional ability that was hampered by a lack of referrals, time constraints, a lack of user compliance and communication challenges. In the next chapter I will present and discuss patterns across the cases.

## Chapter 16

### Identification and Discussion of Patterns Across Cases and Focus Group Discussion

#### 16.1 Introduction

The findings from the eight individual case studies and the focus group discussion were integrated to identify overarching trends in the data. In this chapter these trends are presented as superordinate themes across cases and discussed in relation to EquitAble study findings in this setting, the literature and their possible importance. The following superordinate themes were identified through the process explained in Chapter 6:

- Disability: Experience, conceptualisation, community integration and participation.
- The health care systems used by participants.
- Barriers and facilitators to formal health care access.
- Health care, rehabilitation and wellbeing for persons with disabilities.

#### 16.2 Disability: Experience, Conceptualisation, Community Integration and Participation

To a large extent participants did not use the Afrikaans word for “disabled”, did not identify with being disabled and did not want to be called disabled. This is in accordance with unpublished EquitAble findings where 54% of persons with activity limitations in the study community said no when asked whether they were disabled. Study participants’ reasons for not identifying with disability differed and varied, seemingly from a perception that disability is to be equated with lack of control, dependency and worthlessness, as expressed by Carel and Brenda’s grandmother, to a focus on abilities rather than disabilities and being able to contribute to the lives of others, as expressed by Anita, Dina and Frans. The above impressions concur with literature discussing reasons why many people with impairments do not see themselves as disabled (Clarke & Black, 2005; Iezzoni, 2000). As discussed in the literature review South Africans with disabilities need to be identified in order to access social benefits. But this identification is usually done by a

third party, such as a medical officer completing a disability grant application, and based on the presence of impairments and activity limitations. Thus there might be little advantage to identify with being disabled.

On the other hand calling oneself disabled in this community might have negative connotations because overall case study results pointed towards a focus on impairments and conceptualisation of disability as an individual construct based on the medical and moral approaches to disability. Thus disability might be equated with being sick, a lack of control over one's destiny, worthlessness, charity and pity and people might prefer not to identify with being disabled. Disability did not seem to be seen as a political or human rights issue, though some of the criticism of services expressed by participants could be seen as implicit commentary on socio-political and human rights issues. This is an interesting finding when one considers South Africa's rights based policies and high profile in international disability rights movements. It seems as if national and international developments in this regard have not reached many members of the study community. Possible explanations revolve around transport and access to information. EquitAble findings showed that only 6% of households in the community had access to the internet. While 60% had access to television only 6% of programmes by the national television service (the only free service provider) are primarily broadcast in Afrikaans (Dibetso & Smith, 2012). In addition there was no public transport in the community. Thus contact with neighbouring and more distant communities were very limited.

Carel, his family and Brenda's grandmother conceptualise disability according to the moral approach. It seems as if they perceived disability as a derogatory term and deemed a person with a disability worthless, an object of pity. They saw the causes of disability as supernatural and emphasised the fact that they did not bring it on themselves and could not help their condition. Historically persons with disability were seen as deserving of assistance and charity if they had no control over their impairments while those who were somehow seen as having caused the impairments were undeserving (Iezzoni, 2000; Mechanic & Tanner, 2007). The prevailing attitude seemed to be one of endurance of a bad situation. They appeared to be functioning below their abilities, did not participate in life roles and experienced poor quality of life as described in Chapters 8 and 9. Their conceptualisation of disability and limited participation

might be due to their extreme vulnerability. They were illiterate, had limited social support, suffered through deprivation and were of the poorest I interviewed.

I identified differing trends amongst those who conceptualised their disability according to the medical approach. Dina was apparently receiving high quality health care and was pursuing modification of the impairment. On the other hand Frans seemed less focussed on modification of the impairment even while findings indicated that this might be medically possible. This might be due to his expressed dissatisfaction with services or a preference to live with his impairment. Anita did not allow bodily impairments to dictate her future. She seemed to tap into spiritual, social and psychological resources that enabled her to lead a life of inclusion, participation and quality. She showed flexibility and found different ways to express herself, to be a significant part of the community and to play a role in others' lives. Even so her narrative spoke of a medical approach to disability. She was included because she overcame her impairments, not because societal barriers were identified and removed.

It seems as if support and attitudes of family, employers, and Christian leaders played a role in facilitating or hampering participation of study participants. Christianity and disability have a long often uneasy relationship, as described by various authors in a recent South African text (Claassens, Swartz & Hansen, 2013) as well as Grech (2009), Hutchinson (2006), Otieno (2009) and Scheulka (2013). According to Claassens et al. (2013) and Schuelka (2013) the Bible often portrays disability in a moral or medical sense as punishment for sins, an affliction to be cured or an opportunity for others to do good. However, as is shown by Claassens et al. (2013) and Hutchinson (2006), the connection between Christianity and disability is much more complex. Believing in God can provide succour in difficult times, and fellow Christians can offer acceptance, physical and emotional support. In the current study, the impact of Christianity could be seen in the way participants often described their impairments as an act of God, the belief that God could cure them, the acceptance of charity, and the strength gained from personal relationships with God. In addition, it seems as if Christian leaders in the study community played a positive role and assisted with humanising, acceptance and inclusion of persons with disabilities. They were mentioned in many of the interviews and their role was always reported to be one that facilitated integration in one way or another. Participants were treated as fellow



humans, could freely worship with congregations and even provided teaching. Separately, the actions of these Christian leaders may seem small, but collectively they may be important. Religious leaders can shape the perceptions and attitudes of communities and if they include people with disabilities congregations and communities might follow suit (Otieno, 2009).

Furthermore family members' attitudes and support or lack thereof impacted integration and participation of the person with the disability. Unsatisfactory relationships and negative messages about personal worth from those around one can cause poor self-esteem and lower levels of integration for persons with disabilities. The opposite is also true (Harrison et al., 2010; Hughes & Nosek, 2001; Ikaheimo, 2009). Examples of this were identified in the current study. Anita, Frans, Erik and Dina each had at least one person in their lives that believed in them and allowed them the opportunity to be all they could be. On the other hand Carel and Brenda had loving caregivers, but they inadvertently showed through words and actions that they thought the person different, less worthy and not able to do things. The contrast between the attitude and actions of Brenda's grandmother and Erik's foster mother illustrates the point. Both of them loved and cared deeply about their charges. Erik's foster mother channelled her care and concern in a way that allowed him participation. She guided him during shopping and helped him believe that he had the right to be a customer like everybody else. She assisted him as a job coach, in the process giving him the opportunity to earn his own money and experience the satisfaction and worth of being employed. Brenda's grandmother on the other hand avoided people who asked about her, did not expose her to life and did not built her confidence.

Two other variables that might have played a role in the level of inclusion seen amongst participants were gender and the agrarian nature of the community. Women experience feelings of worth when they are socially connected, participate in mutually meaningful relationships, and can help and nurture others (Hughes & Nosek, 2001). Anita and Dina were socially connected, participated in meaningful relationships and helped others. On the other hand men, especially those living in rural communities, often place value on physical attributes and doing physical things (Elliot-Schmidt & Strong, 1997; Ingstad, Baider, & Grut, 2011). Furthermore in some ways the current study participants lived in a complex throw-back to earlier agrarian societies. Technology and intellectual pursuits existed on the fringes of their lives and had very little

impact on daily tasks and their economic realities. As with pre-capitalist agricultural communities (Schuelka, 2013) theirs was a physical existence where disability was measured against the ability to perform physical labour required by the role agriculture played in the economy of the community.

Thus the difference in physical abilities might account for the differences in feelings of worth and satisfaction Frans and Carel experienced. Frans's impairment left him able to do his work as a farm labourer. Carel's paralysis seemingly prevented him from doing this and might have precipitated the feelings of frustration and worthlessness. I say seemingly, because with the identification and addressing of environmental barriers and through suitable accommodations he might have been able to overcome the environmental barriers he faced and perform many of his previous roles on the farm. Addressing these barriers would require him, his employer and the community to conceptualise disability according to an approach that encompasses the impairment as well as the environment, such as the ICF.

In communities where the focus is on physical powers, intellectual impairments create fewer barriers and even went unnoticed at times (Grech, 2009). In addition, children with mild intellectual disabilities are included in the everyday life of rural communities (McKenzie et al., 2013). This was also seen in the current findings. An intellectual impairment did not prevent Erik from being employed. Gert and Hans had intellectual impairments according to their teachers and the speech therapist. However, their mothers did not identify these, and they were integrated in the community. It is possible that mild intellectual disability is rather common in this community. Anecdotal information reveals that the prevalence of FAS is high and has been high for many years. In addition the community experiences high levels of poverty which might lead to malnutrition and a lack of nutrients essential for intellectual development. Furthermore the children have few toys and little intellectual stimulation before they go to school. These are all factors that can negatively impact intellectual development (Adnams, 2010). However, the prevalence and possible risk factors and causes of intellectual impairment in this community are outside the scope of this study and must be addressed in future research.

In summary it can be said that personal attributes, attitudes and support from others, and the agrarian context impacted the conceptualisation of disability and participant's level of community integration.

### **16.3 Health Care Systems Used by Participants**

The findings indicate that participants relied strongly on formal health care and used other health care systems in the case of less serious ailments, in conjunction with formal care or when formal care was not forthcoming. Some participants used home-made herbal remedies, off the shelf medication and faith healing in conjunction with formal health care. Two participants connected the impairment to sorcery, but neither of them accessed a sorcerer or spiritual healer for healing. EquitAble findings showed that 8% of persons with disabilities and 7% of persons without disabilities in the community needed or accessed the services of traditional/spiritual healers. This might be due to this being a predominantly coloured and white community while folk medicine are more often used by the Black population groups in South Africa as indicated in the literature review. Further explanations might revolve around cost, availability and transport. As indicated in the literature review folk medicine might be more costly than government subsidised health care. Carel said that he did not know where to find a folk healer and according to qualitative EquitAble data there was no folk healer in the community. Thus community members would need transport to access a folk healer.

### **16.4 Health care access**

Study participants accessed primary, secondary and tertiary health care at various times, indicating that some services were available at all three levels. Quantitative EquitAble findings show that 92% of both persons with and without disabilities in Fraserburg felt they received health care services the previous time they needed it. Thus it seems as if persons with disabilities did not have poorer access to health care than their non-disabled counterparts. However current study findings indicated that the quality of the services that were provided varied and often did not meet the needs of study participants. The study findings further created the impression that the challenge were not related to persons with disabilities per se, but that all members of this rural community who access public health care might experience problems and might not receive

care that is consistently of a high standard. EquitAble findings as described by Visagie & Scheffler (2014) support this impression. This might be true for other rural areas in South Africa as well since challenges are similar. No other South African studies that compare health care access for persons with and without disabilities could be found.

Iezzoni (2013) indicated that persons with disabilities are vulnerable to small failings in health care service provision and might provide early warning of challenges that exists. In this instance I think the challenges are clear and affecting all. However, those with disabilities are affected more than those without disabilities due to a greater need for more complex interventions amongst persons with disabilities as described in chapter 5 and seen in the case studies. Eide et al. (nd) shows that for EquitAble study participants the probability of not receiving health care as needed increased with severity of disability (0.07 for those without activity limitations to 0.19 for those with severe activity limitations).

Living in a rural area might have added to the challenges. Persons with disabilities often require input from highly skilled health care professionals from various professional groups. Both skills and availability of service providers are more lacking in rural than in urban areas of South Africa as discussed under 4.4.1. In addition referral services are not as easy to access due to distances and transport challenges as described under 4.5. Thus persons with disabilities in the study community and possibly other similar rural South African communities have less access to the skilled health care services they require than their urban counterparts. Health outcomes of persons with disabilities might have been poor not because persons with disabilities per se received poor health care in this community. All members of the community are at risk for less than optimal health care, but the more complex needs of persons with disabilities leave them at greater risk and in need for more intricate intervention and greater access to allied health care services which were not forthcoming.

## 16.5 Barriers to Formal Health Care Access

### 16.5.1 Health care system barriers

According to study findings, service availability and acceptability were negatively impacted by a variety of systems barriers. My analysis leads me to conclude that the overarching causes of these systems barriers may be related to a lack of resources and the paradigm according to which services were delivered.

A lack of resources was apparently experienced in many ways. For example, few human resources led to situations where only one professional nurse was on duty and users had to wait long periods of time or return home unseen. Therapists had to prioritise and decide which users received treatment and which ones did not. Medication shortages were described by Anita and by numerous participants (users, providers and key informers) in the qualitative EquitAble phase. However only 4% of persons with disabilities and 2% of persons without disabilities indicated shortage of medication as reasons why they did not get health care when needed in the quantitative phase. Users did not receive consumables such as disposable nappies or nutrition supplements. Users could not ask for second opinions. The impact of being overworked and not being able to provide users with the service and products necessary to assist them might have decreased the morale of service providers and could have led to unacceptable services as discussed in the cases of Anita, Brenda and Frans. EquitAble findings showed that 26% of persons with and 30% of persons without disabilities were dissatisfied with the provision of health care services to the community.

Scarce resources are part of the nature of health care service delivery in South Africa and especially rural South Africa. But Cooke et al. (2011), Gaede and Versteeg (2011), and Versteeg et al. (2013) have made the following suggestions for increasing the number of service providers in rural areas:

- Prompt appointment of professionals.
- Improve support structures for rural service delivery.

- Recruitment targets should be part of management agreements and assessed against norms.
- Improve occupation dispensation scaling for doctors.
- Assess the impact of occupation dispensation scaling on recruitment and retention of nurses.
- Give preference to rural areas when placing community service workers.
- Prompt, practical orientation of community service workers.
- Recruit students from rural areas since they are more likely to return to rural areas.
- Locate tertiary training facilities outside major cities.
- Novel approaches like facility-based mentoring and web-based learning to continued professional development.
- Provide career development opportunities.
- Allow flexibility with regard to scope of practice.

In my opinion, the reactive, curative focus of services put further strain on the limited resources. Results suggest that the philosophy of PHC, as presented in Chapter 3, was not employed in this community. Findings from various case studies implied that:

- Health care services were not able to deal with all the health needs of users. Common, recurring ailments were cured, but the causes of these ailments were not explored or addressed through preventative strategies. In addition, it seems as if little attention was given to health promotion and prevention of secondary complications. No evidence of lifestyle activities to ensure good health as described in Chapter 5 or activities focussed on the prevention of secondary complications associated with the various impairments were found. Eric received no advice on lifestyle modification. Carel developed secondary complications that decreased his function and could probably have been prevented (Bromley, 2006). Brenda's numerous acute chest infections and stomach upsets were treated. However, the underlying cause which might have prevented the acute incidents was seemingly not addressed. Her grandmother was not taught postural drainage or basic chest therapy procedures. These are uncomplicated activities that can

be done at home and are effective in the draining of secretions and thus reducing chest infections. This focus on curing acute conditions, mainly through the provision of medication, might have increased workload and pressure on resources as conditions recurred as in the case of Brenda.

I base these assumptions solely on information from users and the focus group with therapists. Other service providers might disagree and it is possible that where education of users was provided, users did not understand or remember this. This would imply that education was not done in enough depth or in a manner that users could understand. The important issue is that the results showed that some users could not manage their health conditions and impairments optimally. In addition findings suggest that a lack of development and “appropriate education” might have left users unable to participate in “planning, organization, operation and control of primary health care” (Declaration of Alma-Ata, 1978, para. 7). Therefore there is either a need to do training and education of users, or if it is being done, to change the way in which it is done to ensure that users fully understand and retain the information.

- Users were not included in the management of their health conditions.

Users described a situation where they were not consulted by service providers and could not participate optimally in their own health management. Frans, Anita and Brenda’s grandmother, felt their health problems were not addressed optimally and had suggestions on how this could be improved. From their narratives it seems as if service providers were not open to these suggestions. Thus it seems as if health care was not patient centred. This might be related to a lack of human resources, which could have led to short consultation times and thus little time for the communication needed for patient centred care. Another possible explanation might be related to the paternalistic way in which health care services were traditionally provided in South Africa. Both service providers and users believed that the provider knows best and should tell users what to do. From this legacy providers might find it difficult to change to a more client centred way of service delivery and some users might find it difficult to ascertain their right to be involved in their own health care. Additionally providers might use splitting and

distancing in order to protect themselves from emotional involvement with users as discussed under 4.4.2.

- Referral systems, while present and used, were not functioning optimally. The case studies created the impression of isolated interventions and actions at different levels that did not form a cohesive whole and did not ensure seamless transition of care between different levels. Communication between levels of service delivery seemed challenged, as described by therapists and deduced from user narratives. Descriptions of high quality diagnostic and curative procedures at tertiary level were given, but it seems as if comprehensive management and follow up strategies were not always provided or adequately communicated to primary level. I cannot be sure that this assumption is correct without access to client folders.

Referral systems and resources might also have been challenged by rigid organisational protocols. Health care users from Fraserburg first travelled west to Calvinia and then northeast to Kimberley, a circuitous route that added hours to the travel distance, time and cost (see Figure 6.1). Cape Town is more than 300km closer to Calvinia than Kimberley. Fraserburg residents preferred tertiary services from the Western Cape to those of the Northern Cape, a preference that could be seen in the choice made by Anita and her husband. This preference might be due to the shorter distance to Cape Town as opposed to Kimberley, a perception amongst users of better service delivery and/or having no social support system in Kimberley which they often had in the Western Cape, due to children and family moving to the Western Cape Province for studies and employment. However, users could not routinely access tertiary services in the Western Cape. Cooke et al. (2011), Gaede and Versteeg (2011) and Van Deventer et al. (2008) also identified challenges with regard to referral services and protocols:

- Essential drugs were not always provided.
- Doubts regarding the skills, both biomedical and social, of health care service providers were raised by the findings.
- Very little rehabilitation was provided (See 16.4.2).
- A food supply and proper nutrition was not always promoted.
- It seems as if early childhood development was not well addressed (See 16.4.2).



- Inequitable. In my opinion Dina was the only participant who received health care according to her needs. This was provided in an expensive tertiary setting far from her home, and the lack of community integration that such services are criticised for (Bury, 2005) is seen in her narrative.
- Since the study focused on health care the involvement of sectors other than health was not specifically explored. Thus I cannot assume that there was no involvement. In addition, I did not gather information on whether services focused on underlying social, economic and political determinants of ill health, safe water and basic sanitation were supplied, maternal and child health care were provided, immunisation against major infectious diseases, and prevention and control of locally endemic diseases were done.

In summary, conceptual changes in the way that services are provided might decrease the curative load in this community and improve health and functional outcomes for study participants and the rest of the community. However, even if service providers change their focus towards providing health care the PHC way and rehabilitation according to CBR principles (WHO, 2010a) they will struggle to provide high quality inclusive PHC because of a lack of resources. While implementation of the principles of PHC should reduce the curative burden it will not remove it. Thus more than one professional nurse per day is needed. Especially in the initial phases where longer consultations will be required to educate and empower users, while professional nurses will also need to step out of the CHCC and engage with the community and determinants of ill health. Similarly, more therapist hours are needed in the community if they are to embark on an effective rehabilitation programme.

### **16.5.2 Barriers to rehabilitation**

Similar to health care in general, rehabilitation service delivery to the study participants apparently suffered from a lack of human resources, and the way in which services were delivered. Therapists were providing an outreach service to the community once a week for four hours. This seemed to be inadequate. Participants reported seeing therapists very seldom and therapists had to prioritise, as was shown in the case of Gert. In addition, it seemed to me during the focus group discussion that therapists did not see themselves as a part of this community.

This is understandable since they live 200km away and spent four hours per week in the community, but this might limit their commitment to finding solutions for the community's rehabilitation needs.

According to therapists, they spent the little time they had in the community on functional restoration. This is an essential component of rehabilitation and a good starting point. However, functional restoration was not adequate. Anita, Carel and Gert needed more assistance in this regard. The reasons why they did not get this assistance seemed to be multiple. It included aspects related to the users such as not seeking assistance from health care services and not keeping appointments. In addition, there were systems-related issues such as limited time and resources as well as providing a facility based service.

Study findings indicate that the South African national guidelines for rehabilitation at primary level (DoH, 2000b), as presented in Chapter 5, might not have been followed in the study setting. Primary, secondary and tertiary prevention was done sub-optimally. Assessment, development of management programmes as well as provision of assistive devices and consumables and training in their use were also found lacking. Challenges with regard to wheelchair provision possibly prevented Carel and Brenda from reaching optimum levels of mobility and function. In a community with no public transport, a wheelchair can ensure community mobility (WHO, 2008b) and thus access to health care, community activities, education and employment (Borg, Lindstrom, & Larsson 2009; Greer et al., 2012; UN, 2006; WHO 2008b). Spectacles might have aided Gert in school. According to therapists, hearing aids were available and Frans did have one, although donated, but it was not fitted.

Training and education of care givers and the community did not get the deserved attention. In addition no evidence of modification of the environment could be found in any of the case studies, and the therapists did not indicate in the focus group discussion that they gave attention to this aspect of rehabilitation. These strategies could have led to bigger functional gains, higher levels of community integration and prevention of complications that required acute health care.

A further barrier to rehabilitation service delivery as described by therapists was that in their opinion not all persons who could benefit from rehabilitation were referred to them. From the

focus group discussion and some of the case studies it seems that professional nurses, the community and people with impairments did not understand the role of rehabilitation and what it has to offer. The therapists said that they did training in this respect, but it seemed that the training had not yet had the desired effect. Assessing the effectiveness of the training was outside the scope of this study.

Early intervention, which is dependent on early referral, is important to minimise the effect of impairments, ensure optimal functional restoration and prevent secondary complications. A lack of early intervention is especially worrying in the case of the three children who suffered from various impairments including developmental delays (Bruder, 2010; WHO, 2010a, 2011), since early childhood development provides the foundation for future educational, social and vocational success (Grantham-McGregor et al., 2002; Olusanya, 2011). Two of these children were known to the therapists and still they did not receive the intervention needed. For Gert intervention did not start early and was terminated due to a lack of resources. While not terminated intervention for Brenda was limited, due to what seems like a lack of resources, possibly a lack of insight into her possibilities, and needs, as well as adherence issues.

### **16.5.3 Barriers related to the rural context**

Service delivery was challenged by the sheer size and remoteness of the setting and the study identified many of the challenges with regard to health care provision in rural areas discussed in Chapter 4. Distances, poor road infrastructure and transport challenges impacted negatively on service delivery as it does in other rural areas. Low population density made it a non-viable setting for government to deploy health care service providers or for private health care providers to practice. Outreach services and referral services were based 200km away. Thus time was lost on travel and services might have been more expensive per capita than in more populous and less remote settings. These challenges were not only experienced by persons with disabilities, but by the entire community. However, the impact seemed to be more severe on persons with disabilities. For instance, most community members walked to access health care services, but users who were paralysed and not provided with a wheelchair could not access the service or had to access it via ambulance, a tedious process involving phone calls to a call centre in Calvinia.

#### 16.5.4 Vulnerability

All of the study participants were vulnerable with regard to health care access if only due to the rural, underdeveloped context, their social circumstances, impairments and health conditions (Mechanic & Tanner, 2007). However it seems as if a lack of personal, financial, social and community resources left Brenda, Carel and Hans in an especially precarious situation with a diminished ability to cope and overcome adversity. Poverty, severe socio-economic challenges, cognitive/intellectual challenges, lack of education, unemployment, limited social support networks, alcohol abuse and violence interacted in their lives and combined to increase vulnerability. For instance poverty caused a lack of choice with regard to health care services, a lack of access to products and technology for stimulation, development and function, as well as nutritional insecurity. Nutritional deficiencies might have increased developmental and educational challenges. Little education and knowledge might have limited their ability to understand and deal with health conditions, adhere to health care management strategies, and demand health care services as described in Chapter 4. For instance Carel demanded nothing from health care services although in my opinion he could have benefited from an array of inputs. Brenda's grandmother said that a lack of knowledge prevented her from providing exercises to Brenda. With guidance she could have been much more than a physical caregiver; she could have stimulated and facilitated function and inclusion.

In addition, low levels of education increase the risk of unemployment, poverty, poor socio-economic circumstances and family deprivation. Family deprivation is a risk factor for lower educational achievement, child neglect and abuse, violence, substance abuse and a lack of social support. Neglect, abuse and substance abuse were seldom described overtly in the case studies, but signs of it could be identified in the cases of Brenda, Carel, Gert and Hans. With regard to social support five participants described dependence on one person and a lack of social support networks. The issue and challenges of Frans's dependency on the farmer was discussed in his case study, as was Dina's financial dependency discussed in her case study. Erik was similarly dependent on his foster mother. It was made clear that she was the only one that really understood him and facilitated his integration. Brenda and Carel were completely dependent with regard to physical care and in both instances the caregivers expressed a worry of what

would happen to them when they, the caregiver, died. In addition to the vulnerability the situation creates for the participant it can lead to caregiver strain. An extended support system would have decreased the vulnerability of participants and provided rest periods and support to caregivers.

## **16.6 Facilitators to Health Care Access**

The study findings indicated an affordable service. In compliance with National Policy health care and transport between services was to a large extent provided free of charge. The only cost that was incurred was out of pocket payment when a second opinion was sought and payment for eye testing and spectacles. In addition, aspects of the service ensured a certain level of availability and acceptability. There was a CHCC that the community could access. After hours service was provided. Emergency transport and transport to referral services were available. The level of curative care in the instance of common ailments such as chest infections seemed good. Doctors and therapists did provide an outreach service. The quality of investigative and curative care that was described for tertiary level services was very positive.

## **16.7 Health Care, Rehabilitation and Wellbeing**

The findings from the case studies confirm the presentation in the literature review with regard to the importance of health status in overall wellbeing and quality of life. Participants often experienced their bodily impairments as negative and as the cause of participation restrictions. The case studies illustrate the importance of quality health care and rehabilitation in ensuring wellbeing and the negative impact that seemingly minute failings in the health care system can have on health and wellbeing. Issues such as a missed diagnosis, failure to access diagnostic services, failure to issue or fit an assistive device, a lack of training in use of an assistive device, failure to provide consumables, failure to provide nutritional support, a lack of education on preventative practices, a lack of long term management planning and, inefficient rehabilitation practices might seem like small omissions if looked at in isolation. However, in conjunction they add up to a picture of a service experiencing serious challenges. And they might have added up to suboptimal health outcomes for most of the case study participants and poor quality of life for some participants.

## 16.8 Summary

Participants conceptualised disability according to the moral or medical approach. They relate it to physical ability; an interpretation that might be linked to the agrarian nature of the setting. Formal health care and rehabilitation access and service provision were challenged through a lack of resources and a curative focus on the side of users and service providers. Poor health and functional outcomes were often the result of a chain of events whose impact accumulated over time. The remoteness and size of the area further hampered service delivery. Support and attitudes of family impacted on function and inclusion of participants, as did a lack of products and technology, a lack of knowledge and education, and poverty. In the following and final chapter of this document I make concluding remarks and look at recommendations that might address the challenges that were identified, and present hypotheses to be explored through further study.

## Chapter 17

### Conclusions and Recommendations

#### 17.1 Introduction

The aim of this study was to describe the experience of living with a disability in a remote, rural setting with a specific focus on barriers and facilitators to health care access. Therefore qualitative data on participants' experiences of disability, community integration and health care access were collected through eight case studies. The data allowed me to explore and generate theory (Silverman, 2013) on the issues being studied. Causal links could not be explored. Therefore this chapter revolves predominantly around hypotheses developed from the findings, suggestions for further study based on these hypotheses, and some tentative recommendations. In addition, I provide information on dissemination of findings to date and reflect on the study and what it has meant to me. The chapter commences with the study limitations.

#### 17.2 Study Limitations

The study is challenged by methodological issues and by my relationship with participants. Case studies are explorative in nature and concerned with understanding what is happening in a specific context. Therefore study findings are aimed at the study community and not meant to be generalised. However, one might be able to apply them in similar communities after careful comparison of contextual factors (Hodgetts & Stolte, 2012).

While the use of multiple case studies increased the robustness of the design and added to the strength of findings (Yin, 2013), the number of participants was still low. It is possible that not all experiences of persons with disabilities in the study community are represented in this document. Furthermore, persons with mental disabilities were excluded. In addition, in some instances I was not able to gather data of the depth that I would have liked. Some participants struggled to explore abstract concepts. They could narrate what happened, but were less vocal when I probed about how the things that happened made them feel.

In some instances the richness of the narrative was compromised during the translation process. Participants conversed in an Afrikaans dialect particular to the study region. At times I struggled to capture in the translation the emotion and emphasis that were displayed through the words they used. I displayed the original Afrikaans text in some of the quotes for the benefit of readers who can understand Afrikaans.

Since the bulk of the data came from persons with disabilities the conclusion and hypotheses are based largely on their views and might not reflect the experiences of service providers. I did not explore the perceptions of the professional nurses employed at the CHCC in any depth for this study. I did interview a professional nurse during the qualitative phase of EquitAble data collection and did explore her views on health care access for persons with disabilities during that interview. Relevant findings from that interview are presented in the discussion sections of this document. I did not collect information from users' CHCC folders. The therapists that I talked to had little knowledge of the study participants.

With regard to rigour I did not ask participants to comment on the completed case studies, patterns across cases and conclusion. While that might have added to the credibility of the findings I was not sure how to go about it. None of the study participants had more than a primary school education. Thus I could not translate the documents into Afrikaans and ask them to read it as Yin (2013) and Smith et al. (2009) suggest. I thought of getting them together in a focus group to discuss the issues, but they were so diverse a group that I was not sure a focus group would have been successful. In addition, Silverman (2013, p. 288) argues that feedback from participants "is a highly problematic way of validating research". Thus I ultimately decided not to seek feedback from participants on the analysed data. In addition data saturation was not actively sought. While trends amongst the case studies showed a level of saturation further sampling of participants to confirm or refute hypotheses would have enhanced the study.

Finally, I lived in the same town as the study participants, but we belonged to different social groups. I am a White, affluent, farmer's wife; they are part of the Coloured farmworker community. In addition, even though I explained that I had no connection with health care services, participants might have perceived me to be connected to services even if just through



what I was doing as a researcher. This might have influenced answers. Thus both my personal and professional context might have created barriers between me and participants and towards my understanding and interpretation of findings. However, the study participants allowed me into their houses; they showed me their faces and a part of their hearts. While I remained an outsider looking in, we shared laughter and tears, and I think I came to some understanding of what living with a disability in the community of Fraserburg meant, and how participants experienced health care.

### **17.3 Conclusions**

It seems from the study findings that while persons with disabilities did receive health care through all levels of care as discussed under 3.4 they as well as other members of this community might lack access to health care that is of a consistent high quality. I concluded that persons with disabilities did not necessarily face much bigger health care access barriers than their counterparts, but that persons with disabilities suffer greater negative consequences due to poor health care access because their greater need for more complex interventions often went unmet.

The case studies underscored the complexity of the concept of disability and in my opinion also underscore the need for a multidimensional framework, like the ICF, for disability. The cases showed the multifaceted interaction between impairment, activity, participation, environment and the person. In some instances personal attributes as well as family, community and employer attitudes and support facilitated community integration and participation despite severe impairments. Others were less functional and integrated than I would have expected from their impairments. I ascribed this to personal and communal socio-economic challenges and health care systems barriers.

As postulated by the EquitAble theoretical framework for access to health care, presented in Chapter 1, results showed that health care services were influenced by systems, contextual, community and personal variables. Barriers under each of these are presented in Figure 17.1. With reference to the health care systems, participants described the CHCC at Fraserburg as a place where common ailments were dealt with rather than a place where a diverse range of health

needs were addressed. Participants described a service that was not client centred, lacked continuity and left users without the knowledge to manage their own health. A referral system was available and used, but it seemed to be fragmented with little communication with and integration of PHC providers and users. Resources were limited and what were available were seemingly utilised to provide curative care rather than health promotion and rehabilitation. Health care services were not provided according to the principles of PHC. Rehabilitation was limited to outreach therapy services that focussed on function, but did not facilitate community integration and participation. Challenges were exacerbated by the remoteness of the setting, poverty and limited education and knowledge amongst users.

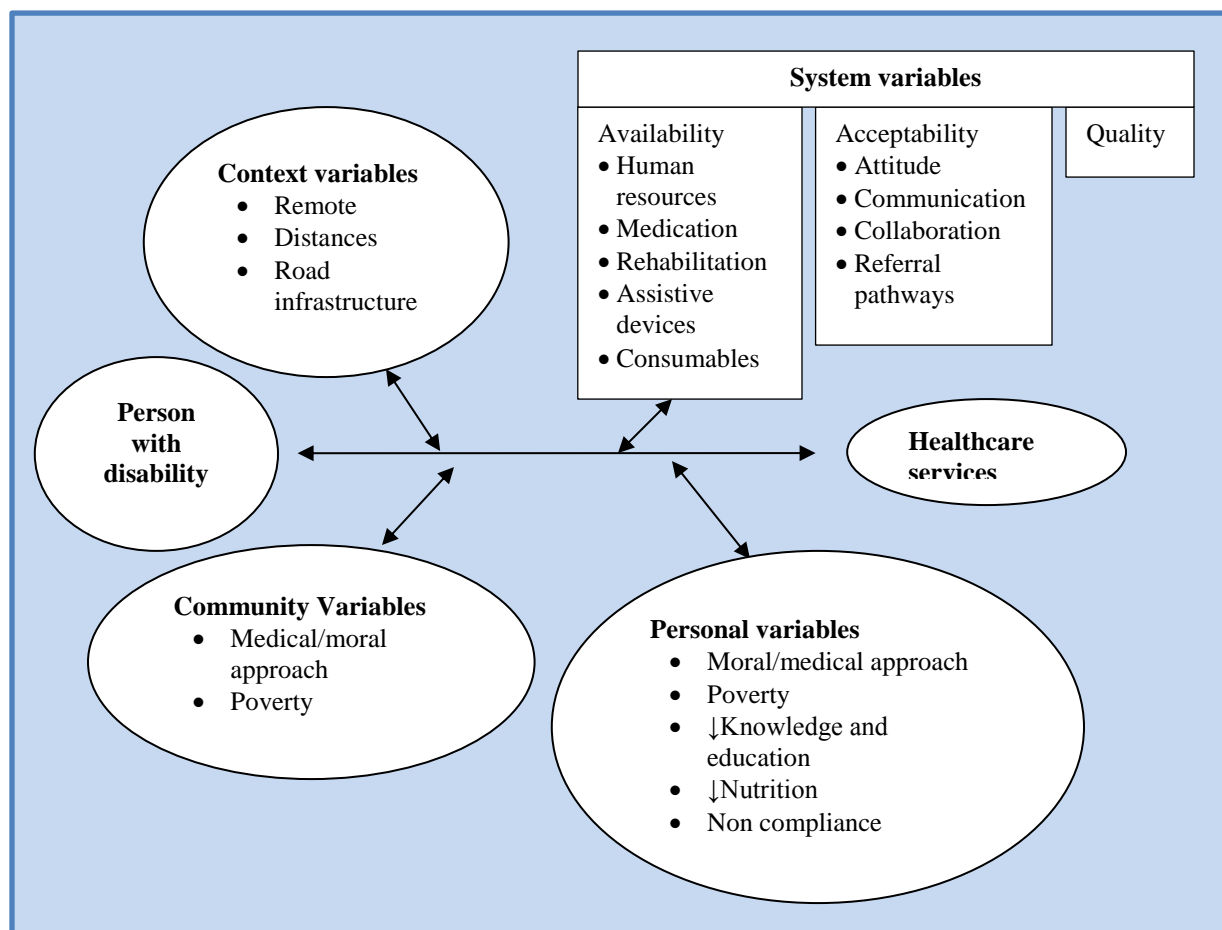


Figure 17.1. Barriers to health care access presented according to the theoretical framework for access to health care

On the other hand health care access was facilitated by the presence of the CHCC, affordability, ambulance transport, outreach services and high quality tertiary care as presented in Figure 17.2.

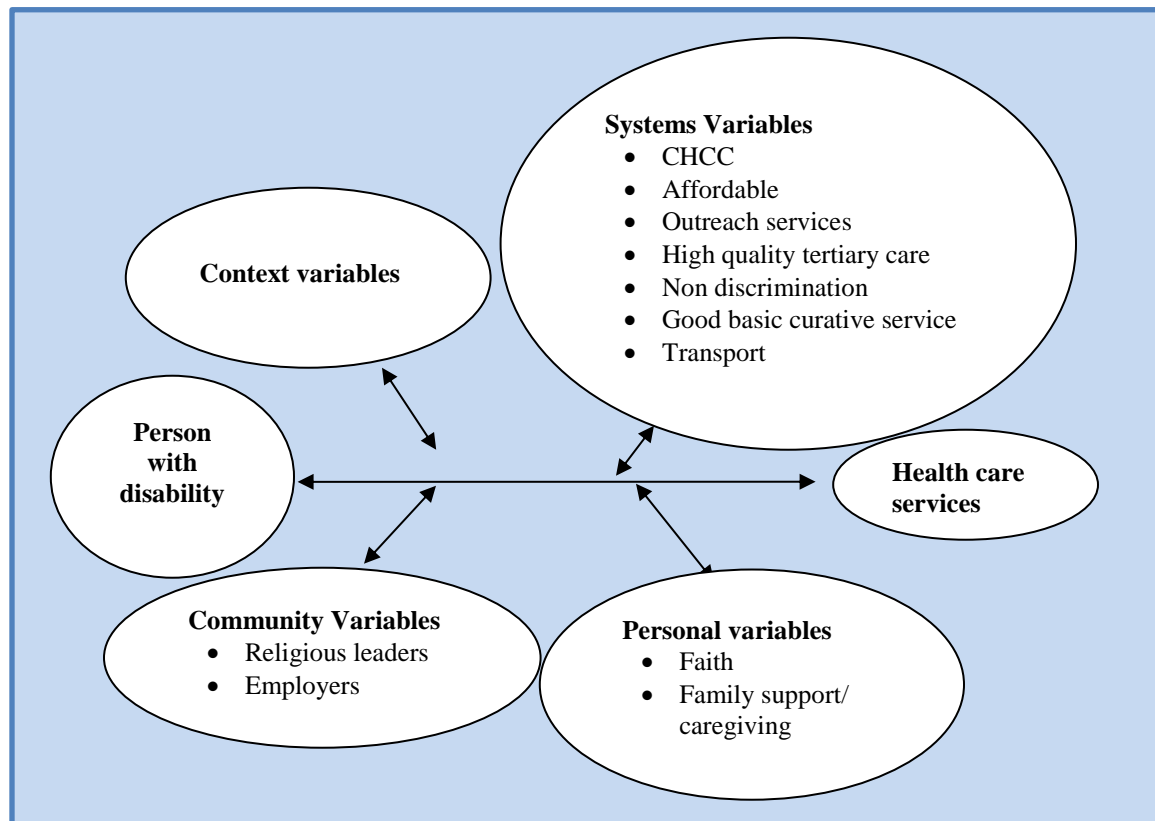


Figure 17.2. Facilitators to health care access presented according to the theoretical framework for access to health care

## 17.4 Hypotheses, Suggestions for Further Research, and Tentative Recommendations

### 17.4.1 Health care service provision

- *PHC is not provided according to the principles of the Alma-Ata declaration (1987).*

I have described my findings in this regard under 16.4.1. I have also pointed out areas of PHC that I did not explore. Thus while my findings strongly suggest this hypotheses some aspects of the provision of PHC require further exploration. In addition there is a need to determine why limitations with regard to PHC provision exist.

Even so my findings left me with the impression that PHC according to the principles of

the Alma-Ata declaration might enhance health care service provision for persons with disabilities in this community. I believe that a clinic staffed with enough providers adequately trained in practical implementation of the principles of PHC can provide a community oriented primary health care service to this community that is holistic and client centred with a strong health promotion component. In my opinion the clinic service manager will play a critical role in this process. In this I argue that it is not as much the profession of the person that should be taken into consideration on making an appointment but rather insight, vision and drive.

Of the processes started to improve PHC service delivery mentioned in chapter 3 I think ward based primary care can assist service providers at the clinic with health promotion, education, early detection and referral and to keep a household health register.

- ***Communication challenges negatively impact health care service delivery.***

The following findings led me to hypothesise that communication problems exist:

- The difficulty to obtain feedback from referral services.
- A perceived lack of clear communication on management strategies and follow up planning between providers from different service levels as well as between providers and users.
- The lack of Afrikaans translators.

If true, this might impact negatively on client centred care and acceptability of services. My findings do not provide enough information to base recommendations on. Thus the hypothesis, reasons for the problem and practical solutions must be further explored.

- ***Continuity of care is poor.***

The case study findings led me to consider that continuity of care was hampered by late or no follow up and rigid referral protocols. The impression was further strengthened by the explanation in the focus group discussion on handover between therapists from one year to another. It seems as if both users and service providers have a role to play in enhancing follow up. Anita and Brenda narrated not receiving appointments. The therapists said users including Brenda did not keep appointments. Gert did not access

services for assessment and follow up as needed. On the other hand, I got the impression that referral protocols did little to allow user autonomy.

I think there is a need for service providers, in conjunction with the community and users, to identify challenges to continuity of care and develop strategies that will ensure greater continuity. For instance, where it does not increase cost of service, users could be allowed more freedom of choice with regard to which tertiary hospital they want to access, even over provincial boundaries. Another suggestion that comes to mind is that therapists keep written records of the aims, target population, inputs, activities, outputs and outcomes of the programmes they offer to provide continuity from year to year.

- ***A constant supply of essential drugs is not ensured.***

This hypothesis is based on findings from Anita. The extent of and reasons for the problem must be explored, and strategies to address it must be developed.

#### **17.4.2 Rehabilitation**

- ***Rehabilitation service delivery in the study setting is unsatisfactory.***

The case studies showed that with the exception of Dina the three components of rehabilitation, as presented in Chapter 5, were not addressed sufficiently:

- Impairments were not modified for Anita, Brenda, Carel, Frans and Gert.
- Assistive devices and training to compensate for loss of function were not provided for Anita, Brenda, Carel, Frans and Gert.
- Environmental barriers like stairs and negative attitudes were not addressed.

In addition very little evidence of the implementation of any of the WHO health guidelines (WHO, 2010a) for CBR programmes, as presented in Chapter 5, could be identified in the study setting:

- Rehabilitation needs for Anita, Brenda, and Carel were not identified.
- Referral and follow up was not facilitated for Anita, Brenda, Carel, Gert and Frans.

- Early intervention and childhood development activities were not provided for Brenda, Gert and Hans.
- Functional independence was not encouraged for Anita, Brenda and Carel.
- None of the study participants were linked with self-help or peer support and training groups.

These findings lead me to consider the possibility that a community-based rehabilitation programme which focuses on the health component of the CBR matrix might improve rehabilitation service delivery in this setting. Since no evidence was found that programmes of this nature existed in the community it seems as if such a programme can be initiated from scratch. The programme should be preceded by a situational analysis to underscore planning, design, implementation, and monitoring (WHO, 2010c). I suggest that the programme is directly linked to the formal health care system, i.e., managed by the ministry of health and implemented through PHC structures in partnership with other departments such as social services, local government and non-governmental organisations such as churches. This strategy has advantages such as increased and more efficient use of resources, better sustainability, and cost savings on tertiary health care (Mannan & Turnbull, 2007; WHO, 2010c). The programme must be sensitive to local culture and socio-economic circumstances and must enjoy support from and include persons with disabilities, the community, local authorities and disabled people's organisations (WHO, 2010c).

- ***Peer counselling and training is not utilised in the study setting.***

I identified no evidence of peer counselling or training. Anita's activities as lay councillor led me to believe that she could play a more formal peer counselling role in the community. In addition I think exposure to peers with similar impairments, but better community integration might have assisted Carel and Brenda's grandmother to realise and explore their potential.

Christian leaders in the community played a positive role in the lives of study participants. Thus I think health care service providers and Christian leaders can

collaborate to develop a peer counselling and training programme. Ultimately the process must be peer driven with professionals providing support and/or training on request.

- ***Rehabilitation programmes in the community should be supported by in-patient rehabilitation.***

The case studies of Brenda and Carel have strengthened my conviction that in some instances a period of in-patient rehabilitation might be beneficial. Their impairments and activity limitations were multiple and required a range of inputs from continence management, through retraining of physical abilities and provision of assistive devices to emotional counselling and empowerment. Thus they can benefit from intensive input by a team of rehabilitation professionals on a daily basis.

The National Rehabilitation Policy (DoH, 2000a) calls for rehabilitation through all levels of health care. De Villiers, Kalula, & Burch (2009) have demonstrated that stroke care can be improved in a limited resource setting by establishing a dedicated stroke ward and management protocols in a secondary hospital in the Cape Town, South Africa. This was done with no additional funding or extra staff. There is a possibility that a similar approach might be suitable for the study setting. Thus I suggest research to determine the feasibility of:

- Designating a number of beds in the secondary hospital at Calvinia for inpatient rehabilitation.
- Implementing the protocols suggested by De Villiers et al. (2009) in this setting.

- ***Compensation for loss of function through the provision of assistive devices is suboptimal.***

The findings highlighted three issues in this regard:

- A lack of provision (Anita and Brenda).
- A lack of fitting and user training (Carel & Frans).

- It seems from Gert's case study that public private partnerships might have created cost barriers that prohibited users from accessing glasses.

The findings pertain to a limited number of people. The extent of the problem is thus not clear. Further exploration of assistive device provision, and deductive studies to quantify challenges in this regard, is required in this and other less resourced settings in South Africa (Lang et al., 2011).

- ***Prevention of secondary complications for persons with disabilities is lacking.***

The case studies of Carel and Brenda suggested that prevention of secondary complications did not receive the necessary attention. While I cannot draw a conclusion from only two cases I think the findings are strongly suggestive that a problem exists. Thus I recommend further exploration on the implementation of secondary prevention strategies in the study setting.

- ***Rehabilitation services are not monitored.***

Therapists indicated that their service to the community was not monitored. It is recommended that a feasible, valid, reliable measuring instrument that provides relevant, useful information on the service they deliver is implemented, and that information gathered is used to improve the service. Furthermore, monitoring should be an integral part of any rehabilitation programmes that are implemented in future.

- ***There is a lack of knowledge on the role of rehabilitation amongst CHCC staff that hampers early referral.***

Case study findings suggested that persons with disabilities were not always referred early for rehabilitation. This assumption was corroborated by therapists in the focus group discussion. The problem seems to persist despite education on the matter from the therapists.

The knowledge of professional nurses at the CHCC on the role of early referral, and rehabilitation must be explored through further study. At the same time the training that



is currently done by therapists must be monitored to determine its impact and identify strategies for improvement.

- ***Some users are non-adherent with regard to therapy.***

This opinion was expressed by therapists. However, they did not know what caused the perceived non-adherence. Thus there is a need to explore the reasons why users stopped attending therapy. Should this exploration find that users experience barriers that prevent them from attending, these barriers must be addressed.

### 17.4.3 Other

- ***The prevalence of intellectual disabilities is underreported in the study community.***

The case study of Gert and the direct replication in the study of Hans suggested that intellectual disabilities in children might not be identified by parents in the study community. While this finding is based on two cases only and thus not at all conclusive it concurs with previous findings as discussed under 14.5.

A quantitative study/studies in this and similar populations is recommended to determine if the WGQ, and thus the questions as contained in the South African census questionnaire, are able to determine prevalence of intellectual disability in these contexts.

- ***Parents are ill equipped to facilitate early childhood development and prepare children for school.***

Findings from the three case studies that involved children points towards an inability on the side of parents and caregivers to provide appropriate early childhood stimulation. A quantitative study to determine whether the problem does exist and the extent of the problem is recommended. If the hypothesis is confirmed, the initiation of a programme that focuses on empowering parents to realise the importance of early childhood development and school readiness and assist their children with this development as described by Pitt, Luger, Bullen, Phillips, and Geiger (2013) might be useful.

#### 17.4.4 Additional suggestions for further research

- The study community conceptualised disability from an individual approach as opposed to the societal approach used in national policy. There is a need for further studies in diverse South African communities to create a comprehensive picture on how disability is understood in the country in order to ensure that policies and policy implementation strategies are adaptable enough to suit the needs and requirements of culturally diverse communities (Gaede & Versteeg, 2011; Ingstad, 2007; Kalyanpur, 2011). In addition education on the role of environmental barriers in disability might assist the study participants and community to expand their views on disability, the possibilities of persons with disabilities and how they can be assisted towards community integration through the removal of environmental barriers.
- This study focussed on the perceptions of users. Providers might perceive the situation with regard to health care access for persons with disabilities as being different. A study/studies that assess provider perceptions on these issues in this and other districts in South Africa is recommended.
- It is recommended that longitudinal case studies are done, with selected persons with disabilities as participants, simultaneously to the implementation of recommendations from this study to assess the impact of interventions and identify optimal intervention strategies.

#### 17.5 Dissemination

As indicated in Chapter 1 part of the purpose of the study was to provide in-depth personal information on the everyday experiences of persons with disabilities with regard to health care access in order to provide a personal context against which to interpret EquitAble data. Thus data from this study were used during dissemination of the findings from the EquitAble study. Articles, conference addresses, training and feedback sessions as described below incorporated findings from both studies.

### **17.5.1 Dissemination to community**

- Feedback of findings was presented to the community at a meeting.
- A written report on the findings and recommendations were submitted to:
  - Service providers at the Fraserburg CHCC.
  - The Karoo Hoogland Municipality.
  - Agri Fraserburg.
- The findings were presented at the Women's agricultural union's annual regional meeting at their request.

### **17.5.2 Dissemination to policy developers and managers**

- Findings and possible solutions were discussed during a meeting with the district manager for health care, and two members of the Fraserburg community.
- A written report of the findings and recommendations were submitted to:
  - Northern Cape DoH.
  - Namakwa District Health manager.

In September 2013 the NCDoh published a policy document on Hospital Boards, CHCC and clinic committees (NCDoh, 2013), which led to the nomination of a clinic committee for the Fraserburg CHCC. While neither this study nor the EquitAble study can take credit for this development, the establishment of community health forums were included in the recommendations of the above reports and might have aided the process in a small way.

- Findings and recommendations from the four South African sites were presented to national stakeholders during a feedback workshop at Stellenbosch University.

### **17.5.3 Academic dissemination**

#### ***Congresses and conferences***

- Afrinead Congress; November 2011:  
Delivered a paper on the Provision of Wheelchairs in less resourced settings.

- Invited guest speaker at the International Bobath instructors and trainers association's pre-congress workshop; August 2013:  
Topic: Contextual factors and health care access in SA: Results from the multi-centre EquitAble study.

### *Papers to scientific journals*

Visagie, S., Scheffler, E., & Schneider, M. (2013). Policy implementation in wheelchair service delivery in a rural South African setting. *African Journal of Disability* 2(1), Art. #63, 9 pages. <http://dx.doi.org/10.4102/ajod.v2i1.63>

Visagie, S., & Schneider, M. (2014). Implementation of the principles of primary health care in a rural area of South Africa. *African Journal of Primary Health Care and Family Medicine* 6(1), Art. #562, 10 pages. <http://dx.doi.org/10.4102/phcfm.v6i1.562>

In draft:

- The conceptualisation of disability by a poor rural Global South community.
- The relationship between vulnerability and access to primary health care services: A presentation of case studies from South Africa.

## **17.6 The Road Forward**

- I developed a proposal for the implementation and assessment of a programme that might improve early childhood development in the community and am in the process of sourcing funding for this project.
- Some of the EquitAble partners and I have developed a proposal that focus on monitoring and guiding the implementation of EquitAble findings in the South African sites.

## 17.7 Reflection

Trained and nurtured in Western Medicine I knew about treatment, assistive devices, environmental barriers and accommodations when I embarked on this study. I thought I understood the concept of disability. I knew there were concepts like PHC and CBR, but I never really explored them in any depth and was not sure how one would go about practically applying the principles.

This study has shown me that I did not really understand the concept of disability. Moreover, that there is not a single concept of disability, but many concepts, that these concepts change and that I need to understand and keep up with global trends as well as engage with individual persons continually if I want my understanding of disability to keep evolving. Study participants opened my eyes to the need to engage with people and not only theorise when it comes to understanding disability.

Furthermore, this study confirmed to me the opinion of Shakespeare (2014) that a lack of high quality medical intervention for persons with disabilities will lead to exclusion and poorer quality of life. In addition, this study has left me with a better understanding on how PHC and CBR can be used to make a difference in the lives of persons with disabilities. For the first time I have been able to envision how one can practically move away from a treatment focused approach to one focused on the determinants of disease and disability. I believe it can be done and that the outcomes will improve the community integration and quality of life of persons with disabilities without necessarily putting increased pressure on resources. At the same time I remain convinced that impairments must be addressed through trans-disciplinary teamwork, families, peer trainers and counsellors, as well as community workers. However, my beliefs and visions are theoretical in nature and need to be put to the test in the clinical environment.

Experiences and insights gained through this study have provided new depth to my academic activities. I have drawn on the case studies in co-authoring a chapter on disability management in the PHC sector (Scheffler & Visagie, 2014). I have utilised the case studies on a number of occasions during workshops and tutorials. I will keep drawing from them, because I believe the stories of people as told by them, much more than statistics, create awareness for the challenges

faced by persons with disabilities in various communities, and will ultimately be responsible for change in the communities.

A crucial feature of this study, though not one which was altogether surprising to me as someone who lives in this community, is what I term the disjunction between various worlds. As a white, professional person with connection to a research-driven university in South Africa, I am conversant with contemporary theories about disability and health care access. I attend meetings where it is expected that all people present will know about and apply the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). South Africa has played a major role in the international political and policy context which gave rise to the UNCRPD. It is also true that in South Africa some very sophisticated services are available for persons with disabilities, in the field of health care but also in other areas such as education. One of the cases I present here shows how accessing health care in another province led to high level care which would be comparable to that received in a high income country. But many of the barriers experienced by participants, if not most of them, would be similar to those experienced in low-income countries.

It is well established that South Africa is one of the most unequal countries in the world. This inequality continues to be experienced racially (the overwhelming majority of poor South Africans are not white), but also spatially. The participants in this study inhabit a world which is not only unequal in itself (compare, for example, the health care access available to the farmer as opposed to that available to the average farm worker), but which is also remote from the mainstream. As I have indicated, even media such as radio and television are relatively inaccessible to this population because of language issues, and though cellular telephone penetration is substantial in South Africa, data costs are prohibitive and out of the reach of most. Racially, the participants are part of a 'coloured' group which though disadvantaged and disenfranchised under apartheid, is commonly viewed as having been less oppressed and excluded than were people classified as 'Black' African under apartheid. The general statement that coloured people were better off than Black people under apartheid is true, but in an atmosphere in which redress has to be prioritised for the most obviously excluded, this group of people can be easily ignored. They are not visible to those in the urban metropolises and they are

racially part of a group which is seen as having experienced (and continuing to experience) relative privilege compared to most South Africans.

In the transition to democracy in South Africa, strong mechanisms were put in place for tripartite negotiations between government, business, and worker organizations to work together to improve services. As Friedman (2006) notes, however, negotiating structures like these excluded a number of groups including rural dwellers, unemployed people, and people with disabilities, and an attempt has been made to include such groups in various ways. But as the data from this study show, in the field of health care, there are many South Africans who remain excluded from development processes. During the course of my research I met many people, professionals and others, who are very committed to improving the lives of people with disabilities. But I was also reminded of the extent to which marginal people and their needs can be forgotten and overlooked in a world in which other challenges are so much more obvious, pressing and overwhelming.

I cannot pretend to have any solution for this problem. I have used the results of this study to raise awareness and to give a face to what exclusion and lack of provision can mean. I will continue to do this dissemination work. But the reality is that we need more work shedding light on places and experiences which are effectively hidden from view. I have little doubt that the stories told here will have resonance with many other stories. We need to harness these stories to help bridge the gaps between rhetoric and reality. South Africa is good at talking about equality and about disability rights. The participants in this study in general not only do not have the access the UNCRPD requires them to have – they are also excluded from the talk and the debates about access. This thesis will not be of use unless it becomes part of an activist agenda in which people's rights are made to surface and can be fought for.

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## Appendix 1

### DEELNEMER INLIGTINGSBLAD EN TOESTEMMINGSVORM

**TITEL VAN DIE NAVORSINGSPROJEK:**

Disability and health care access in an isolated quarter of the Karoo

**VERWYSINGSNOMMER:** N10/07/236

**HOOFNAVORSER:** SJ Visagie

**ADRES:** Posbus 40; Fraserburg; 6960

**KONTAKNOMMER:** 0533912 Vra 4440

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorser daarvoor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

**Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiekkomitee van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).**

### **Wat behels hierdie navorsingsprojek?**

Die navorsingsprojek word in Fraserburg dorp en omgewing uitgevoer. Vyf gestremde persone en hulle gesinne sowel as kliniek personeel sal aan die projek deelneem. Die doel van die studie is om gestremde persone se ervarings en gevoelens oor gesondheidsorg in 'n afgelee, landelike area te beskryf.

Deelnemers sal tydens onderhoude uitgevra word oor hulle ervaring van gesondheidsorg. Omdat tyd en geld dit nie moontlik maak om met alle gestremdes wat in die gemeenskap bly te praat nie gaan ons mense kies om deel te neem. Persone met verskillende gestremdhede, van verskillende geslagte, kleur en inkomstegroepe sal gekies word om soveel as moontlik inligting te kry.

Daar gaan geen ondersoek of medisyne in die studie gebruik word nie.

### **Waarom is u genooi om deel te neem?**

U word genooi om aan die studie deel te neem omdat u gestremd is, van die kliniekdiens gebruik maak, of gesondheidsdienste aan gestremde persone lewer en 'n waardevolle bydrae kan lewer om die doel van die studie te bereik.

### **Wat sal u verantwoordelikhede wees?**

Van u sal verwag word om die vrae so volledig moontlik te beantwoord.

### **Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?**

U mag dalk nie onmiddellike of persoonlike voordeel trek uit die studie nie. Maar op die lang duur behoort resultate te help om die diens vir gestremdes in die gemeenskap te verbeter.

### **Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?**

Daar is geen risiko's vir u indien u sou deelneem aan die projek nie.

**Wie sal toegang hê tot u mediese rekords?**

Die studie maak nie gebruik van mediese rekords nie. Dus sal niemand wat by die studie betrokke is toegang hê tot u mediese rekords nie.

**Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?**

U sal nie betaal word vir deelname aan die navorsingsprojek nie. Die navorser sal u by u huis kom besoek om die vrae te vra. Deelname aan die navorsingsprojek sal u niks kos nie.

**Wat sal gebeur indien u enige besering opdoen as gevolg van u deelname in die studie.**

Dit is baie onwaarskynlik dat so iets sal gebeur omdat u in u eie huis besoek sal word en daar net onderhoude met u gevoer gaan word.

**Is daar enigiets anders wat u moet weet of doen?**

- U kan Surona Visagie kontak by 0544912 vra 4440 indien u enige vrae oor die navorsing het.
- U kan die Gesondheidsnavorsingsetiekkomitee van die Universiteit Stellenbosch kontak by 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur die navorser hanteer is nie.
- U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

### Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,....., om deel te neem aan 'n navorsingsprojek getiteld "Disability and health care access in an isolated quarter of the Karoo".

#### Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm geles het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is.

Geteken te (*plek*) ..... op (*datum*) .....

.....  
**Handtekening van deelnemer**

.....  
**Handtekening van getuie**

### Verklaring deur navorser

Ek *SJ Visagie* verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan .....
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te (*plek*) ..... op (*datum*) .....

.....  
**Handtekening van navorser**

.....  
**Handtekening van getuie**

## Appendix 2

### Initial Interview Schedule

This is a guideline to ensure all areas are covered during the interview; not to be followed rigidly.

- Information on the impairment/disability
  - Tell me about what is wrong with you?
  - How and when did it start?
  - What caused it?
  - How did it progress?
  - Why do you think this happened to you?
  - Do you think your condition can improve and if so in what way / what will assist with that improvement?
- Impact of the disability
  - How does it impact on your life and that of your family?
  - How does it influence your daily functioning?
  - How does it impact on your ability to participate in community activities
  - Does it influence your ability to work? Please explain.
  - How does it impact on your happiness and emotional status?
  - How happy are you with your life?
- Interpretation of concepts such as health, disability and vulnerability
  - Do you see yourself as disabled? Please explain.
  - What does being disabled mean to you?
  - When do you think someone is disabled?
  - Do you see yourself as healthy or sick? Why?
  - What does being healthy mean to you?
  - Does this condition require that you use health care services more often than other family members? Please explain.
- Information on health care needs and services
  - Tell me about the services you received at the onset of the disability/problem and ongoing with regards to the disability/problem? Elicit information on all services such as formal and informal health care.
  - Elicit information on the participant's experiences as well as feelings and satisfaction with various services.
  - Could you tell me about your current health care needs?
  - To what extent and in what way are these needs addressed?
  - How do you get to the various points of service delivery and back home? How long does it take? What does it cost?
  - Is the facility and service physically accessible to you?
  - How busy is the facility – overcrowding, waiting times, seating?



- Do you receive preferential treatment elsewhere?
- Do you always receive all treatment that you need?
- Are you comfortable at the facility and with the various service providers?
- Did they ask your opinion on your health and on what can be done to improve it?
- Did service providers explain to you what is wrong with you, what your treatment entails and what your role is in it? Can you tell me what you were told?
- Did you receive advice about prevention of complications and, if relevant, deterioration of the condition?
- Do you think you have been referred for specialist assessment and intervention as required?
- Do you think staff was adequately trained to deal with your disability / problem and on how to assist you / assess you?
- Explore aspects related to:
  - Medication
  - Rehabilitation
  - Assistive devices
  - Consumables
  - Adaptations in house
- Did you experience any other problems at the service? (ask for descriptions, explanations and examples)
- Do you postpone going to see a health care provider? If yes why?
- Information on the person's material needs and situation
  - Do you have an income? Tell me about it, DG / employment / informal
  - If you work does your condition influence your ability to work?
  - To what extent is the money enough to support you / your family?
  - If the money is not enough how do you manage?
- Information on the person's lifestyle and support system
  - Describe a normal day in your life.
  - If you need assistance with what do you need assistance and who helps you?
  - Do you have someone with whom you can freely discuss your feelings?
  - Tell me about your relationship with these people and how you feel about them?
  - What is your role in the family?
  - Does your condition influence your family roles? In what way?
  - In what community activities do you participate?
  - What helps or hinders this participation?
  - Are there some activities that you cannot participate in but would like to? Please explain why you do not participate in these.
- Information on the community in general and the role of the person in it specifically
  - How easy/difficult is it to physically access the town and buildings in it?
  - How does the community generally feel about disability and act around persons with a disability?
  - Does the community of the town accept you – please explain?
- Information on social and community support
  - Are there any groups that you can attend /belong to? Tell me about it please.

- Are there any organisations such as DPOs / NGO/ churches/ development projects – in the community? What do they do? How do you connect with them? How helpful do you find them?
- Do you receive social support? Please explain.

Close the interview:

- Acknowledge the informant's cooperation, time spent and information shared.
- Ask whether he/she/they want to share anything else.
- Indicate that this visit might be followed by further visits.

### Appendix 3

#### Summary of methodologies used in studies referred to in the discussion on health care access

Reference	Focus	Setting	Design & Data collection methods	Population & sampling	N
<b>Global North countries</b>					
Arcury, Gesler et al., 2005	The role of topography on health care use in rural areas	North Carolina, USA	Quantitative; Used household survey data	Community members; Three-stage sampling, stratified by county and ethnicity	1,059
Arcury, Preisser, Gesler, & Powers, 2005	The impact of transport on rural health care use	North Carolina, USA	Quantitative; Used household survey data	Community members; Three-stage sampling, stratified by county and ethnicity	1,059
Brems, Johnson, Warner, & Roberts, 2006	Barriers to rural health care access as perceived by service providers	Alaska & New Mexico, USA	Quantitative; Surveys	Service providers; Random	1,555
Brugge, Edgar, George, Heung, & Laws, 2009	Influence of language on patient - provider communication	Boston, Massachusetts, USA	Qualitative; Focus groups	Groups of English, Spanish and Cantonese speaking people; Snowball	85
Buchanan et al., 2006	Explore rural/urban differences in barriers to health care access, among people with MS.	USA	Quantitative; Telephone survey	Members of the National MS society; Random	1,518
Chipp et al., 2011	“...to inform future practitioners, educators, and policy makers in avenues through which to enhance training, recruiting, and maintaining a rural workforce . . .” (p. 122).	Alaska & New Mexico, USA	Qualitative, Focus groups	Health care providers; Random	127

Fitzgerald et al., 2001	“... explore and describe what it means for people to have chronic illness ... bring attention to the needs of people who are chronically ill and inform professionals so that they may offer more appropriate support in rural communities” (p. 236).	Northern New South Wales, Australia	Interpretive phenomenology; Unstructured interviews	People with chronic conditions; Recruited through media	18
Graber et al., 2008	Impact of involvement in quality improvement on staff burnout and morale	Midwest & West central, USA	Quantitative; Mailed surveys	Staff at 145 health care centres participating in a health disparities collaborative programme Purposive & random	622
Hiscock, Pearce, Blakely, & Witten, 2008	Impact of travel time and access to the closest GP and pharmacy on health care use and satisfaction	New Zealand	Multilevel logistic regression; Used data from New Zealand Health Survey	National population Sampling strategy not given	1,383 surgeries 1,170 pharmacies 12, 529 people
Iezzoni et al., 2006	Explore health care experiences of persons with disabilities living in rural areas	Rural Massachusetts & Virginia, USA	Qualitative; Focus groups	Independent living centres; Convenient	35
Lee et al., 2010	Health care use by Asian Americans	Montgomery County, Maryland, USA	Qualitative; Focus groups	13 communities; Purposive & convenient	174
Lovelock, 2012	“... explore the meaning attached to injury and disease and to examine the socio-cultural field of agriculture” (p. 576).	New Zealand	Qualitative; In-depth interviews	Farmers throughout New Zealand; Sampling strategy not given	26
McPhedran, 2011	“... investigates different types of	Australia	Quantitative;	National population	313 regional

	community involvement, levels of perceived social support, and self-reported life satisfaction among regional people with disability relative to their counterparts living in major cities” (p. 40).		Data from Household, Income and Labour Dynamics in Australia	Sampling strategy not given	respondents 541 city respondents
Newman & Maylor, 2002	Satisfaction, dissatisfaction and retaining of nursing staff	London, England	Qualitative; Semi-structured interviews	Clinical nurses and midwives; Volunteers	131
Turner-Goins et al., 2005	Barriers to health care access as experienced by older rural adults	Rural West Virginia, USA	Qualitative; Focus group	Community-dwelling adults, 60+; Sampling strategy not given	101
Wagner et al., 2011	Role of health insurance and public health care services on access to care and drugs	70 countries	Quantitative; Analysed WHS data	Not given	286,803 households
<b>Global South studies</b>					
Cameron, Ewen, Ross-Degnan, Ball, & Laing, 2009	Availability and cost of medicine	36 middle- and low-income countries	Quantitative; Analyse data from WHO/HAI surveys	Medicine outlets Sampling strategies varied	45 Surveys
Falkingham, 2004	Role of out of pocket payments on health care access	Tajikistan	Quantitative; Analyse data from a Living Standards Survey	Not given	2,000 households 14,142 individuals
Mosadeghrad, 2013	“... define healthcare quality to encompass healthcare stakeholder needs and	Iran	Qualitative; Interviews and focus	National population; Purposive	384 users 266 providers,

	expectations” (p. 203).		groups		100 key informants
Tonoyan & Muradyan, 2012	Health care provision and use	Armenia	Quantitative; Telephone survey	National population; Stratified random	1000
Trani & Barbou-des-Courieres, 2012	“... equity in health and healthcare utilization. . .” (p. 219).	Afghanistan	Quantitative; Analysed Household survey data	National population; Random clusters and households	2,696; 958 with a disability
African studies					
Ansah et al., 2009	“... impact of free health care on health outcomes” (p. 0048).	Ghana	Randomised control trial; Clinical testing for anaemia & mortality	Children under five Random	2,592
Atinga, Abekah-Nkrumah, & Domfeh, 2011	“... how communication, provider courtesy, support/care, environment of the facility and waiting time predict patients’ satisfaction with quality of healthcare” (p. 548).	Ghana	Quantitative; Questionnaires	Out-patients from two hospitals Convenient	324
Bakeera et al., 2009	“To explore community perceptions among three different wealth categories on factors influencing healthcare utilization” (epub).	Uganda	Qualitative; Focus Groups	Three villages in the Iganga/Mayuge Demographic Surveillance Site; Purposive	88
Dillip et al., 2012	“... bridging the gap between local and biomedical understanding of convulsions” (epub).	Tanzania	Qualitative; Interviews	Caretakers of children who suffered convulsions; Consecutive	88
Hjortsberg & Mawikisa, 2002	Explore equality in access to health care	Zambia	Quantitative; Analysed data from a household expenditure survey	4 provinces Random	900 households 5600 individuals
Ingstad,	Exploring a connection between disability,	Malawi	Qualitative;	Community of Mangochi	64 persons with

Munthali, Braathen, & Grut, 2012	poverty and malaria		Ethnographic	District; Snowball	disabilities 21 health care providers
Khan et al., 2006	Impact of community level poverty on availability, quality and use of PHC and health outcomes	Tanzania	Quantitative; Analysed data from the Tanzania Demographic and Health Survey & Tanzania Service Availability Survey	Tanzanian population; Three-stage sampling	8,900 households
Kiwanuka et al., 2008	Health care access for the poor	Uganda	Systematic review	Not applicable	48 articles
Mills et al., 2012	“. . . system analysis of the equity of health-system financing and service use” (p. 126).	Ghana, South Africa, and Tanzania	Quantitative; Analysed data from National household surveys	Not given	Not given
Toda et al., 2012	Impact of economic status of area on health care services	Kenya	Quantitative; Structured interview	All dispensaries & health centres in Kenya; Two-stage cluster random sampling	248
South African studies					
Ataguba, Akazili, & McIntyre, 2011	To examine the relationship between socio-economic status and health inequality	National	Quantitative; Analysed data from three South African General Household Surveys	National population; Multi-stage stratified	Not given
Ataguba & McIntyre, 2013	Distribution of health service benefits across socio-economic clusters	National	Quantitative; Survey	National population; Sampling strategy not given	4,800 households

Bateman, 2012	Access to rehabilitation in rural areas	Eastern Cape, KwaZulu-Natal & Mpumalanga	Qualitative	Occupational-, speech- & physiotherapists; Sampling strategy not given	Not given
Botes, 2011	Exploring the social needs of farmworkers	Koup; Western Cape (Adjacent to study area with similar geographic features)	Qualitative; Focus groups	Farm workers and owners; Purposive	28 workers 13 owners
Cleary, Birch, Chimbindi, Silal, & McIntyre, 2013	“... the affordability of using public sector health services for three tracer conditions (obstetric care, tuberculosis treatment and antiretroviral treatment)” (p 37).	Two urban sites (from Western Cape & Gauteng) Two rural sites, (from Mpumalanga & KwaZulu-Natal)	Quantitative; Interviews	Communities; Random	3,727 51% from urban sites 49% from rural sites
Cleary, Birch, Moshabela, & Schneider, 2012	Barriers to health care access experienced by Anti Retroviral Therapy users	Two urban sites (from Western Cape & Gauteng) Two rural sites, (from Mpumalanga & KwaZulu-Natal)	Quantitative Interviews	All Anti Retroviral Therapy facilities in study settings Random	1,267 Anti Retroviral Therapy users
Couper, Hugo, Tumbo, Harevey, & Malete, 2007	“...key issues in functioning of two differing primary care clinics in the same community” (p 124).	North West	Qualitative; In depth case study	Not given	2 clinics 57 users
Eygelaar & Stellenberg, 2012	Factors that impact quality of nursing	West Coast Winelands region; Western cape	Quantitative; Questionnaire	Nursing staff employed at hospitals in the region; No sampling	280
Gilson, Khumalo,	“Exploring the Influence of Workplace Trust	“... rural North East	Qualitative;	Providers and communities:	62 providers



Erasmus, Mbatsha, & McIntyre, 2004	over Health Worker Performance” (p. 2).	part” of South Africa	Policy analysis Interviews	Purposive	60 users 13 key informants
Goudge et al., 2009a	Poor households access to chronic care	Mpumalanga	Qualitative; Case studies	Users; Purposive	34
Goudge et al., 2009b	To measure health care cost burden as a percentage of household expenditure	Mpumalanga	Quantitative; Survey	Households in study setting; Stratified according to socio-economic profile	280 households
Hall, Wisborg, Shirinda, & Zamchiya, 2013	“... explores what is happening to farm labour and to agricultural capital” (p 47).	Limpopo	Qualitative; Interviews and observation	Farms in Limpopo; Purposive	4
Harris et al., 2011	Explore health care access barriers	National	Quantitative; Survey	National population; Random	4,668 households
Harris et al., 2014	Barriers to quality health care	National	Qualitative; In-depth interviews Observations	Not given	45 users 67 providers 12 facilities
Hasumi & Jacobsen, 2014	Challenges experienced during health care visits	National	Quantitative; Analysed data from General Household survey	National population; Two stage Stratified	23,562 household representatives
Lemke, 2005	“... the link between nutrition security, livelihoods and HIV/AIDS” (p 844).	North West	Qualitative; Observations and interviews	Farmers and key informants	Not given
Mashia & Van Wyk, 2004	“... geographic, functional, financial and cultural accessibility of health care” (p. 37).	Kungwini Local Municipality, Mpumalanga	Quantitative; Questionnaires	Users; Random	260

Mashiri, Maponya, Nkuna, Dube, & Chakwizira, 2008	“. . . the influence of mobility & access on rural healthcare delivery . . .” (p. 4)	Thaba Chweu municipality, Mpumalanga	Mixed methods Qualitative: In-depth interviews, Focus groups, Life histories, Observation Quantitative: Questionnaire	Four villages; Purposive	Not given
Patel, Gauld, Norris, & Rades, 2010	User perceptions on the quality of drugs	Durban, Cape Town & Johannesburg	Qualitative; Focus groups	Population not given, but persons from middle- and low-socio-economic groups were sampled using purposive & snowball sampling	73
Peltzer, 2000	“community perceptions of availability, accessibility, acceptability and affordability of biomedical health care services” (p. 55).	Limpopo	Quantitative; Structured questionnaire	Residents of the Gamolepo area; Multistage cluster sampling	174
Peltzer, Mosala, Shisana, Nqueko, & Mngqundaniso, 2007	Investigate knowledge on and access barriers to prevention of mother to child transmission	Eastern Cape	Quantitative; Survey	Pregnant woman and family members; Consecutive	1,534
Schoeman et al., 2010	“. . . PHC facility infrastructure and services, and the nutritional status of 0 to 71-month-old children and their caregivers attending PHC facilities” (p. 21).	Eastern Cape & KwaZulu-Natal	Structured interviewer-administered questionnaires and anthropometric survey	Users and nurses from two rural districts in each of the study provinces; Random	40 Chief nurses 1,986 0 to 71-month-old children and their caregivers

Tshitangano, 2013	Factors contributing to nurse turnover	Limpopo	Quantitative; Self-completed questionnaires	Registered professional nurses in public health care; Convenience	141
Van Deventer, Couper, Wright, Tumbo, & Kyeyune, 2008	“... to evaluate clinic-based mental health services” (p. 137).	North West	Qualitative; Focus groups & In-depth interviews	Users and mental health coordinators from all clinics and CHCCs in setting; Stratified random	35 users 8 Health coordinators 8 providers
Versteeg et al., 2013	“... to identify the challenges and priority for rural health care provision in South Africa” (p. 119).	South Africa	Qualitative; Delphi technique	“A panel of rural health practitioners and other stakeholders” (p.199).; Purposive	34
Walker & Gilson, 2004	Nurses experience on the implementation of National Health policies	Johannesburg, Gauteng	Quantitative: Questionnaire Qualitative: In-depth interviews	Professional nurses from seven urban, primary health care facilities; Sampling strategy not given	113 10
Westaway, Rheeder, Van Zyl, & Seager, 2003	Effects of demographic characteristics and health status on satisfaction with care	Precise location not given	Quantitative; Questionnaire	Black users who attended outpatient diabetic clinics at two hospitals; Consecutive	263

## Appendix 4

### Summary of methodologies used in the studies referred to in the discussion on health care access for persons with disabilities

	Focus	Disability Definition/identification	Setting	Design & data collection methods	Population & sampling	N
Global North countries						
Brucker, 2007	Substance abuse amongst Americans	Presence of physical, mental or emotional problem that prevent or limited ability to work	USA	Quantitative; Analysed data from national survey on drug use and health	USA population Multistage probability	54 079
Buchanan et al., 2006	Explore rural/urban differences in barriers to health care access, among people with MS	Not applicable	USA	Quantitative; Telephone survey	Members of the National MS Society; Random	1518
Chevarley et al., 2006	Comparing health status and access to prevention and cure of women with and without functional limitations	Presence of functional limitations	USA	Quantitative; Analysed data from National Health Interview Survey, Supplement on Disability	Women 18 or older; Sampling strategy not given	77 762 women 16% with functional limitations
Drainoni et al., 2006	Health care access barriers encountered by users with disabilities	Not given	Massachusetts, USA	Qualitative; Focus groups	Identified through disability organisations and advocacy groups;	87

					Convenient	
Gulley & Altman, 2008	Impact of severity of disability and availability of health insurance on access, use, satisfaction with and quality of health care services.	Non severe: Persons with a functional limitation but no activity limitation and some ability to work. Severe: Persons with functional and activity limitations and are unable to work.	USA & Canada	Quantitative Analysed data from Joint Canada/United States Survey of Health data	Canadian and American household members aged 18 or older; Not given	3505 Canadians 5183 Americans
Harrington, Hirsch, Hammond, Norton, & Bockenek, 2009	“To determine what percentage of persons with disabilities have a primary care provider, participate in routine screening and health maintenance examinations, and identify barriers to care” (p. 852)	“... diagnosis of spinal cord injury, brain injury, stroke, lymphedema, amputation, postpolio syndrome, or other conditions” (p. 854)	USA	Quantitative Survey	Users of health care at a specialized, hospital-based out-patient rehabilitation clinic; Consecutive	334
Harrison et al., 2010	The impact of timing of impairment on healthy life styles	“... physical or sensory impairment that prevented them from living the life they would prefer (p. 819)”	Texas, USA	Qualitative; Interviews	Women with impairments (43 to 79 years old); Convenient	45
Harrison, 2006	Health promotion for persons with disabilities	“... limitation in performing socially defined roles and tasks” (p. 13s)	Not applicable	Systematic review	Not applicable	23 articles

Hughes, Nosek, Groff, Mullen, & Howland, 2003	“. . . test a health promotion intervention for women with physical disabilities” (p. 182)	Not given	Texas, USA	Pre-test; post-test Questionnaire	Convenient	15
Iezzoni et al., 2000	The impact of mobility problems on the use of screening and preventive services	Difficulty with or inability, to walk and climb stairs	USA	Quantitative; Analysed data from National Health Interview Survey	National population; Sampling strategy not given	77 437 adults 10% with mobility impairments
Iezzoni et al., 2001	Screening and preventative services used by women with disabilities	Functional difficulties	USA	Quantitative; Analysed data from National Health Interview Survey	National population; Sampling strategy not given	11 339
Iezzoni et al., 2002	Satisfaction with health care of persons with disabilities	Functional status in five categories (vision, hearing, walking, reaching overhead, grasping and writing)	USA	Quantitative; Analysed data from Medicare Current Beneficiary Survey	National population; Sampling strategy not given	16 403
Iezzoni et al., 2003	To determine if persons with disabilities experience more problems with technical and interpersonal quality of health care services than persons without disabilities	Functional status in five categories (vision, hearing, walking, reaching overhead, grasping and writing)	USA	Quantitative; Analysed data from Medicare Current Beneficiary Survey	National population; Sampling strategy not given	16 403
Iezzoni et al., 2006	Explore health care experiences of persons with disabilities living in rural	Not given	Rural Massachusetts &	Qualitative; Focus groups	Independent living centres; Convenient	35

	areas		Virginia, USA			
Iezzoni et al., 2011	Examine barriers to health care of uninsured adults with disabilities	Functional difficulties and the use of assistive devices	USA	Quantitative; Analysed data from medical Expenditure Panel Survey	National population; Sampling strategy not given	93 839 observations from respondents
Kroll, Jones, Kehn, & Neri, 2006	Access barriers to preventive health care for persons with physical disabilities	Not given	North Virginia. USA	Qualitative; Focus groups	Adults with physical disabilities; Convenient	36
Mitra et al., 2009	Estimation of health care cost for persons with disabilities	Major activity or functional limitation	USA	Quantitative; Analysed data from medical Expenditure Panel Survey	Americans with disabilities; Sampling strategy not given	1996:10 987 1998:11 407 2000: 12 082 2002:18 854 2004:16 459
Neri & Kroll, 2003	Perceived scope and consequences of poor access to health care	Not applicable	USA	Qualitative; In-depth interviews	Americans with SCI, MS or Cerebral Palsy (CP); Snowball	30
Parish & Huh, 2006	Compare health care access for women with disabilities to access for women without disabilities	Positive response to: “Do you have a physical, mental, or health condition that limits the kind or amount of work you do?” (p. 9)	USA	Quantitative; Analysed data from national telephone survey	National female population; Sampling strategy not given	54 243 women 8721 had a disability
Parish & Ellison-Martin,	Health-care access and use among working-age USA	Self-reported based on positive response to the	USA	Quantitative; Analysed data from the	National population; Sampling strategies not	5894 women on Medicaid

2007	women	question: “Do you have a physical, mental, or health condition that limits the kind or amount of work you do?” (p. 111)		National Survey of America’s Families	given	2371 had a disability or chronic condition
Pharr, 2014	Accommodation of persons with disabilities at PHC clinics where structural barriers exists	Not given	USA	Mixed methods; Survey with some qualitative questions via e-communication	Primary care practice administrators from across the USA; Convenient	63
Ravesloot, Seekins, & White, 2005	“Investigate effectiveness of a health promotion intervention for adults with mobility impairments” (p. 239)	Not given	USA	Quasi-experimental; Random assignment to treatment start date	Persons with disabilities from nine Independent Living Centres in eight states; Convenient	188
Ramirez, Farmer, Grant, & Papachristo, 2005	Difference in cancer screening use between persons with and without disabilities	“... respondents reporting poor health status, assistive device needs, and the presence of any health limitation in 7 or more of 9 adult-normative activities”	California, USA	Quantitative; Telephone survey	Households; Geographically stratified, random-digit-dialled	55 428
Scheer, Kroll, Neri, & Beatty, 2003	Barriers to PHC, rehabilitation and specialists for persons with SCI, CP or MS	Not applicable	USA	Qualitative; Interview	National; working-age adults with SCI, CP or MS; Purposive	
Smedema & Ebener,	Substance abuse and psychological outcomes	Not given	Not applicable	Systematic review of literature	Not applicable	11 articles



2010	amongst persons with disabilities					
Smith, 2008	The relationship between disability and access to health care for women with disabilities	Def 1: Difficulty performing tasks without the use of specialised equipment Def 2: Inability to perform activities of daily living mobility, and memory	USA	Quantitative; Analysed survey data from the 2006 National Health Interview Survey	National; Sampling strategy not given	24 275 adults Number with disabilities not given
Story, Schwier, & Kailes, 2009	Accessibility and utility of medical equipment	Self-reported	USA	Qualitative; Focus groups	Population not given. Participants identified through organisations like independent living centres and senior centres; Convenient & snowball sampling	75
Winitzer, Bisgaier, Grogan, & Rhodes, 2012	Access to specialist care for children with special needs	Children “. . . at greater risk for chronic physical, developmental, behavioural, or emotional conditions and require medical and related services beyond what is typical” (p. 26)	Cook County, Illinois, USA	Qualitative; In-depth interviews	Caregivers of children with special health care needs; Purposive	30
Global South studies						
Ahmad, 2013	Access and barriers to health	Not given	Rural	Mixed method;	People with physical	245

	care for persons with disabilities		Pakistan	Semi-structured interviews	disabilities (15-35 years old); Quota	
Fisher & Shang, 2013	Health care service provision to Chinese children with disabilities	Assessed by survey doctors – definition not given, but focused on impairments	China	Quantitative Survey data Qualitative Case studies In-depth interviews	National population Stratified random Snowball	1002  8 children; 38 interviews
African studies						
Eide, Loeb et al., 2011	Living conditions of persons with disabilities	Persons with activity limitations as defined by the ICF	Namibia, Zimbabwe, Malawi & Zambia	Quantitative; Questionnaire	National populations In selected enumeration areas identified households with persons with disabilities and control households without persons with disabilities	8,635 with and 7,737 without disabilities
Mlenzana & Mwansa, 2012	Persons with disabilities satisfaction with PHC	Not given	Zambia	Quantitative; Questionnaire	Persons with disabilities (18 -65 years) in Ndola district; Convenient	191
Trani et al., 2011	“ . . . health status and access to health services for persons with disabilities . . . in comparison to non-disabled members of the same community” (p. 1478)	Based on the ICF	Sierra Leone	Survey; Personal Interview	National population Three stage Random	189 persons with disabilities & 235 without disability

Van Rooy et al., 2012	Experiences of persons with disabilities in accessing health care	Not given	Rural Namibia	Qualitative; Interviews	Population not given Purposive	25 persons with disabilities
South African studies						
Bateman, 2012	Rural health care service provision for persons with disabilities	Not given	Eastern Cape, KwaZulu-Natal & Mpumalanga	Qualitative	Population; Sampling strategy not given	Therapists (numbers not given)
De Koker, De Waal, & Vorster, 2006	Social, economic and demographic profile of social grant receivers	National	Quantitative	Interviews	National population; Sampling strategy not given	6996 social assistant grant recipients
Eide, Schür et al., 2011	Knowledge on HIV/AIDS amongst persons with disabilities	Not given	Western Cape, KwaZulu-Natal & Gauteng	Survey	Population not given; Purposive & Snowball	285 persons with disabilities
Kahonde et al., 2010	Experiences of rehabilitation services at CHCCs	Not given	Cape Town; Western Cape	Qualitative; Interviews	Persons with physical disabilities; Purposive	10
Kritzinger et al., 2014	Challenges to health care access as experienced deaf users	Not applicable	Worcester, Western Cape	Qualitative; Semi-structured interviews	Members of the National Institute for the Deaf; Sampling strategy not given	19
Maart & Jelsma, 2013	Access to health care for persons with disability in a	Activity limitations identified through WGQ	Cape Town, Western Cape	Quantitative; Questionnaire	Random cluster sampling	151 persons with

	middle income country					disabilities
Mlenzana, Frantz, Rhoda, & Eide, 2013	Barriers and facilitators to rehabilitation access	Based on the ICF	Not applicable	Systematic review	Not applicable	6 articles
Ntamo et al., 2013	Reasons for poor physiotherapy attendance by stroke patients	Not applicable	Mthatha Eastern Cape	Mixed method Interviews	Stroke patients referred for physiotherapy at Mthatha general hospital; Random	85
Rhoda, Mpfu, & DeWeerd, 2009	Organisation of stroke rehabilitation	Not applicable	Cape Town Western Cape	Quantitative; Interviews	Stroke patients and therapists from Cape Town CHCCs; Consecutive	100 people with stroke 16 therapists
Saloojee et al., 2007	Explore access to education, rehabilitation, assistive devices and social grants	Activity limitations due to a health condition	Orange Farm, Gauteng	Quantitative; Semi-structured interview	Children with disabilities under 18 years; Snowball	156
Wasserman et al., 2009	Assess post stroke outcomes, needs and prevention of secondary complications	Not applicable	Jozini, KwaZulu-Natal	Quantitative; Outcome measures & Questionnaire	Stroke patients from district hospital; Consecutive	30